

THE ACCESSIBLE CHURCH: TOWARD BECOMING THE WHOLE FAMILY OF GOD

Opportunities and Responsibilities for Ministry with People with Disabilities

This is an appeal to the churches in Massachusetts and Rhode Island to re-examine our ideas about disability and how our attitudes, expectations, behavior, communication, and architecture often create barriers for people with disabilities. It is a call to be reconciling communities of faith, committed to making our worship, programs, and physical structures fully accessible so that all can participate. This appeal is the result of much work by lay and ordained people in ministry, many of whom live with disability. It is issued jointly by the Board of Directors of the Massachusetts Council of Churches and the Governing Board of the Rhode Island State Council of Churches.

The appeal has the wholehearted endorsement of the following religious leaders:

The Rev. Stephen Alspach, Worcester County Ecumenical Council
The Rev. Erwin Bode, Massachusetts Conference, United Church of Christ
The Rev. Richard Brondyke, Presbytery of Boston, Presbyterian Church (U.S.A.)
The Rev. Edward R. Dufresne, Inter-Church Council of Greater New Bedford
The Rev. Robert Dvorak, East Coast Conference, Evangelical Covenant Church
Presiding Elder Rev. Herbert Eddy, African Methodist Episcopal Church, Boston District
Mr. David Edwards, Greater Lawrence Council of Churches
Mr. Rafael M. J. Guiu, Church of the New Jerusalem (Swedenborgian Church) Massachusetts Association
The Rt. Rev. Barbara Harris, Episcopal Diocese of Massachusetts
Bishop Susan Wolfe Hassinger, New England Conference, the United Methodist Church
The Rev. Dr. H. Daehler Hayes, Rhode Island Conference, United Church of Christ
Bishop Charles L. Helton, Christian Methodist Episcopal Church, Seventh Episcopal District
The Rev. Diane C. Kessler, Massachusetts Council of Churches
The Rev. Sharon Key and The Rev. James Miller, Rhode Island State Council of Churches
The Rev. Janet Long and the Board of the Attleboro Area Council of Churches
The Rev. Stephen Macchia, Vision, New England
His Eminence Metropolitan Methodios of Aneon, Presiding Hierarch of the Diocese of Boston
Rhoda Mowry, Rhode Island – Smithfield Quarter of the Society of Friends
Bishop Margaret Payne, Evangelical Lutheran Church in America, New England Synod
Presiding Elder Nathaniel K. Perry, African Methodist Episcopal Zion Church, Boston District
The Rev. Dr. Donald Rasmussen, American Baptist Churches of Rhode Island
The Rev. Karen Rucks, Council of Churches of Greater Springfield
The Rev. Donald W. H. E. Ruffin, Hartford and New Haven Districts, African Methodist Episcopal Zion Church
The Rev. Carl Scovel, The Council of Christian Churches within the Unitarian Universalist Association
The Rev. Susan Scribner, Cape Cod Council of Churches
The Rt. Rev. Gordon Scruton, Episcopal Diocese of Western Mass.
The Rev. Dr. Linda Spoolstra, The American Baptist Churches of Massachusetts
Lt. Col. Fred Van Brunt, The Salvation Army, Massachusetts Divisional Headquarters
The Rev. Dr. Jane L. Searjeant Watt, Synod of the Northeast, Presbyterian Church (U.S.A.)
The Rev. Robert H. White, Synod of the Northeast, Presbyterian Church (U.S.A.)
The Rev. K. Gordon White, Associate General Secretary, Consultation on Church Union
The Rt. Rev. GERALYN WOLF, Episcopal Diocese of Rhode Island

The Roman Catholic dioceses of Massachusetts already have established policies regarding people with disabilities. The Boston Archdiocese, for example, has issued in its Synodal statement of 1988 a call to all members of the Church to ensure that all those with physical and psychological disabilities feel themselves part of the Church and that all structural and attitudinal barriers to full participation be eliminated as far as possible. Consequently the Roman Catholic Church encourages the efforts expressed in “The Whole Family of God” to bring to the awareness of Christians the need for generous attention to those who labor under significant disabilities.

The Roman Catholic diocese of Providence, Rhode Island already has established policies regarding people with disabilities. The Providence Diocese has issued a Pastoral Letter to all members of the Church to ensure that all those with physical and mental disabilities feel themselves part of the Church and that all structural and attitudinal barriers to full participation be eliminated as far as possible. Consequently the Roman Catholic Church encourages all efforts to bring to the awareness of Christians the need for generous attention to those who labor under significant disabilities.

THE PROBLEM / THE CHALLENGE

Fifty years ago the majority of people with significant disabilities¹ spent their days secluded at home, or housed in large institutions — virtually “out of sight, out of mind.” This has changed significantly in the last three to four decades as legislative reform has eliminated many of the barriers to education, transportation, employment, and communication experienced by people with disabilities. In our churches, however, people with disabilities are still largely absent, excluded from full participation because of inaccessible buildings and programs, left out of the communication loop, and too often made to feel like inconvenient objects of pity. Some have been told they would “be happier elsewhere.” For many the only way to escape condescending and paternalistic attitudes and retain their dignity has been to leave the church. Typically, when one person feels unwelcome and leaves, his or her whole extended family also leaves the church.

¹ The Americans with Disabilities Act defines an individual with a disability as a person who:
 a) has a physical or mental impairment that substantially limits a “major life activity”,
 b) has a record of such an impairment, or
 c) is regarded as having such an impairment.

“Major life activities” include functions such as walking, seeing, hearing, speaking, breathing, bathing, and dressing oneself, performing manual tasks, learning, working.

Examples of physical and mental impairments include, *but are not limited to*, such diseases and conditions as visual, speech and hearing impairments, spinal cord injury, amputations, paralysis, muscular dystrophy, epilepsy, rheumatoid arthritis, multiple chemical sensitivity, Alzheimer disease, diabetes, asthma, multiple sclerosis, heart disease, cerebral palsy, emotional illness, specific learning disabilities, cancer, mental retardation, HIV, and AIDS, spina bifida, attention deficit disorder, chronic fatigue syndrome, tuberculosis, cystic fibrosis and post polio syndrome.

Impairments may be readily obvious or “hidden” and not so apparent. The condition may be static or progressive. It may be congenital or the result of later disease, accident, or injury. The person may be any age — a tiny child or a teenager, middle aged or quite elderly.

A “record of such an impairment” might be an earlier diagnosis of cancer that is now in remission, a past hospitalization for a psychiatric illness that is now well managed with drug therapy.

A person “regarded as having an impairment” might be someone with scars, a birthmark, or facial difference.

This pattern means that many Christians are without a community of believers to share their joys and struggles; it means that many congregations are impoverished and incomplete. Our limited understanding of God's hospitality and grace and what it means to be human threatens the integrity of the Body of Christ. Why do we find ourselves in this situation? How do we begin to work together for changes so that all may worship and be one in Christ?

I. A Biblical grounding and a statement by the World Council of Churches: Creation is good. We are made in God's image. We are one body. In Christ we are made whole.

Coming from a variety of Christian traditions, we are united by our common belief in a just and loving God and the integrity of God's handiwork. After creating all of heaven and earth and every form of life, God saw that "...indeed, it was very good." (Gen.1:31) We believe that humankind is created in God's image, "according to God's likeness" (Gen. 1:26) so that each person reflects part of that divine mystery. With the breath of life God has imbued each person with dignity and worth. We believe that God became incarnate in the person Jesus. "He is the image of the invisible God, the first born of all creation; for in him all things in heaven and on earth were created, things visible and invisible..." (Col. 1:15-16) Walking the earth in human form — teaching, feeding, touching, healing all kinds of hungry, and hurting people — Jesus showed us that bodies matter. There is nothing about us that is foreign to him. He invites us to join him in this solidarity with all who are oppressed. He said that God's reign is like a banquet for all people, that "the kingdom of God is among you." (Luke 17:21) We believe what the apostle Paul taught that the Church is made up of many different parts like the human body and that all are necessary to the whole. None is less valuable than the others. If all parts are alike the body cannot function. Each has something unique to contribute. (I Cor.12:12-27) We believe that Jesus called for an end to the political and social divisions that privilege some and alienate others. "...for in Christ Jesus you are all children of God through faith... There is no longer Jew or Greek, there is no longer slave or free, there is no longer male and female; for all of you are one in Christ Jesus." (Gal.3:26-28)

The problem is not what we profess as Christians, nor is it that the issue has never been seriously considered until now. Twenty-five years ago at its Fifth Assembly in Nairobi the World Council of Churches proclaimed that

A church which seeks to be truly united within itself and to move towards unity with others must be open to all...The church cannot exemplify "the full humanity revealed in Christ," bear witness to the interdependence of humankind, or achieve unity in diversity if it continues to acquiesce in the social isolation of disabled persons and to deny them full participation in its life. The unity of the family of God is handicapped where these brothers and sisters are treated as objects of condescending charity. It is broken where they are left out...We ask the churches to ...do everything possible to integrate the disabled fully into the life of the Church at every level. (What Unity Requires: Papers and Report on the Unity of the Church, Faith and Order Paper No. 77. World Council of Churches: Geneva, 1976)

In the following decade numerous denominational bodies followed suit with similar resolutions. With these beliefs we hold in common about the goodness of creation and the value of each

person, and these exemplary statements outlining our intentions, why are we still so far short of this goal?

Perhaps the task is much harder than we realized. Maybe we have not asked the right questions or listened attentively to people with disabilities. Perhaps we have not done the critical thinking, political analysis, and prayerful reflection necessary to unmask our biased patterns of thought, language, and behavior which belie our prejudice and discrimination against people with disabilities. The “disability community” has developed a vibrant core of articulate questioning and research devoted to disclosing this systemic prejudice. Public debate and theological discourse, however, have remained essentially ignorant of this scholarship and critique. Our current grasp of “integration” with regard to people with disabilities is comparable to how many of us understood race relations in the mid 1950s. We have assumed the task to be much easier than it is. We have not dug beneath the surface. Our greatest error may be in thinking that we already understand the problem and know how to fix it. If we take to heart what the prophet Micah says about what the Lord requires, “... *to do justice, and to love kindness, and to walk humbly with your God,*” (Micah 6:8) we will understand that people with disabilities are not welcomed into the Body of Christ by just wishing them well with a pat on the shoulder or giving them spare change because we feel sorry for them. In recent years many of our churches have struggled to comprehend the insidious nature of “sexism” and “racism.” We must also grapple with how the concepts and structures of “ableism” contribute to the marginalization and systemic oppression of people with disabilities.

II. The current situation: stereotypes, myths and other barriers to participation.

"Ableism" names a subtle and pervasive bias that assumes able-bodied people (people with no physical or mental impairments) are the norm and that people with disabilities represent an undesirable deviation from this norm. The impairments and limitations become the defining characteristic of the person. Discrimination against people with disabilities rests on this prejudicial measure of a person's worth and acceptability. We let our thinking about disability get channeled into rigid classifications that see an individual as either healthy or sick, good or bad, broken or whole, obstinate or compliant, smart or stupid, beautiful or ugly, strong, or helpless. These interpretations leave no room for the ambiguity, fluctuation, and unpredictability that frequently characterize the lives of people with disabilities. We set up standards that frequently are unattainable by people with disabilities – climbing stairs, reading 12 point type, comprehending algebra, speaking clearly – and then hold people in bondage to these expectations. We blame, reject, ignore, ridicule, pity, discount, or even despise and punish all who cannot meet our rigid ableist criteria.

In the North American context, most of us are not so likely in this day and age to think that “demons” cause illness or impairment or that God sends physical and psychological afflictions to punish us for sin. Yet we persist in seeing disease, disability, and disfigurement as evidence of some wrongdoing, and we search unceasingly in heaven and on earth for a place to lay the blame. Too often, by not acknowledging our own vulnerability, we project our fears and anger onto someone else, onto those with disabilities. These people then become the scapegoats who

bear our own inadequacies and pain. We either condemn them or venerate what we interpret as “their suffering.”

We have let the medical diagnosis define the whole problem and solution; the person with a disability is always the “sick” patient in need of corrective treatment. We have let a biblical focus on healing become a fixation on “cure,” which too often means making the person with the disability look and function like the majority even when the procedure is at their expense and discomfort. We persist in viewing disability as a personal dilemma to be privately endured; we tolerate the individual who makes a cheerful and courageous effort to “overcome her disability.” We have placed all the responsibility to adapt on the individual and failed to acknowledge that disability is a social, political, and theological concern. All of us must be held accountable for the barriers society has erected and the economic and environmental conditions that contribute to disability.

In our history as well as in our churches individuals with disabilities often seem to be invisible or missing. In our literature and entertainment media they are more evident, though usually as a prop in someone else’s story or playing the narrowly prescribed roles of inspirational hero, naive dupe, tragic victim, comic sidekick, or evil villain. Such myths and labels perpetuate images of disability as pathetic, burdensome, or shameful --outside the realm... of normal life experience. They box people in, imprison their potential, and wall out freedom and possibility; they deny people the choice of being uniquely themselves. By using these stereotypes to distance ourselves from people with disabilities, we avoid dealing with the radical reality and integrity, the uniqueness and wonder of each person.

III. Disability is about difference — a natural, ordinary part of life.

Although we may not anticipate it, disability is a natural occurrence in our lives, a contingency of being human. Helen Keller said, “Life is a great adventure or nothing at all,” and we know that most great adventures entail an element of risk and the high probability that we might incur some injury along the way. Living is risky business. It has been the Creator’s design to place this breath of life in fragile earthen vessels. “...We have this treasure in clay jars so that it may be made clear that this extraordinary power belongs to God and does not come from us.” (II Cor. 4:7) As medical and scientific advances continue to reduce the death rate from infection, injuries, and other conditions, more people survive to continue life with some disability. How many people are we talking about in this minority? Recent statistics suggest that close to twenty percent of the US population identify themselves as having some level of disability, and half of these say their disability is severe. For people over age eighty the percentage is even higher. This means that all of us will be touched by disability in some way or another, at some time or another.

Disability does not fit into neat, orderly categories; it is not one of those adventures we can arrange on our own terms. It may be unpredictable and full of paradox. A disease or disability can manifest itself differently in each person, and some people have more than one disability. Any situation involving disability in an individual, a family, or a community will be affected by numerous factors besides the actual medical diagnosis or pathology. What is the impact of the

person's gender, age, race, class, culture, housing situation, religion/spirituality, and economic status? Is there a family or community support system? What are the personal relationships of the people involved? Is there access to appropriate health care? Is the disability obvious or is it "hidden?" Can/does the person "pass" as non-disabled? Is the disability recent and requiring great adjustment in self concept, or has the person been disabled since birth or early childhood so that the disability has always been part of his/her identity? Is the condition stable, sporadic, progressive, degenerative, or painful? Is or was extensive medical treatment required? We need to keep in mind that because of all these varied circumstances, two people with identical diagnoses may have very different attitudes, approaches, and outcomes relating to the disability.

Being relegated to the sidelines of life to await some miraculous change in circumstance is not a very satisfactory existence for most people, and neither is the constant striving to simulate a life typical of someone who is not disabled. A person learns to live with disability, not "overcome" it. The physical or mental impairment a person has is not *who* the person is, but it is *one* of the many attributes that makes this person unique; it is a *part* of who she is. It is not something to ignore or pretend we do not notice; such behavior can make a person feel invisible. Disability is about difference, and it is about letting each person be his/her unique God-given self, celebrating the gifts each individual brings to life, and making a place where everyone can belong. It is about bringing together all the different pieces of the puzzle so the picture is complete. Healing is not so much about having something fixed or corrected as it is about becoming whole and being restored to one's rightful place in the community. This wholeness happens when all the parts of our individual and corporate lives that have been left out, neglected, or excluded are brought together in love. It is easy for an individual with a chronic illness or disability to be angry at that part of himself and see his body as the enemy. It can be hard work to see the disability as part of who he is, and the references in scripture to the mind as pure and the flesh as weak and corrupt can be particularly troublesome in this effort. Our bodies are just as much a part of who we are as our psyche, intellect, and spirits. This task of integration is challenging work both for the individual person and for the church as we try to create a space where everyone can participate and feel valued.

We are not alone on this journey. In case we presumed that Job and the men and women in the Gospel healing stories accounted for all the people with disabilities in the Bible, we need to look again. Others, though perhaps less noticed for their disabilities, have been there all along. Moses had trouble speaking and tried to use this as an excuse for not doing what God was asking of him. God did not let him off the hook so easily, but sent Aaron to be Moses' voice. This may well be the earliest recorded example of an interpreter being provided for someone with a speech impediment. (Exodus 4:10-17) When Jacob was about to cross over into a new phase of his life, he spent an exhausting night wrestling in the dark with some unknown being. While he gained a new name for himself (Israel) in keeping with his new role, he also emerged from the struggle with a serious injury to his hip. Nowhere do we read that God thought this mobility impairment disqualified Jacob from his role as patriarch of his people. (Genesis 32:24-32) St. Paul mentions more than once his appeal to God about the "thorn in his flesh." Here indeed was a man of faith, yet God did not respond by removing the "thorn." What Paul heard God saying was "My grace is sufficient for you, for power is made perfect in weakness" (Gal. 4:13-16; II Cor.12: 7b-8a), that there was meaning to be found in this physical infirmity for his evangelistic work. Even Jesus after being resurrected from the grave still bore the wound in his side and the impairments

to his hands and feet where the nails had fastened him to the cross. These injuries became very much a part of the risen Christ, not something to be hidden. (Luke 24:36-39; John 20:24-28)

IV. God calling us to new possibilities and wholeness in Christ

What can we learn from this experience of life with hard limits and weakness as well as rich potential and possibility? In our lifelong journeys to become whole, to become fully who we are, to live into our birthrights as beloved sons and daughters of God, can we wrestle meaning from the adventure of disability and bring it under God's blessing? Can we trust that "God's foolishness is wiser than human wisdom, and God's weakness is stronger than human strength"? (I Cor. 1:25) Finding ourselves at the border of this unfamiliar territory, we sense our vulnerability and unpreparedness. To be thrown unexpectedly into a strange place, a new situation outside the realm of our experience with people whose appearance and way of doing things are different often makes us uncomfortable and anxious. We want life to be ordered and predictable, but disability, whatever its cause, will most likely require changes, new ways to do familiar tasks, new routines, new ways to relate to people.

We will be called to stretch our imagination to include the unexpected and ambiguous. This is not a comfortable task! We might be angry at the prospect of life with disability — whether we are talking about impairment in our own bodies, in someone close to us, in the people with whom we meet on the street, at work, and in our church. We may need to mourn the loss of some functions, loss of life the way we expected it to turn out, and the loss of an earlier identity. We may have to relinquish some false sense of security, let go of the belief that if we maintain an honest, upright life, then no adverse fate will befall us. And most importantly, we must confess our fears: fear of our own mortality, fear of losing independence, fear of losing control, fear of difference, fear of causing inconvenience or being a "burden," fear that we will not know what to say or do, and fear of making mistakes.

We need to bring these struggles into our worship so that the symbols of the liturgy will be meaningful to us. Both the drama of liturgy and the drama of disability deal with the fragility of our lives and our dependence upon God. Our worship should be a reality check on who we are and who we intend to be with each other and God. Along with liturgies of praise, confession, intercession, and petition perhaps we should allow more time for lamentation and debate. At the same time we need to become more aware of how the language we use in worship can unintentionally alienate some of our brothers and sisters. Our common use of metaphors that equate lack of faith, compassion, or understanding with blindness, deafness, or paralysis are not the most insightful ways to proclaim the Good News to people who live with such impairments. Can we find other metaphors to express more accurately what we are trying to say? In scripture readings and in our daily lives we must learn how to listen for the voices of people who have not been allowed to speak for themselves, who are seldom alluded to and only rarely mentioned by name. Those of us with disabilities who have timidly let others speak for us, telling our stories in

their words (and frequently leaving out the best parts), must break our submissive silence and claim our authority to proclaim the truth.

We need to consider how our experience and expression of worship engages the whole human being, the senses as well as the intellect. We place a great significance on words in our preaching, teaching, and study. This is an important and vital part of our faith. Verbal descriptions help clarify certain points or stimulate our imagination, but words can be confusing for some people with little education, with a short attention span, with mental retardation, with learning disabilities or difficulty following an intricate discussion. Sometimes we “hear” God’s Word, we grasp God’s message and know the mystery and majesty of God’s presence in our lives through a sensory experience, through the perception of an image, light, color, silence, music, dance, a solemn procession, or clasped hands around a circle. Appreciation of sensory experience in liturgy is helpful for all of us, but especially when we include an awareness of disability in our planning of corporate worship and its setting. Acoustics will be particularly important for people who are blind or hard of hearing. Lighting is crucial for everyone with limited vision and anyone who needs to see the speaker’s lips or the sign language interpreter. A clear path of travel and sure footing with no stairs are necessary for those unsteady on their feet. In the arrangement of space, people who use wheelchairs need to have seating choices so that they can sit with family and friends as part of the gathered body: they should not be limited to a space way in front or far behind everyone else, or stuck out in an aisle. There should always be a place for some to sit.

In general, individuals who have lived with disability for some time say that **the real limitations to living, moving about, working and relating to others are not their particular physical or mental impairments but the barriers they encounter in the social and physical environment.** Much of this environment, whether we are speaking of architecture or attitudes, is a constructed reality; it is something humankind has created. However, if we built it, we can also take it apart and reshape it. “Let us no longer pass judgement on one another, but resolve instead never to put a stumbling block or hindrance in the way of another.”(Rom.14:13) God has imbued us with the imagination, creativity, and power to change this cultural and physical environment so that there will be space for all to participate fully and we can celebrate the gifts every human being brings to life. “To each is given the manifestation of the Spirit for the common good.”(I Cor.12:7) Long ago God told us to “Enlarge the site of your tent, and let the curtains of your habitations be stretched out.” (Isaiah 54:2) We are being challenged to open up this place we call church, to re-imagine and reconfigure it, to remodel and reshape our worship, our programs, our education, and our buildings. This can only happen when we allow the Spirit of Truth to uncover our errors, when we accept God’s forgiveness and all-embracing love, and manifest the hospitality of Jesus in all our relationships.

We are being called to companion each other on this journey. We are all members of a wondrous, diverse, interdependent web of life, and there is an integrity to this creation. God is about this full spectrum of embodiment with all its limitations and possibilities. We are called to live in the midst of contradictions with hope, so that out of the tension and chaos creativity and new life can emerge. It is in Christ we are made whole. The Spirit is reaching from God’s future into our present, inviting us into new possibilities, into new and eternal life together.

SUGGESTED FIRST STEPS

1. Begin printing several copies of your bulletin/order of worship in large print and announce to the ushers and congregation that these are available. Use an 18 point font size on your computer or enlarge the original on the photocopier, using legal or 11" x 17" paper.
2. Let the members know that the newsletter is also available on audiotape, in **large print** or via E-mail.
3. Provide verbal cues throughout the service so that people who cannot follow the printed bulletin will have a clearer sense of what is happening and be ready to participate.
4. Be sure all promotional materials and the message on your church answering machine mention whether or not your building is wheelchair accessible and where that entrance is located.
5. Make the use of a microphone a regular part of all worship services and meetings. Help those who are hesitant to use this technology understand that it is important to make all presentations and discussions accessible to people who are hard of hearing.
6. Express your commitment to removing barriers to participation by joining the *Accessible Congregations Campaign* sponsored by the National Organization on Disability.

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