

WESTON JESUIT

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**From Otherness to Openness:
Towards a Theology of Access;
What Our Perceptions and Stereotypes
of Disability Reveal to Us About Our
Own Understanding of Personhood
and Personal Significance**

Jennie Weiss Block



The Sixth Annual Margaret E. Pyne Memorial Lecture
March 15, 1997

THE SIXTH ANNUAL MARGARET E. PYNE MEMORIAL LECTURE

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Jennie Block has been involved in the disability field for twenty years as a family member of a person with a disability, a friend of many people with disabilities, and a professional. In 1988, she opened a consulting company specializing in organizations. Her areas of expertise include advocacy, strategic planning, staff training and development, policy development, board governance, grant and manual writing, grant management and operation of disability organizations, and meeting and conference planning.

Ms. Block is the author of *Project Neighborhood*, a publication on community living for people with disabilities. She has developed and implemented a comprehensive, statewide Disaster Preparedness

Training Program for people with disabilities, service providers, and policy makers. She was lead grant writer and project consultant to Miami-Dade Community College for PROJECT STEP I and II, a federally funded adult literacy program for direct care workers in the disability field. She has coordinated several statewide and national disability conferences and has been a guest presenter at numerous national conferences including the National Medicaid Conference and the American Bar Association. In 1992, she was one of 100 Americans selected to represent the United States at an International Conference on Disabilities held in the Vatican by Pope John Paul II.

Her clients include the Florida Developmental Disabilities Council, Miami-Dade Community College, the Junior League of Miami, the National Coalition of Disability Councils, the National Association of Disabilities Council, RESPECT of Florida, the Children's Services Council, the Broward ARC, Sunrise Community, and the HRS District Eleven Health and Human Service Board.

Ms. Block has a Master's Degree in Business Administration and was awarded the Barry University Leadership Award. She resides in Coral Gables, Florida and is currently working on her Master's Degree in Theology.

Professor Margaret E. Pyne, in whose memory this lecture series is named, was a lifelong advocate for disabled persons. A former Associate Dean of Special Education at Lesley College, Margaret Pyne had a particular vision of the need to educate theological students about ministry for and with persons with special needs. Through the Endowment Trust established by her estate for this purpose, students at Weston Jesuit School of Theology and other students of the Boston Theological Institute will be assisted to expand their ministerial formation by pursuing courses and attending public lectures related to these special ministries.

Margaret E. Pyne Memorial Lecture

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by Ms. Jennie Weiss Block

**“From Otherness to Openness: Towards a Theology of Access;
What Our Perceptions and Stereotypes of Disability Reveal to Us About
Our Own Understanding of Personhood and Personal Significance”**

I. Introduction

Disability is complex and multi-faceted. Many contemporary moral, ethical and religious issues such as poverty and economic injustice, health care and allocation of medical resources, education, bio-medical ethics, feminism, spirituality, liturgical exclusion, and public policy, intersect with disability issues. Reflection on the discrete reality we call “disability” raises age-old and profound theological questions related to suffering, the plight of those shunned by society, and the dramatic themes of oppression, liberation, and transformation. Grappling with disability issues can be a provocative challenge.

I am not a person with a disability and I do not speak for people with disabilities. They are quite capable of speaking for themselves and are best able to articulate their personal and individual experiences. I come to reflection on the topic of disability because of my life experiences as a family member of a person with multiple disabilities, a friend to many people with disabilities, and eighteen years as a disability professional and because I believe that my experience is valuable and worth sharing. My remarks are primarily addressed to non-disabled people.

I begin with my own story. I am the oldest of eight children; five of whom were adopted by my extraordinary parents. The youngest of my siblings, my brother, Bobby, was adopted when he was four years old. We knew he was mentally retarded, had many physical disabilities, and had been subjected to extreme mental abuse in the first four years of his life. His psychiatrist told us he had experienced more trauma the first four years of his life than most adults will ever experience. He had several serious medical conditions, terrible behavior and emotional problems and a certain charm that transcended all of his problems. Our whole family adored Bobby and was devoted to him. In 1974, when Bobby was twelve, and I was twenty-eight, our mother died, after a long and terrible illness, just six months short of her fiftieth birthday. Her last words to me were, “Take care of Bobby.” I kept my promise, and until Bobby died thirteen years later, I was his primary caretaker. I learned to be an advocate the hard way: trying to find services, schools, and knowledgeable and caring

medical personnel for Bobby. Even with adequate financial resources and my tenacious personality, I was often overwhelmed and depressed. The lack of services and programs; the blatant discrimination; the misunderstandings about what disability is; the ignorant fears of others... "No, it's not contagious;" the stares and mean comments; the downcast eyes and pitying glances—all had made me aware of the pervasive oppression that permeates the lives of people with disabilities.

In 1979, I responded to a "call" of sorts to go and work in the disability field. Leaving a career and job I loved was difficult, but I knew I had to go. For the next sixteen years, I pursued many avenues of service: administration, policy and organizational development, national conference planning, grant writing, project development and management, legislative advocacy, and staff training and education. My work, on behalf of people with disabilities, has been intense, frustrating, and extremely rewarding. The disability field is not glamorous. I was appalled by the terrible injustices I encountered. I was naively shocked by the lack of funding, programs, and services that were available. I was horrified to learn that many people with disabilities had no job, no home, no friends...all the things I took for granted. My work has always been fighting uphill battles. Working to educate medical personnel, the press, national, state, and local officials, parents, and the community allowed me to see first-hand how people with disabilities are perceived and treated.

In 1995, I made the difficult decision to leave my work in the disability field to study theology thus fulfilling a long held personal dream. I am aware that I come to theological reflection with a somewhat "secular" view and orientation. The integration of the secular and theological perspectives, although challenging, has the potential to be creative and interesting. While the differences are obvious and significant, I believe that common ground exists and an examination of these commonalities is fruitful.

As a result of my reflection on disability issues, four insights have become clear to me. First, people with disabilities are oppressed and this oppression has a devastating effect on their lives. Second, to reflect on disability is to reflect on the mystery of God's love and the great paradoxes of the Christian message. Third, through advocacy as a form of social justice, we have an obligation to respond to the injustice of oppression by challenging the systems and perceptions that keep people oppressed. And, fourth, people with disabilities will never truly be liberated until, no longer viewed as "the other," we welcome them as friends into our lives and communities.

The illustration of these four points are the focus of this presentation. You are asked to keep in mind two things. First, these remarks are about the oppression and liberation of everyone who is oppressed. While people with disabilities are used in this paper as an example of a group that suffers from oppression, they are, in fact, joined in solidarity with all who are oppressed. Second, this is not intended to be merely an interesting discussion. It is intended to raise consciousness, provoke thought, and ultimately impel us to action.

II. Disability

An Overview

It is estimated that there are 43 million Americans with one or more physical or mental disabilities, and this number is increasing as the population as a whole grows older. ¹ Over 500 million people world wide have a disabling condition—ten percent of the world population. ² There is wide diversity within the disability community. There are people with developmental disabilities; physical disabilities; mental disabilities; and sensory disabilities, such as blindness or deafness. Many people have multiple disabilities. Some people are born with their disability; others become disabled as a result of illness or accident. Some disabilities are permanent; others are temporary. Unlike gender, race, national origin and sexual orientation, one can join the ranks of “the disabled” at a moment’s notice. This information is descriptive, but general. In order to consider the oppression of people with disabilities, we must attempt to define disability.

What Is a Disability?

This is a complicated question. Is it physical in nature? Is it social reality? Is it a problem relating to the ability to function? Many theories, theologies and definitions attempt to explain what a disability is and what it means to be disabled. Beyond the clinical definitions of particular disabling conditions, is it possible to define what disability actually is? A number of definitions and perspectives are offered demonstrating the range of thought on this question.

The Americans with Disabilities Act of 1990 defines a disability as, “...A physical or mental impairment that substantially limits one or more of the major life activities of an individual; b) a record of such an impairment; or c) being regarded as having such an impairment.” ³ This definition locates disability within a legal context and focuses on activity and human rights.

Susan Wendell, in her article, "Towards a Feminist Theory of Disability," says disability is, "...socially constructed from a biological reality."⁴ This definition acknowledges the power that dominant cultural norms have in shaping the perceptions we have of people with disabilities and what it means to be disabled. This definition locates disability within a sociological context and focuses on perceptions, stereotypes and cultural norms.

Nancy Eiesland, in her book, *The Disabled God: Towards a Liberatory Theology of Disability*, argues for a "reconception of the symbol of Jesus Christ, as disabled God..."⁵ This definition locates disability within a theological context and focuses on the spiritual aspect of disability.

Another view is expressed by Al Condeluci in his book, *Interdependence: The Route to Community*. Quoting Frank Bowe in *Handicapping America*, he states: "The concept that handicaps result from interactions between disabilities and environments is well illustrated in primitive cultures; survival depends upon strength and agility, so physical disabilities become handicapping." Condeluci adds, "in this perspective, one is only handicapped when the interaction between the individual and the environment is interrupted. If something can augment the interruption, the handicap would be removed."⁶ This definition locates disability within a functional context and focuses on abilities.

Attempts to name and describe disability generally reflect the philosophical position of the individual suggesting the concept. No singular definition is conclusive. Thus, an inability to articulate a definition with certainty and clarity remains. The definition that best informs my work is the recognition of disability as paradox, only truly comprehensible in a metaphorical sense. However, if we are to grapple with complex philosophical and practice issues related to disability, we must attempt to develop a personal definition of disability. As we consider this evasive question, we will find our definition subject to fluidity and change and leading to reflection on perhaps an even more difficult and related question: Who is disabled?

Are We All Disabled?

Many propose the idea that we are all disabled, just in different ways. Certainly, we all share the experience of brokenness and limitation; however it is important not to ignore the particular experience of people with disabilities. Barbara J. Blodgett, in her article, "Graced Vulnerability," says "...we should not imply that we are all in some way 'disabled.' Disabilities are discrete conditions that, because of the way they get defined socially, mean suffering and oppression for certain people."⁷

Charles Gourney expresses his opinion in this way:

Some well meaning theologians...say that disability is relative, that we are all disabled to some degree even if we do not think of ourselves that way: I have an ache here and a pain there, I get a stomachache every Tuesday afternoon, I have a rotten temper, I'm bald, I have a terrible singing voice. Everyone is disabled, so we should not judge anyone. While well-intended, this attitude sweeps under the rug some very real problems that people with disabilities must face. It may be true that no one has a perfect body, and that many of these imperfections are genuine inconveniences, but they do not usually reach the point where one feels and is excluded by mainstream society. This is one crucial difference between being disabled and being physically perfect. ⁸

Others claim that there is no such thing as a disability. If we are all disabled, then no one is disabled. In his article, "Deaf is Beautiful," Andrew Solomon says,

It is tempting, in the end, to say there is no such thing as a disability. Equally, one might admit that almost everything is a disability. There are as many arguments for correcting everything as there are for correcting nothing. Perhaps it would be most accurate to say that "disability" and "culture" are really a matter of degree. Being deaf is a disability and a culture in modern America; so is being gay; so is being female; so, even increasingly, is being a straight white male. So is being paraplegic, or having Down's syndrome. ⁹

The same problem is associated with both theories. Both discount the difficulty and suffering experienced by people with disabling conditions. It is not easy to be disabled in a world that is designed for non-disabled people. People with disabilities cope with particular problems that are not experienced by non-disabled and we do them an injustice by not recognizing and respecting their uncommon situations.

And yet, Dennis Schurter makes the point that "...we dare not exclude ourselves from the family of those who have disabilities, for then, we are at risk of excluding ourselves from the kingdom of God, as did the Pharisees of old. We each have our own physical, emotional, and spiritual limitations. It is only when we recognize our own needs that we can be open to receive God's healing power in our own lives." ¹⁰ Let there be no doubt that our support for those who are disabled and the acceptance

of the explicit reality of our own brokenness are not mutually exclusive activities but are, in fact, deeply related and connected.

Perhaps, in the end, it is best for all people, disabled and nondisabled alike, to acknowledge that our solidarity is found in the sharing of the human condition from which no one is excluded. Our unity can be found in our common, but different, experience of pain, loss, limitation, and suffering, and in our shared dependency on God's love and mercy.

A meditation on disability takes us right to the heart of the mystery of God's love and self-communication. Haunting questions arise. One senses that within the mystery of disability, valuable insight and knowledge can be found. How does one access this insight? Why are people disabled? What does disability tell us about God? How do we make sense of the suffering associated with disability?

The Mystery of Suffering

Avoidance of pain and suffering is a life-long pursuit for many people. Even Jesus wanted to avoid pain and suffering. Even those who don't pray, echo Jesus in asking God "to let this cup pass me by." And yet, no matter how we may try, at sometime in our life, the dreaded cup overflowing with suffering is passed to us.

Throughout the ages, theologians have struggled to understand and communicate the mystery of suffering. Disability often brings a very visible kind of suffering. Physical pain and weakness, exclusion from the mainstream of society, significantly increased family responsibilities, blatant discrimination and economic injustice are examples of some of the common experiences that cause suffering within the lives of people with disabilities.

I am skeptical of the idea that we can learn something special from the suffering of people with disabilities. I don't believe that some people are disabled to teach people who are not disabled important lessons. I am more comfortable with the somewhat out-of-date and old-fashioned notion that there is a spirituality of brokenness through which God communicates with all of us. Suffering is suffering. And it definitely comes with a message. We are reminded of what Beldon Lane says, "...used to be called the *via negativa*—the discovery of God's presence in brokenness, weakness, renunciation and despair." ¹¹

A meditation on disability forces us to examine our own lives for clues suggesting God's presence where we least expect it. The great paradoxes of the Christian message are proclaimed. The sacramentality of the world is revealed. Obscure and in some ways beyond our understanding, we encounter great beauty in what is thought to be, at first, ugly; we experience

transformation through suffering; and we realize wholeness through recognizing our poverty and not our capacity.

III. Oppression

On July 26, 1990, President George Bush signed the Americans with Disabilities Act. This landmark civil rights legislation "...provides a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities."¹² This law ushered in a new era for people with disabilities. Disability has become somewhat "politically correct" as evidenced by the plethora of books and articles on a formerly ignored topic.¹³ Notwithstanding the significant strides in this decade, historically, people with disabilities have been, and still are, oppressed. Alienation and isolation are common life experiences for people with disabilities primarily because of how they are perceived by society.

What is oppression? Al Condeluci says, "A person is oppressed when they are held back, either physically or psychologically, from the goals they aspire to, and the norms of society...oppression is closely linked to devaluation and loss of power."¹⁴

A first step towards liberating the oppressed is an understanding of the ways people with disabilities are oppressed and how this oppression affects their lives.

How People With Disabilities Are Oppressed

In *Interdependence: The Route to Community*, Al Condeluci states: "The manifestations of oppression have taken hold of our culture and institutions. Oppression against people with disabilities is so intense, that our system had adjusted to it."¹⁵ Much of the time, we are not even aware that entire groups of people are being oppressed. Oppression occurs at both the institutional and cultural levels. On the institutional level, oppression is encountered in housing, employment, education, religion, health services, legal services, transportation, recreation, and within the media. On the cultural level, oppression is encountered in language, standards of behavior, logic systems, within the arts and societal expressions, and particularly in development and expression of values and norms.¹⁶

Stereotyping of minority groups is common; however, it is particularly pervasive among people with disabilities. It is so prevalent that when the disability rights lobbyists in Washington set out to pass the Americans with Disabilities Act (ADA), they made a highly unorthodox strategy decision. There would be little attempt to explain the sweeping anti-discrimination legislation to the press. As the lead ADA lobbyist, Patrisha Wright, of the

Disability Rights Education and Defense Fund, put it: "We would have been forced to spend half our time trying to teach reporters what's wrong with their stereotypes of people with disabilities." ¹⁷

Perceptions and stereotyping of people with disabilities are a mechanism that nondisabled people use to figure out and understand the different person. Even people who are serious about acting justly often participate in stereotyping, without malice, but without reflection. Stereotyping is inherently dangerous for several reasons. First, these perceptions create invisible, but very real, barriers that imply a different strand of humanity: Keeping the person with a disability at arm's length, viewing the person as "the other." Wolf Wolfensberger, in his classic work, *The Principle of Normalization in Human Services*, describes another danger when he says, "When a person is perceived as deviant, he is cast into a role that carries with it powerful expectancies. Strangely enough, these expectancies not only take hold of the mind of the perceiver, but of the perceived person as well." ¹⁸ It is well known that people tend to become what they are told they are. Finally, these perceptions and stereotypes are almost always a reflection of the socio-political times. There is enormous power in the roles that these perceptions create because theologies, legislation, human service principles, medical treatment, and personal interactions tend to reflect these perceptions. It is not a coincidence that shortly after the passage of the ADA, the movie *Forrest Gump*, the rather unlikely story of a likable young man with multiple disabilities, won numerous Academy Awards and captured the hearts of audiences. Nor is it a coincidence that we have an emerging theology centering around a disabled God. ¹⁹

Stereotypes of People with Disabilities

Stereotypes about people with disabilities can be divided into three general categories: Historic, Religious, and Contemporary. All who are committed to the liberation of people with disabilities must become familiar with these perceptions and be prepared to challenge them whenever necessary.

Historic Perceptions

These perceptions provide a look at how people with disabilities have been viewed throughout history. While many of these perceptions are no longer prevalent, vestiges of even the most unenlightened views still remain.

- The person is viewed as a *sub-human organism*. This was a prevalent perception in the nineteenth century and even into the early twentieth century. The pejorative term, "vegetable,"

developed as a result of this perception. In the late 1800's, huge numbers of people with disabilities were put in warehouses with no heating, as it was thought they had no feeling.²⁰

- The person is viewed as a *menace to society*, dangerous and likely to do harm to others. Unfortunately, this perception still exists today. Examples of this can be seen at zoning hearings when people with disabilities are moving into a neighborhood.²¹

- The person is seen as an *object of pity*; in need of charity. This is still a common perception as evidenced from telethons, "Jerry's Kids", and poster children. Although well intended, this perception does not allow us to see the person as an equal.²²

- The person is seen as *sick* and their disability is viewed as an illness. Diagnosis, treatment and cure are emphasized. It is from this perception that a "medical" model of service developed.²³

- The person is viewed as a *burden to society*; making no contribution and draining off scarce resources. Current proposed federal policy, as well as the concept of managed care, support this perception.

- The person becomes an *object of ridicule* and is made the butt of jokes or encouraged to act in inappropriate ways which others find amusing. Often the person is so happy to be receiving attention, they are willing participants.²⁴

- The person is viewed as an *eternal child*. This creates a situation where the reasonable developmental demands are not made and the individuals are not held accountable for their actions.²⁵ This perception also promotes treating a person as if they are a child in an adult body which denies the person's sexuality and can lead to inappropriate behavior.

- The person is viewed as *bizarre and grotesque* and is seen as a freak; sometimes an interesting novelty; often frightening. Displays of persons with disabilities as sideshows in carnivals used to be common practice. Examples of this can still be found in Ripley's Believe It or Not museums.

Religious Perceptions

Some of these perceptions are drawn from interpretations of stories about disability in the Hebrew and Christian scriptures. Others are a result of interpretations of theological concepts.

- The person is thought to be *possessed by demons*. It is likely that the people described as “possessed” had epilepsy or another type of seizure disorder.
- The person is seen as *lacking adequate faith*, suggesting if they had more faith, they would be cured. Many people with disabilities tell stories of how strangers approach them suggesting that if they had more faith they would be able to stand up and walk.
- The person is viewed as a *holy innocent*; without sin; incapable of any wrong doing; saved by virtue of their disability.²⁶ Often people with mental retardation are told they don’t need the sacraments because they are already going to heaven.
- In spite of the fact that Jesus makes it clear that disability is not *caused by sin*,²⁷ there are many people who view having a disability or giving birth to a child with a disability as a punishment for sin. This creates extremely painful, sometimes lifelong, feelings of guilt and shame.
- The person is viewed as a *prophet*; one sent with a special message communicated by or through their disability. We are all sent with a message; not just people who we perceive as different.

Perhaps the most harmful religious perception that plagues people with disabilities is the idea that they are automatically “the least of my people”²⁸ because of their disability. It is true that many people with disabilities are poor and oppressed and, in fact, are the people Jesus is referring to in his mandate for social justice in Matthew’s gospel. However, we must remember that their poverty and oppression are a result of the way they are perceived and treated by society. They are not necessarily “the least” because they happen to have a disability.

Contemporary Perceptions

As the disability community develops an identity as a group with minority status, new perceptions and stereotypes are emerging.

- If successful and accomplished, the person is seen as a *superhero*. This creates false expectations for all people with disabilities. As within the general population, there is a small percentage of people with disabilities who are overachievers.

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- The person is seen as *special*. Actually a reversal of the sub-human perception, the person is seen as so different they must have a distinct designation.
 - The person is *devalued*, seen as without ability and capabilities. This is evidenced by the fact that so many people with disabilities are unemployed or underemployed.
 - The person is treated as if they are *invisible*, as if they are not present, as if they do not exist. People share stories of being spoken about as if they were not present; or having questions directed to someone else as if they were not there.
 - The experience of being disabled is *romanticized*; seen as having special status or an aura of mystery. This is a reflection of the political correctness now associated with disability issues.

In spite of the fact that twenty different perceptions are described here, this list is not exhaustive. While space does not permit a complete examination of all of the ways people are oppressed, two additional areas must be briefly mentioned; language, and domination by nondisabled people.

Oppression through Domination by Nondisabled People

People with disabilities are often dominated by nondisabled people. Often this domination is unintentional, or well intended. It is sometimes subtle, sometimes an attempt to assist or to "fix" things and create the outcome the nondisabled person thinks is best for the disabled person. (It is interesting to note that it is usually not what the nondisabled person would select for themselves.) Often dedicated professionals and concerned family members are involved in this process. It usually involves making major and minor life decisions for the person, often without even asking for input or preference. Huge service systems have developed that are entirely dominated by non-disabled people. Imagine if you had not been able to decide where or with whom you wanted to live or what job you wanted or what you wanted to do for leisure activities. Domination sends the strong message that the person is not capable. Advocates for people with disabilities must insist on their inclusion on governing boards, as staff members in disability organizations and as spokespeople for the disability movement.

Oppression through Language

Everything we say about and call people comes with an implicit and explicit message. Language can be a way to exclude people, hurt people,

and oppress people. People with disabilities have been called derogatory and pejorative terms like "idiots," "crips," "retards," "deaf and dumb," "lame," "spaz." They are called euphemistic terms like "different-abled," "physically challenged," "mentally different," and "partially sighted." Discussion about disability is sensationalized and dramatized by terms like afflicted, crippled, victim, and deformed. "The" is often placed in front of a category, such as "the retarded," "the disabled," effectively creating distance and implying "the other," with no emphasis on the individual person. Sensitivity in language is an important step in the liberating process. Anyone who is serious about the liberation of people with disabilities needs to become familiar with acceptable and appropriate disability language and use it.

This discussion begs the obvious question: "How should people with disabilities be perceived?" People with disabilities, like all of us, should be perceived as unique individuals, created in the image and likeness of God, with great gifts and talents to share...as people who are inherently valuable and of inestimable worth. All of us are entitled to live with dignity and respect. Pope John Paul II, in his Address to the International Conference on the Concerns of Persons with Disabilities, says, "Every human person...is the subject of fundamental rights which are inalienable, inviolable and indivisible...every human being is always worthy of maximum respect and has the right to express his or her dignity as a person fully." ²⁹ No two people, with or without disabilities, are alike. The focus should be on the person, and on their abilities, not their disabilities. I have a friend who wears a funny little button that says, "Labels are for cans, not people." Her button is right.

The Effects of Oppression on People with Disabilities

Oppression has devastating and debilitating effects. When people with disabilities openly share their thoughts and feelings, we become aware of how deeply these stereotypes and misperceptions affect their lives.

Oppression causes isolation and a sense of despair. Charles Gourney, in an article entitled, "Faith, Despair and Disability," says, "Having a disability can be socially isolating, creating a sense of rejection and fears of abandonment, even by God. The social consequences of physical disability can leave one with a sense that one's life has lost its meaning." ³⁰

Many people speak of the shame they feel for being disabled. Mary Stainton tells of an experience she had while hearing Judy Heumann, a disability advocate who is paralyzed and uses a wheelchair, speak about the rights of people with disabilities. Stainton says, "As she spoke a realization

struck me with high voltage intensity and held me, establishing itself somewhere deep inside of me. 'My God,' I thought, 'I don't have to be ashamed of having a disability.' At some level that was the first time this idea had occurred to me...you don't have to walk to have worth." ³¹ She was thirty two years old at the time and had spent her entire life ashamed of not being able to walk.

Problems associated with having a disability go beyond the physical limitations imposed by the disability itself. Charles Gourney describes common feelings of people with disabilities: anger, low self-esteem, a sense of inferiority, a sense of meaninglessness, despair, even loss of faith. ³² Others describe public humiliation, overwhelming feelings of powerlessness and resentment, a deep fear of being rejected and dependent.

There is much self-hate associated with disability. Deborah Creamer, speaking of herself and other people with disabilities says, "For many of us, the awareness of our embodiment is a fact of life—we are always aware of our bodies because of chronic pain, muscle weakness or limited abilities...many people with disabilities hate their bodies and their disabilities, wishing they were different." ³³

Oppression creates many practical problems. Sixty eight percent of people with disabilities aged 16 to 64 are not employed. ³⁴ Many people who are working are underemployed. They are more likely to be poor and dependent on public assistance. Forty percent of adults with disabilities live in households with annual earnings of \$15,000 or less. ³⁵ Accessible housing is scarce and attendants for people requiring assistance with personal needs even less available. Social and recreation opportunities are often limited for people with disabilities. Their sexual needs are usually ignored. Their opportunities for intimacy and interpersonal relationships are limited. For many people with disabilities, the only significant relationships they have are with paid staff members. It is not uncommon for people with disabilities to have no friends.

IV. Liberation

What is our role in helping to move people with disabilities move towards liberation? Initially, we must examine our own understanding of disability and what we can learn from the sometimes obscure mysteries of disability. We must then become familiar with the types of oppression people with disabilities experience and acknowledge the devastating effects of this oppression. At this point, we must be prepared to become advocates for people with disabilities.

Advocacy

Advocacy is a central activity within the disability field. Advocacy, quite simply, means to plead the cause of another. What do advocates do? How do they create change? How do they challenge systems and misperceptions? There are many different types of advocacy. One person directly assisting another person, in finding a solution for a problem, is case advocacy. A group of people challenging an unfair situation is class advocacy. The many lawsuits that resulted in the closing of institutions around the country are an example of legal advocacy. System advocacy is when an individual or organization works to correct an injustice. Helping someone find a job or housing is advocacy. Speaking up when someone uses a derogative term like "retard" is advocacy. Working to improve accessibility in the places you frequent is advocacy.

Al Condeluci names four vital elements to advocacy. They are passion, position, presence and perseverance. He believes passion is the starting point for advocacy. He calls position the stand we take on the injustice that arouses our passion. He sees presence as forging appropriate strategies to advance our position and creating a viable presence. He suggests perseverance is accepting that fighting oppression is difficult work, real change is slow to occur, and that a long term commitment is required. He encourages advocates to find ways to include others, renew themselves and celebrate together.³⁶

Advocacy as a Form of Social Justice

I suggest that those who are committed to theologies of liberation and social justice can learn from the commitment and good work of disability advocates; and that disability advocates can learn from the Catholic teachings on liberation and justice. Advocacy is, in fact, a form of social justice for its goal is to liberate those who are oppressed. I realize that this suggestion asks much of people who are probably overworked and overcommitted, and perhaps even suspicious of those who have a different philosophical approach. We cannot, however, afford to be closed to learning when the potential outcome may help people who are oppressed. The limitations of this proposition are obvious. Disability advocates, unless affiliated with a religious organization, operate within a secular context. Social justice, in the Catholic sense, is not a secular or humanitarian matter; it is intimately tied to God's relationship with us and the Gospel mandate for justice. However, even within these limitations, there is much to be learned. Disability advocates would be enriched and motivated by studying the

Catholic teachings on oppression and the concept of a "preferential option for the poor." The dedication and commitment of disability advocates and the techniques they use to fight oppression have the potential to be helpful to those who work for peace and justice within the Church.

Advocacy and social justice are hard work, often accomplished at great personal cost. Working for justice can be disruptive and exhausting. Being an advocate is rarely convenient and sometimes requires confrontation. Results may not be immediate and failure is common. Such is the work of justice and the work of love. And yet, as important and valuable as they are, advocacy and social justice are not enough...we must offer more. We must offer our friendship.

Friendship

I am deeply committed to principles of advocacy and social justice. However, my experience has shown me they are not enough. No laws, Bishops' letters, human service paradigms, social programs, or encyclicals, will ever truly liberate people with disabilities. Personal relationships and genuine friendships must become the foundation of any approach to advocacy and social justice. I speak of friendship in the spiritual sense; as Jesus does when he said, "I call you friends...and what I command you is to love each other." ³⁷

People who are not disabled usually take friendships for granted. Robert Perske, a well-known disability professional, abandoned his prestigious clinical work to write about friendship when he discovered the "pain experienced by people with disabilities when they are deprived of mutually satisfying friendships with ordinary people." ³⁸ In his groundbreaking book, *Circle of Friends*, Perske shares stories of simple and beautiful friendships of disabled and non-disabled people showing how these relationships have enriched their lives. In a chapter entitled, "Why Friends Are Important," Perske makes the following observations about the familiar but elusive term, friendship. "While we need our families, friends help us stretch beyond our families. Friends help us rehearse our adult roles and serve as fresh role models. Sometimes we choose certain friends because we see something in them that we wish for ourselves. Good friendships are a mystery. Friendship is attractive; others watch interactions between friends with great interest. Friendships generate their own energy and are a haven from the stresses of everyday life. People in authority often frown on friendships. Friendships are reciprocal, providing opportunities for giving and taking." ³⁹

In his wonderful book, *Crossing the River: Creating a Conceptual Revolution in Community and Disability*, David Schwartz says that,

The only real protection for a person are other people. ...I am fortunate to have a family and friends. It is they whom I count on, and they count upon me. This is the case with me and everyone I know who does not have the label "client." This is how the world works, and how it has always worked. In the case of vulnerable persons, however, we have forgotten this idea, driven by our vision of formal advocacy.⁴⁰

A perfect illustration of the combined power of advocacy and friendship is the Gospel story of the man who was paralyzed.⁴¹ In the story, four men carry their friend who was paralyzed to see Jesus. They carry him a long way and when they finally get there, it is so crowded that they cannot get anywhere near Jesus. I like to imagine that, like most advocates, they are tired and frustrated. The mattress was heavy, it was hot outside, and people were staring at them as they trudged along. I like to imagine that, as his good friends, they are bitterly disappointed because they think they are letting their friend down. After some discussion, someone has the crazy idea to climb up and cut a hole in the roof and lower the man down so he can see Jesus. Talk about advocacy! Talk about friendship! I am sure that all four of those men had other things to do that day. I am sure that the owner of the building was less than thrilled about the hole in his roof...perhaps they even had to pay for the repairs. And yet, their friend would not have been cured and "the works of God could not have been visible through him"⁴² without the help of his friends. It is notable that Jesus said, to all five of them, "Your sins are forgiven."⁴³ And the message of this story of advocacy and friendship is as relevant today as it was almost two thousand years ago.

One of the reasons that it is so important for us to challenge stereotypes of people with disabilities is because they make real friendship impossible. As long as we continue to view a person with the disability as "the other," the person we need to "help," cast in the role of "the least," we close off the possibility of friendship. Imagine for a moment what your life would be like without your friends. And, then you will begin to understand the reality of an oppression that is so terrible that it renders people friendless. You will understand why we are called to action.

V. Conclusion

In conclusion, I return to my personal story. Our family did everything we could to make sure my brother had a good life. I think I was a good advocate for him. There were many hard decisions along the way. Even though he had a terrible temper and inappropriate outbursts; even though he limped and looked different; even though he couldn't read and had a limited vocabulary, we chose to let him make his way in his world. Well meaning friends and smart professionals questioned my judgment and advised me to wait until he was older and, hopefully, better behaved and less likely to fail. I ignored them, believing in what Bob Perske calls "the dignity of risk." ⁴⁴ Bobby had limited academic success so I looked for other ways for him to succeed. He became a champion swimmer and a great dancer; and he had an appealing personality which he learned to use to his advantage. At first, our family friends became his circle of friends, but I wanted him to have friends his own age and friendships that he established on his own. Against the advice of almost everyone, I let him go to a large inner-city high school with a decent special education program and where, because of the enlightened attitude of a great school principal, he would have the opportunity to attend some classes with nondisabled kids. Initially his friends were from his special ed class, but he soon became friends with a very unlikely group of inner-city kids. His relationship with them was a perfect testimony to the mystery of friendship. My brother's friends were mostly Afro-Americans, tough, street smart and independent. He was white, rather spoiled and mentally retarded. They put up with none of his nonsense (they did more to curb his temper outbursts than ten years of behavior management programs!); and he gave them the opportunity to let them expose their vulnerable side. In some unexplainable way, it worked. I will always remember that they included him at the senior prom where, dressed in a tacky tuxedo, surrounded by his friends, he danced the night away. He told me he was the best dancer there.

Bobby's kidneys failed on his nineteenth birthday, and he was very sick for three years before he died. Many of his friends, some I didn't even know, came to his funeral to say good-bye to him and tell us how much they loved him.

Throughout my career, I have lectured on disability all over the country. After I finish talking about things like service models, political trends, funding formulas and community inclusion, I always mention my brother.

I say that if I had waited until he was older, or better behaved or “ready” to go out into the world, he would never have known what it was to have a friend and be a friend. I say this during my lectures, and I say it to you now, to create a sense of urgency.

Wolf Wolfensberger is probably the most influential disability professional and advocate of this century. He is considered the architect of contemporary human service models, and his work planted the seeds of the community inclusion movement. It is telling that Wolfensberger, the great secular humanist, uses spiritual metaphors to describe what he thinks is most important, when he says:

There are many people, especially wounded and handicapped people, who now do not have viable, relatively unconditional one-to-one supportive relationships. If people are no longer willing to engage in those kinds of relationships, laws can be passed, unlimited funds can be allocated—and still nothing will work...if individuals, **on a personal basis**, do not bind the wounds of the sick, do not give bread to the hungry, do not console the brokenhearted and visit the imprisoned, do not liberate the captives of oppression and do not bury the dead, then nothing will work.⁴⁵

As Christian people trying to live the Gospel in the late twentieth century, we are called to respond to the challenges of our times. We are called to fight oppression, even at personal cost. We are called to advocate for those that are oppressed, those who find themselves pushed to the margins by a contemporary society that values self-sufficiency and competence. We are called to offer our friendship to those who are viewed as different. We are called, on a personal basis, to bind, to give, to console, to visit, to bury and to liberate our brothers and sisters. These holy and timeless actions are what are needed now; indeed, what has always been needed. We are called to recognize that we do this, not for others, but for ourselves with the profound understanding that this is where we will discover our own liberation and encounter Christ in our world today.

Footnotes:

1. *Americans with Disabilities Act, Statutes At Large*, S.933 (1990).
 2. Pope John Paul II, Address to the International Conference on the Concerns of Persons with Disabilities, Vatican City, Italy, October, 1988.
 3. *Americans with Disabilities Act, Statutes At Large*, S.933 (1990).
 4. Susan Wendell, "Towards a Feminist Theology of Disability," *Hypatia*, Vol. 4 (2), (Summer 1989), 75.
 5. Nancy L. Eiesland, *The Disabled God: Towards a Liberatory Theology of Disability*, (Nashville: Abington Press, 1994), 98.
 6. Al Condeluci, *Interdependence: The Route to Community*, (Winter Park, Florida: PMD Publishers Group, Inc., 1991), 35-36.
 7. Barbara J. Blodgett, "Graced Vulnerability," *Journal of Religion in Disability and Rehabilitation*, Vol. 2,(3), (1995), 79.
 8. Charles Gourney, "Disability and Destiny," *Journal of Religion in Disability and Rehabilitation*, Vol. 2,(1), (1995), 74.
 9. Andrew Solomon, "Deaf is Beautiful," *New York Times Magazine*, 28 August 1994, 67.
 10. Dennis D. Schurter, "Jesus' Ministry with People with Disabilities: Scriptural Foundations for Churches' Inclusive Ministry," *Journal of Religion in Disability and Rehabilitation*, Vol. 1,(4), (1994), 47.
 11. Beldon Lane, "Grace and the Grotesque," *The Christian Century*, Vol. 107:33, 14 November 1990, 1068.
 12. *Americans with Disabilities Act, Statutes At Large*, S.933 (1990).
 13. Some examples are: 1) The appearance, in 1994, of a publication dedicated to disability issues, the *Journal of Religion in Disability and Rehabilitation*; 2) Numerous books such as Nancy Eiesland's *The Disabled God: Towards a Liturgical Theology of Disability and Developmental Disabilities and Sacramental Access*; 3) Disability was recently the topic of Nathan Mitchell's Amen column in prestigious *Worship* magazine, (January 1996, Vol. 70, No. 1.); 4) Many articles in newspapers and magazines such as Christopher Reeves appearing on the cover of *People* magazine after having made an appearance at the Academy Awards (twenty years ago, he would probably not have gone out in public or been featured on a popular magazine).
 14. Condeluci, *Interdependence: The Route to Community*, 16.
 15. *Ibid.*, 18.
 16. From a Disability and Oppression Workshop, Conducted by Ploof, D., and Spruill, L., Pittsburgh, Pa., (1990).
 17. Joseph Shapiro, "Disability Policy and the Media: A Stealth Civil Rights Movement Bypasses the Press and Defies Conventional Wisdom," *Policy Studies Journal*, Vol. 22, No. 1 (1994), 123.
 18. Wolf Wolfensberger, *The Principle of Normalization in Human Services*, (Toronto: National Institute on Mental Health, 1972), 15.
 19. As an example see *The Disabled God: Towards a Liberatory Theology of Disability* by Nancy L. Eiesland, Abington Press, Nashville, 1994.
 20. Wolfensberger, *The Principle of Normalization in Human Services*, 16.
 21. *Ibid.*, 19.
 22. *Ibid.*, 20.
 23. *Ibid.*, 22.
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24. Ibid., 23.
 25. Ibid., 23-24.
 26. Ibid., 21-22.
 27. John 9:1-6
 28. Matthew 25:31-46
 29. Pope John Paul II, Address to the International Conference on the Concerns of Persons with Disabilities, Vatican City, Italy, October 1988.
 30. Charles Gourney, Ph.D., "Faith, Despair and Disability," *Journal of Religion in Disability and Rehabilitation*, Vol. 1,(3), (1994), 52.
 31. Mary Stainton, M. Div., "Healing Stories: Critiquing Old and Creating New," *Journal of Religion in Disability and Rehabilitation*, Vol. 2,(4), (1994), 68.
 32. Gourney, "Disability and Destiny" 75.
 33. Deborah Creamer, "Finding God in Our Bodies: Theology from the Perspective of People with Disabilities," *Journal of Religion in Disability and Rehabilitation*, Vol. 2,(1), (1995), 29.
 34. Janet Miller Rife and Ginny Thornburgh, *From Bridges to Barriers: A Community Action Guide for Congregations and People with Disabilities*, (Washington, D.C.: National Organization on Disability: 1996), 4.
 35. Ibid., 4.
 36. Condeluci, *Interdependence: The Route to Community*, 150-157.
 37. John 15:14-17.
 38. Robert Perske, *Circle of Friends*, (Nashville: Abington Press, 1988), 12.
 39. Ibid., 12-13.
 40. David Schwartz, *Crossing the River: Creating a Conceptual Revolution in Community and Disability*. (Brookline Books, 1992), 166.
 41. See Mark 2:1-12, and a slightly different account in Luke 5:17-26.
 42. John 9:3.
 43. Luke 5:20.
 44. In 1972, Bob Perske wrote an article in *Mental Retardation*, Vol. 10,(1), called "The Dignity of Risk" which argues that people with disabilities are often denied their fair share of risk-taking. He claims this is sometimes done in clever ways by limiting their spheres of behavior and interactions in the community, jobs, recreation, and relationships with the opposite sex. "While the intent of these actions are to 'protect,' 'comfort,' 'keep safe,' 'take care,' 'watch,' and are usually benevolent and helpful, if they are acted on exclusively or excessively, they tend to keep people from experiencing the risk-taking or ordinary life which is necessary for normal human growth and development."
 45. Wolf Wolfensberger, *A Multi-Component for Advocacy/Protection Schema*, (Toronto: Canadian Association for the Mentally Retarded, 1977), 66.