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Issue Theme: Religion, Spirituality, and Disability
 Guest Editor for this issue: Fred Hafferty

Editor's Preface

Disability Studies Quarterly originated as the Disability Newsletter. This newsletter was started by Natalie Allon who published the first issue (volume one, number one) in July 1980. There is no record of any further issues published in 1980 and in 1981. In July 1982 Professor Irving Kenneth Zola published volume two, number one, and renamed it the Disability and Chronic Disease Newsletter. In that issue Irv wrote that Natalie could not continue to publish it due to an accident, but that he would do so. He renamed it Disability Studies Quarterly in 1986. Irv, the first president of the Society for Disability Studies, also established links between Disability Studies Quarterly and the Society which continue today.

After Irv's death a Disability Studies Quarterly Steering Committee was created. It is composed of Judy Norsigian, Howie Baker (Heller School, Brandeis University), Gunnar Dybwad (Heller School, Brandeis University), Janet Boudreau (former Managing Editor, Disability Studies Quarterly), Elaine Makas (Lewiston Auburn College of the University of Southern Maine), Adrienne Asch (Wellesley College), and David Pfeiffer (Suffolk University). The Steering Committee and the Society are working together to establish a permanent home for Disability Studies Quarterly.

The Samuel Gridley Howe Library in Waltham, Massachusetts, is the repository for past issues of Disability Studies Quarterly. Irv's papers and books as well as the books, papers, and manuscripts of Rosemary and Gunnar Dybwad are also deposited there. Bonnie Stecher is the librarian at the Howe Library. Bonnie deserves the credit for the historical information about the origins of the Quarterly.

As a result of the hard work of Janet Boudreau, Howie Baker,

Richard Scotch, Beth Haller, and others the Winter and Spring 1995 issues of Disability Studies Quarterly were published. This Summer 1995 issue is the first one under the editorship of David Pfeiffer who will continue as editor in 1996 and possibly 1997 as the Society and the Quarterly Steering Committee work together to secure its future.

The Fall 1995 issue will have the theme of disability culture with Steve Brown (Institute for Disability Culture) as guest editor. The Winter 1996 issue will be a generic one continuing Irv's tradition. At present it is anticipated that the Spring 1996 issue will have the theme of ethnicity and disability with Elaine Makas as guest editor. Other planned issues are: developmental disabilities (Summer 1996) with Phil Ferguson as guest editor, the new economics of disabilities (Fall 1996) with Corinne Kirchner as guest editor, a generic issue (Winter 1997), and disability history (Spring 1997) with Paul Longmore as guest editor. An editorial board is being created.

The editors, the Steering Committee, and the Society thank Suffolk University and Brandeis University for their support in publishing this issue. We also thank you, the subscribers, for your support which is critical for the continued existence of Disability Studies Quarterly.

David Pfeiffer, Editor

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Introductory Essay

Fred Hafferty
Guest Editor

This special issue on Religion, Spirituality, and Disability is the second of three special issues conceived and organized by Irving Kenneth Zola prior to his untimely death on December 1, 1994. As fate would have it, Irv and I were able to spend a scant 20 minutes brainstorming what this issue should look like and how it might come together. In response to my protest that I knew even less about religion

and spirituality than disability, Irv replied; "Don't worry. Just put a couple of things together and I'll take care of the rest."

What follows is my attempt to construct a broadly-based overview of this topic area. I wanted to provide readers with a diverse collection of "snapshots" or "takes" with the hope that across the sum total of these individual contributions, readers would be able to construct for themselves some sense of the range of issues that could fall under this banner. To maximize the number of contributors and

topics covered, individuals were asked to limit their writing to a brief 3-4 pages. My personal interest involved how the scriptural foundations of different religions traditions depicted issues of disability in their sacred writings. Similarly, I was interested in any official statements or policies emanating from religious heads regarding issues of disability. Readers will see this interest reflected in some of the articles that touch upon the New Testament along with an informative glimpse into Asian disability history. On the other hand, due to the vagaries of people's schedules along with the omnipresent influence of chance, readers will find little on the Old Testament or on other religious traditions such as Mormonism, Native American, or indigenous African religions--to name but a few.

A second area of interest--given my Ivory Tower roots--was how different academic disciplines might come to frame issues of religion, spirituality, and disability. Three contributors, Andrew Achenbaum (history), Nora Groce (anthropology) and Robert Enteen, (Health Services Research) represent examples of how disciplines other than disability studies or religion might frame questions and seek answers to questions about the relationships among the topics of religion, spirituality, and disability.

As I began to identify possible contributors, I quickly found myself drawn into a network of individuals and organizations that was more service oriented than academic and that was decidedly Christian

in its religious orientation. This is not to say that only Christian-based organizations are committed to addressing issues of access and participation for persons with disabilities, but I did find it interesting that a rather strong formal and informal network does exist within the Christian religious community with respect to issues of religion, spirituality, and disability. There most certainly are other religious organizations and service networks out there. I just didn't happen to encounter them. Individual readers will do well to explore what is--and what is not--available within their own communities.

In spite of the rather dominant theological and organizational presence of Christianity in this issue, readers will be quick to note that all of the contributors do not view either the issues or their solution through a similar lens. Across the individual contributions, readers will encounter a number of points of view--not always complementary. As might be expected, issues of religion, spirituality, and disability are broad ranging, multifaceted, and always involving some measure of ambiguity. Topics range from scriptural, to issues of access and service, to the training of religious leaders on how to address issues spirituality and disability in their ministry. On a more political front readers will find that the relationship between the Americans with Disabilities Act and religious organizations is not without its own set of conflicts and controversies.

If I learned anything

singular message about the topics of religion, spirituality, and disability in my brief foray, it is the emergent and nascent nature of this field. The networks are new, highly personal (rather than organizationally based), and anchored by individuals often elementally involved in the disability community and who hold deep religious convictions. Given that my own inclinations are more spiritual than religious, the opportunity to talk with many of these remarkable people has been a personal as well as a learning experience. One thing I can claim with absolute confidence is that this is not the last time you will hear about these topics. Conferences are being organized (see Announcements section), a few important books and resource materials have been published (see Resources), a journal has been formed (Journal of Religion in Disability and Rehabilitation), and readers should note an upcoming special double issue of Rehabilitation Education, with the table of contents and ordering information reproduced later in this issue.

Whenever possible, I have endeavored to provide enough information about contributors to allow interested readers to contact them. They are a special group of people.

In closing, I want to restate my appreciation to Irv for the opportunity to be involved in this project. He had a penchant for taking me in directions I never dreamed possible.

Focus

Religion and Disability Studies: Thoughts on the Status and Future of an Emerging Dialogue

by Nancy L. Eiesland, Ph.D.
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The experience of disability has been an enduring area of religious involvement and spiritual exploration. Avalos (1995) has traced discussion of disability to religious writings from Mesopotamia, Greece, Israel, and other areas of the ancient Near East. Temples, he argues, played a particularly important role in the care of the disabled in these ancient societies. In the Middle Ages, religious organizations, such as monasteries and hospitals, also often assumed responsibility for the care of people with disabilities (Whyte 1995; Turner 1984). Historically, religious charitable societies assisted with often humane care and financial support.

However, religious institutions have also been implicated in long-standing cultural interpretations that construe people with disabilities as tragically or sinisterly sinful or flawed (Fontaine 1995). Organizations which took it as their religious duty to care for people with disabilities sometimes devolved into segregationist lock-ups for those deemed unworthy. Though the notion of disability has never been religiously neutral, its meanings within diverse religious, cultural, and

historical contexts have only very recently begun to be explored as a significant thematic in religious studies.

In Part I of this essay I will present a general overview of the emerging field. In Part II, I present a summary and some pressing issues concerning disability studies in religion.

Part I. A Sketch of the Current Status of Disability Studies in Religion

The exploration of disability in religion has proceeded in three directions, i.e., religious autobiography and biography of people with disabilities and/or their caregivers; pastoral care, religious ethics, and theology; and disability in religious studies. Religious biographies and autobiographies offer experiences and exemplars which are important sources for the spiritual identity of people with disabilities. The examination and elaboration of religious ideas by pastoral and/or academic specialists has been another area of ongoing research. This effort includes theology, religious ethics, and pastoral care and liturgical or ritual guidance. To date, most of this work in English has been done in Christian and Jewish traditions. Finally, disability in religious studies designates academic work which utilizes social scientific and humanistic theories and methods in understanding disability within a multicultural religious context. To be sure, considerable overlap exists among these categories. Yet each area within disability studies in religion defines its distinct primary goals, audiences, and methods.

The body of literature generated by individuals with disabilities who have written their lives, often in terms of their religious struggle and spiritual survival or loss of faith, has flourished in modern times. The narratives of these individuals, such as Helen Keller, Nancy Mairs, Reynolds Price, and Joni Eareckson Tada, reveal that religion and spirituality often have created space for his or her own self-determination in diverse historical and social settings. These people often seek to understand, evaluate, change, and/or embrace religious ideas for him or herself in terms of his or her own experience of disability. On the whole, this genre is individualistic and directed as inspiration, comfort, or challenge to other individuals. Sometimes these accounts are stylized narratives of spiritual overcoming, while others aim to raise consciousness among people with disabilities and the able bodied and to develop a plausible and workable religious worldview as it relates to personal experience. Though these religious stories of people with disabilities sometimes do not fit easily into the socio-political rubric of contemporary disability studies, they are a largely untapped resource for researchers. Now internet discussion groups are also providing important forums for interchange among people with disabilities often about spiritual and religious experience.

Theology, religious ethics, and pastoral care and liturgical guidance, written by academic and pastoral specialists,

represents the vast majority of the scholarly work in disability studies in religion. This body of literature represents the intellectual reflection on the experience of the nature of ultimate reality, of human life in its individual and collective forms, and/or of the natural world of which human beings form a part. Though audiences for this work are varied, the common factor is that it is directed primarily toward people of faith in order to promote religion and spirituality. The intellectual scope in this work is tremendous. Theologies which address concerns of people with disabilities may be liberationist (Lane 1993; Eiesland 1994), Reformed (Cooper 1992; Webb-Mitchell 1994), feminist (DeVries 1994; Roundtable 1994), Lutheran (Govig 1989), or philosophical (Pailin 1992). They may emphasize other-worldly or this-worldly responses. Ethics may emphasize communitarian or rights-oriented goals (Bishop 1994). Pastoral care manuals represent an array of religious traditions (Wilke 1980; Foley 1994). The new Journal of Religion in Disability and Rehabilitation largely publishes work in this class. I also include in this category official theological statements endorsed by official religious bodies, such as denominations.

The tone and perspective of this work also varies widely. Historically, the experience of people with disabilities has been an untapped source for theology, often even theology related to disability. However, increasingly people with disabilities write about themselves, about their

experience and interpretation of faith, their ministry in the churches, their self-understanding. People with disabilities have become the subject of a new theological approach rather than simply being the object of theology, creating theology, ritual, and care-giving strategies rooted in the religious experience of people with disabilities themselves.

Finally, an emergent genre in disability studies in religion is research which employs humanistic and social scientific methods and theories to explore disability as a thematic in religious studies, as has been the case with gender, racial, and ethnic perspectives. The primary goal of this work is not to promote religious belief or practice, but rather to understand it contextually, comparatively, and multiculturally. Examples of this type of research in disability studies in religion are less numerous than the previous two types. Nevertheless, the inauguration this year of a consultation in religion and disability studies in the American Academy of Religion represents an important development. The consultation's call for papers attracted an unusually large number of submissions, indicating the existence of extensive work in religion and disability studies which has, to date, lacked a scholarly forum. Over time, this consultation will hopefully provide a location for cross-cultural, inter-religious discussions of the relation of religion and disability. Topics to be addressed over the life of the religion and disability

studies unit will include ritual innovations for and by people with disabilities; people with disabilities and theological interpretations of theodicy and tragedy; HIV-AIDS and religious belonging and meaning-making; healing movements and people with disabilities; Deaf aesthetics and inter-religious dialogue; legitimation of religious leadership among people with disabilities; religious response to the Americans with Disabilities Act; religious pluralism and the Disabled Peoples' International; and other issues, topics, and historical figures which emerge from the ongoing conversation.

Another sign of development in the field is the matriculation of the first doctoral student in a joint program in religion and disability studies at Garrett Evangelical Theological Seminary and Northwestern University. The establishment of such programs can result in a new area of scholarship that embraces a wide range of subjects which pertain to disability studies and to the study of religion and spirituality.

Part II: Challenges and Prospects

The establishment of a dialogue between those engaged in the study of religion and those whose work is primarily in disability studies has begun to reveal the existence of multiple discourses and complex historical processes in how people with disabilities are understood in relation to religion, ethics, biology, and the institutional structures of society. For example, Ingstad (1995) highlights the

distinction between the general religious beliefs and contextualized explanatory models which were revealed in anthropological field research in Botswana. This type of research is beginning to provide a nuanced and careful exploration of the role of religious beliefs in shaping the myths and attitudes about disability.

In the past, religion, particularly Christianity, often has been carelessly cited as the source of destructive myths about people with disabilities. An example illuminates: "Many people, including the disabled, still believe the traditional myths about the disabled. Some of these negative attitudes have their origins in ancient religious beliefs that regarded the disabled as devil possessed, or as corporeal manifestations of family guilt" (Israel and McPherson 1983:14). Though this statement may be true, it is at best only partial truth that fails to address the particularities of religious and cultural milieus in which such myths and beliefs emerged. For example, Whyte (1995), following Henri-Jacques Striker, contends that Christianity in the Middle Ages did not specifically distinguish impairments from other forms of suffering. She writes, "Infirmity [impairment] and poverty were part of God's varied creation--the order of things. The response to difference was charity, spirituality, and morality" (269). Whyte goes on to argue that it was not ancient religious beliefs which have shaped the contemporary attitudes toward disability but rather it was the quest to

control difference borne of Enlightenment medical views. The role of ancient religious notions in shaping contemporary beliefs and attitudes about disability is an area ripe for research and exploration.

Another area of research yet to be adequately explored is the multiple roles that religion and spirituality have played in resistance, solidarity, and survival among people with disabilities. In the arena of religion, people with disabilities have found support systems, personal fulfillment, and ultimate purpose that cannot be ignored by scholars in disability studies. This history must also be related. In so doing, we also counter the prevailing sentiment that the religious practices and history of the able-bodied constitute the only relevant spiritual pulse and narrative, and that whatever is outside this ambit is of little if any significance to the study of religion.

In challenging this false universalism in others, scholars of religion whose focus or purview includes disability studies are also challenged to develop greater inclusivity within their own work--relating gender, ethnicity, race, and diverse disabilities to the study of religious life. Such diversity can ensure that we no longer have the problem experienced by the editors of the anthology, With the Power of Each Breath, who wrote: "We planned to include a chapter on spirituality. Many women with disabilities seek spiritual assistance for strength and solace as we face the things that can't be fixed. But the articles we received did not

represent a broad enough spectrum of what spirituality can mean for us" (Brown, Connors, and Stern 1985, 11).

In addition to challenging and enriching the study of religion, disability studies in religion is beginning to reveal the contributions it can make in the multidisciplinary milieu of disability studies. It must be understood that religion designates a significant aspect of a major portion of the human population throughout its history. Yinger (1970) defines religion as "a system of beliefs and practices by means of which a group of people struggles with [the] ultimate problems of human life" (7). For people with disabilities challenging the problem of oppression, religion is likely to remain an important resource. Even as the study of religion is increasingly influenced by disability studies and culture, so must disability studies expand its intellectual map adequately to include the study of religion.

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Pastoral Counselors/Religious Professionals and People with Disabilities

William A. Blair, M.Div., D.Min.
and Dana Davidson Blair, R.N.,
M.A.

The author of God, the Christian, and Human Suffering quotes the Jewish philosopher A. Heschel: "The most precious insights into the human situation were not discovered through peaceful introspection or systematic research, but always through the shock of dramatic mistakes. . . . It is continually in moments of deep frustration, crisis and self-disappointment that a person comes to radical reflection...." (Arts 1993:13) This is a statement of great value to spiritual caregivers, for it describes very succinctly much of what they, as professionals, need to acquire - insights - and what they will encounter - human suffering, faltering faith and doubt. It is also a good description of the pain many people with disabilities feel when acceptance of their circumstances has not been reached.

Whether or not these professionals will have the education, experience, compassion, and insight a ministry to the differently-abled demands is debatable. Most of them will probably find there is no specific training for such a ministry included in their education. Some of them will find pastorates that are hostile to the idea of inclusion and acceptance. Others will learn to be chaplains in rehabilitation facilities and in time become genuinely helpful.

If the clergy have no career plans to work with the differently-abled, does it really matter how effective they are in addressing the issues of disability? Is it going to impact on the lives of a pastoral counselor's clients? Yes, in both accounts. Religion serves ordinary people who have accidents and diseases, who bear children with congenital conditions and develop heart problems and arthritis and much more in maturity. Life is change, not always for the better. And very often the parish minister will be the spiritual helper to whom people will turn. He or she is the pastoral counselor.

Long before we became the editors of the Journal of Religion in Disability and Rehabilitation, we were aware that even well-educated and experienced clergy, including pastoral counselors, often did not know how to minister to people with disabilities. This is especially true when it first becomes apparent that a disability is permanent, when people are doubting and blaming God, blaming themselves and are filled with fear, anger, and bitterness. Of course, this is the time of greatest need as well as a time when spiritual and physical suffering coexist in its rawest form. We have been called to speak with people whose spiritual advisors labeled them as sinners, questioned their faith, chastised them for feeling angry, told them they were "chosen by God" to be "an inspiration," or avoided any discussion of the dramatic life changes these people and their families were facing. We find no scriptural or theological

support for such notions or behaviors; no indication, either, that people with disabilities are loved less by the Creator and therefore deserve less the love of humankind. These ideas are the result of tradition, fear, and peculiar interpretations of scripture, much of which has been taken out of context. Too often these responses of blame and dismissal are used as answers to the unanswerable mystery of human suffering and do far more harm than good. Oftentimes the same well intentioned religious professionals who walk roughshod over scripture and feelings of their congregants with disabilities are ignorant of their denomination's resources for help in these regards.

Another consideration is the medical profession's disregard of spirituality as a part of healing. Some facilities routinely include chaplains or pastoral counselors as part of the health care team, primarily in rehabilitation facilities, but very often their services are thought to be peripheral or even a hinderance to the delivery of the more important aspects of technically-based care. This value climate permeates medicine and limits the ability of religious professionals and patients. Religious professionals have not always been allowed to evaluate the spiritual needs of people in crisis, much less minister to these needs. This has begun to change as spiritual strength and the power of faith become more apparent as aids in healing, but it is still not uncommon for the spiritual counselor to be

ignored altogether or at best consulted as an afterthought.

Support for people with disabilities and their families can mean the survival of the family unit, and the most effective religious professionals know what support is needed and where to find it. It is not unusual for families to consult a minister for advice about counseling, effective support groups, shared care programs, and sources of economic aid. Even more common is the family's need for strength, hope, and understanding. They, too, are adjusting. Yet it is a rare minister or counselor who can look at such a family, individually and as a unit, and see the universal human condition and need in them: "...the immense suffering of humanity during the centuries....people...crying out with an anguished voice: 'My God, my god, why have you forsaken us?'" (Nouwen 1988:160). But we all face losses over time, and where life changes are inevitable, the helper's knowledge is a necessity.

The religious system that permits its spiritual guides to remain ignorant about the place of those who are differently abled in God's world must eventually question the depth of its own and its members' commitment to God's service. Those who understand that Divine love is not limited to the young and strong and perfect must also acknowledge that a ministry based on that love cannot be limited.

Resource List

The following resources can be consulted for information on ministry to people with disabilities: Virginia Thornburgh, Religion & Disability Program, National Organization on Disability, 910 16th Street, NW, Suite 600, Washington, D.C. 20006; National Council of Churches, News & Information Office, Room 850, 475 Riverside Drive, New York, NY 10115; World Council of Churches, Justice, Peace & Integrity of Creation, 150 Route de Ferney, P.O. Box 2100, 1211 Geneva, 2, Switzerland; The United Synagogue of America/Association of Conservative Synagogues in North America, 155 Fifth Ave, New York, NY 10010-6802; Torah Organization for Disability Access, 3409 Shelburne Road, Baltimore, MD 21208. A denomination's administrative offices may also be consulted.

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Strategies of Religious Education and People with Disabilities

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In the past twenty years,

with the social movement of "normalization" and "deinstitutionalization" in the 1960s and with the Americans with Disabilities Act (ADA) in the 1990s, more people with disabilities who were once behind institutional walls, are now in America's neighborhoods. People with either a developmental disability, mental illness, a physical impairment, visual impairment, those who are hard of hearing or deaf, as well as people who are visually impaired or blind are no longer only the receivers of care, but are now more active participants in various sectors of public life, including congregations and parishes. In response to the place and presence of people with disabilities in congregations and parishes, there has been the growth of curricular materials in religious education. Both Christian and Jewish educators alike have attempted to educate people with disabilities in these congregations about the religious beliefs of that particular religious community, as well as teaching members of religious communities the issues facing people with disabilities with the purpose of including people with disabling conditions into those communities.

The materials that have been published by religious educators, primarily Christian religious educators, for people with disabilities, especially people with mental retardation, are based upon secular educational strategies of special education that are currently utilized in public schools. There are primarily four general approaches that are used in educating people with

disabilities: segregated class approach; an inclusive or adaptive approach; special Sunday school or "Sabbath" Sunday approach; and a non-interventionist approach.

The segregated class approach takes people with certain disabilities, especially persons with mental retardation, and places all people with this kind of disability into one classroom and one set of activities, separate from other able-bodied classrooms. Separate curriculum is published for this segregated Sunday School class, based on the assumption that the people in the classes will have a certain level of social, cognitive functioning, and is not based upon grade or age-appropriate placement. There is usually a teachers' guide, student handbook, homework sheets, and an audio cassette and filmstrips.

The inclusive or adaptive approach assumes that people with mental retardation or a learning disability will be in a grade or age-appropriate classroom, give or take a grade, and gives adaptation guides that supplement the regular materials. The majority of these materials are written primarily for early grades, kindergarten through sixth grade, but not necessarily for adult learners. The majority of the materials for this approach are aimed at people with mental retardation, behavior disorder, and those with learning disabilities.

The "special" Sunday School or Sabbath day is based upon a similar model of multigenerational events or activities in congregations or parishes. On

special Sundays or Sabbath days, a congregation or parish will engage in an activity that all people may participate in, regardless of their abilities or limitations. It is a day set aside once a year, in which the worship services, youth programs, Sunday school classes, or fellowship hour will be open to all people, disabled and non-disabled alike, to be involved in an activity which is inclusive of the differences that people with disabilities bring into congregations and parishes. On these special days, people with various disabling conditions like physical or sensorial impairments, are included.

The non-interventionist approach is taken by those congregations who do not necessarily have any special curriculum for Sunday school, are not program or curriculum based in educating members, nor do they have a special Sunday or Sabbath day set aside to recognize the presence of people with disabilities in congregational life. Nonetheless, people with disabilities are included as much as they or the community of able-bodied people desire into the worship life of a congregation or parish, depending upon the adaptations made by these religious communities in enabling people with disabling conditions to be part of a congregation's daily life.

A combination of the above approaches are used by many congregations. And in terms of educational strategies for people with a speech or communication disorder, hearing impairment, deaf, visual impairment, blind, mental

illness, behavior disorder, or medical conditions, the adaptations made in secular, public settings may be employed in religious communities.

Research Paper

Spirituality in Children Whose Parents Have Multiple Sclerosis

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Abstract

Ideas about what constitutes spirituality vary since spirituality theorists represent a broad range of disciplines and perspectives. This paper will apply what appears to be a consensus definition of spirituality: an awareness of one's self, in a positive relationship with significant others, and with a greater universal community or power.

The experience of positive relationships usually has been described in association with hopefulness (Jourard, 1970), another important component of spirituality. Hope for transcendence has been identified in various domains such as transcendence over present time (Wendell, 1993), space (Nabigon, 1994), bodily condition (Miller, 1992; Wendell, 1993), current developmental stage (Maslow, 1970), mortality (Jourard, 1964) and life circumstances (Wendell, 1993; Miller, 1992; Hastings, 1992).

Many see spiritual

consciousness as a resource developed through overcoming difficult circumstances. In turn, this resource can then be beneficial in coping with problems in other circumstances (Miller, 1983; Hastings, 1992). Antonovsky (1987) describes a sense of coherence as a personal coping resource which allows individuals to see themselves as participants in shaping their fate and to believe that a legitimate authority or spiritual power is controlling events in their best interest (Antonovsky, 1987:13).

Like other concepts, the notion of spirituality can be better understood by examining particular empirical cases. By grounding definitions in empirical data from children whose parents have multiple sclerosis, this paper identifies the ways in which these children demonstrate evidence of spiritual development.

Children of Parents with Multiple Sclerosis

The case of children whose parents have a chronic disease, such as multiple sclerosis which can impair motor function and less often cognitive function, easily lends itself to an investigation of spirituality for a number of reasons. Unpredictability in the severity and the particular symptoms of parental MS can result in difficult circumstances for children who may experience disruptions in schedules (Beanlands, 1989). Other aspects of life which may be problematic for these children include stigma, low family income, and inaccessible housing, recreation, or transportation, that precludes the

sharing of many activities with their parents. While most early literature describing this population assumed negative outcomes for these children (Arneaud, 1959), children with MS may serve as an example of how one can develop and articulate a sense of spirituality and a feeling of hopefulness given often difficult circumstances. The importance for children with chronically ill parents of valuing friends and of hopefulness is supported by findings of a previous study in which this author investigated family communication (Blackford, 1990). Following is a quotation from a teenager from that study whose father has MS: "It makes you appreciate your friends, what you have...it shows you that you can't look back ...because you can't look at what you could have done...you kind of just look ahead. It makes you live more for right now...what's going on right now in your life." (Blackford, 1990: 20).

In the present study, this author explored the experiences of children whose parents have multiple sclerosis in Ontario, Canada, between 1991 and 1993. Parents who have multiple sclerosis responded to a request for volunteers circulated in MS Society newsletters and neurological clinics. After appropriate explanations, consents to participate in the research were obtained from each family member involved. Private interviews were then conducted with chronically ill parents, their spouses, and each of their children. A total of 18 families and 29 children aged 8 to 16 years old comprised the study population. Participants' described in this paper from 7

of these families have been given pseudonyms in order to protect their privacy, although surnames reflect their ethnicity. Content analysis of interview data related to children's spirituality fell into the following categories: awareness of life, mortality and disability; hopefulness about their own future and about the course of their parent's multiple sclerosis; and a sense of concern for the universal community or of communion with a greater power such as God.

Awareness of Life, Mortality and Disability

Philosopher Susan Wendell (1993) refers to special knowledge and awareness that comes from intimate experience with disability. In this study, children and also their parents with MS referred to looking differently at life, at disability, and at death. One mother with MS, Martha St. Denis, shared the following reflections: "I think with illness, I started to really question what do I want out of life. And life is fragile. So I really needed to define what my needs were and what the quality of life that I wanted whatever was left of it. So, I thank the disease... because it did give me courage. I think I have been somewhere. I have had experiences that no amount of Ph.D's can buy from sitting in a wheelchair, waiting in a mall for somebody to open the door; from, all kinds of you know, a whole side of humanity. That needing someone to feed me. [I] couldn't see for a while. I had acute problems with my eyes. So, those experiences have made me so rich." (Martha St. Denis, mother with MS)

Willis Mills is an eight-year old whom I think of as a "poet philosopher," since he presented with knowledge far beyond his years. Willis faced his uncle's death and chose to say goodbye to him in his own way. Willis' father describes here an incident which clearly showed a willingness on the part of his family, and an understanding on the part of Willis, to acknowledge that we are mortal: "That December my brother-in-law James, who was twenty-four, was rushed to the hospital. He was dead before we got there. This is my wife's youngest brother. He was the one that cared for Willis when I was in the hospital. My wife and him were very close. Willis and him were like this [gestures holding two straight fingers together]. The way Willis dealt with this at the funeral is important. We had to explain to him about death. This isn't just anybody. This is his Uncle James, the one that had bought his first fishing kit. James would always sneak Willis pop. That was one of the things he could drink with ulcerative colitis. James was at his parents. We left Willis there to be babysat by his "Ma Mere." James would be there. They'd watch hockey games together. They had their own relationship on their own." (Luke Mills, Father with MS)

After sharing this background of the relationship between Willis and Uncle James, Mr. Mills went on to describe how Willis demonstrated unusual knowledge about how to communicate his feelings: "Willis went to the funeral. He saw his uncle in the casket. They have the kneeling pedestal. You pray

right by the casket. Willis asked me if he could have a pop. I got a pop. He goes upstairs. He climbs onto that thing. He sits on it. I never stopped him. My mother-in-law is watching all this. She knows of the relationship. He sits there, leans over, pats James' hand, leans back, pops the can of pop with all these people around him and throws [drinks] it back and leans over and holds his uncle's hand. The tears come down his eyes. And he dealt with it. And we knew he would. This is what he did and this is part of the make up of what Willis is. He's very loving, a really sensitive kid. He's had to give up things too. But we've always tried to compensate and he does too. He goes half way. Not all the time. He's still a kid you know." (Luke Mills, father with MS).

We see here a family and a boy for whom the order of life includes disability and death. Family members make room for ideas from both adults and children about how to say goodbye when death comes. Willis has come to understand that we are all touched by mortality. He participates in the process of grieving and chooses his own way to say goodbye. In one respect his experience is a deep burden. In another, it is a form of liberation, a knowledge of the human condition which many others only arrive at much later in life.

Hopes for the Future

Children in the study also expressed hopeful, yet realistic attitudes about the future of family members, including their ill parents, and about their own

future. Penny Chapman described her hopes regarding her father's physical condition: "I'm not asking for a miracle that he'll walk someday. But getting better, where he'll maybe be able to use his walker and walk with the walker around, stuff like that, or have enough strength. Like, when we go on vacation, we can't take his electric wheelchair because of the acid batteries, so we'll take his push wheelchair. Maybe just enough strength to push that." (Penny Chapman, age 11).

Penny's expectations for her own future are also hopeful, yet realistic enough to include contingency plans. "I plan to go to university, either (the local) university or somewhere down in Toronto. In figure skating, I'm going to be professional. I enjoy it a lot because now I'm at the stage where I travel for competitions. If I go into coaching full-time, I'll probably during the day do something like secretarial work. If I don't go into coaching, I plan on being something like a psychiatrist or a nurse" (Penny Chapman, age 11).

Nine-year-old Jillian Workman is younger than Penny, so that her ideas about the future are a bit less realistic. None the less, she is clearly hopeful about the future and still able to allow for contingencies. "My Mom is getting better though. You'll see. I expect she'll get better. I hope she gets better. I'm praying that she gets better, but I don't know if she will or not. I'll live with my Mom until she gets better. Then I'll buy a new house and I'll get married. Cathy will probably be married and be out of the

house by then. My Mom will hopefully be better by that time." (Jillian Workman, age 9).

Alain Gagnon also describes his hopeful plans for himself and for his father who has MS. "No I might not stay in [this town]. I might be going into say the NHL. St. Louis, Boston, anywhere. Dad'll probably move. This house is getting too old anyways. He doesn't like the city. He'd stay around here. Get another house. (Alaine Gagnon Jr., age 10).

I asked Willis if he expected to live in the same house when he grows up. His answer reveals a generally optimistic view of the future and faith in his father who is also hopeful. "No, I don't. I don't think so because my dad has a real hope in his mind that he can get a better house in the country or something or build his own. The MS, it'll be pretty much the same." (Willis Mills, age 8).

Charlotte Brothers describes her wishes for the course of her father's MS and for her personal future in these terms: "I wish that my Dad never gets bad with MS. And in my synchronised swimming I want to be like Carolyn Waldo. I swim almost every week when I'm at school. My teacher says that I probably will make it to be like Carolyn Waldo. I'm the youngest swimmer in my level. I'm a star five." (Charlotte Brothers, age 11).

Children's participation in fund raising for medical research can be both a source of and a sign of hopefulness. My interviews revealed that many children and many parents long for a cure and see research as a possible avenue to curing MS. In spite of the representation of

people with MS as dependent and unable to have children for which many organisations such as the MS Society have been criticized in the past (1) (Blackford, 1993), participation in fund raising for research brings hope that there is some concrete way of making life better for an ill parent or for others with MS.

Simon Brothers shares his views on fund raising for support services: "There was a time when I found out that my Dad had it [MS]...A friend, the woman that lives across the street from her, has it. [My friend] goes over there and watches her. [The woman's] at the point where she has to have someone there or she 'freaks out.' So we were going to get sponsors, make some money [for this neighbour]. We thought of lots of ways. We talked to people. But nobody took us seriously of course, because of our age. Maybe in the future when I get older, I'll raise some money for it." (Simon Brothers, age 15).

In this case we see Simon concerned about a disabled woman's need for supportive care, and willing to organise a sponsorship plan so that she will be able to afford such services. Eventually children are frustrated when their work is dismissed 'because of age.' However, Simon expresses a sense of hope that his fund raising interventions "in the future when I get older" will improve the life of someone with MS.

Communication with God and Concern About Others Around the World

Finally, these children describe hope that extends beyond the individual and the

concrete, reflecting a global understanding of the world. Some adults with chronic illnesses have reported increased affiliation with organised religions, an affiliation which they see as inspired by their experience of disabilities (Hastings, 1992). In this study, Penny Chapman (age 11) and her eight-year-old brother, Jillian Workman (age 9) and Willis Mills (age 8) referred overtly to religious faith and prayer. "We pray about them. We don't know what's going to happen. We always have to pray for them. We just go, 'Well I hope my Mother is alright.'" (Jillian Workman, age 9).

Willis Mills admits that he is: "Always hoping that the next day will bring something that can cure MS or something. Everyday. Because I'm a Christian, eh. I have a little bible and a big one that we share. [Dad and I], we tell each other about stuff." (Willis Mills, age 8).

Children in this study also described ideas for improving the general health of the population at large. Such global considerations are spiritual in the sense that these children see themselves as part of a larger universe of shared responsibility for caring. Some dreamed researchers would find a cure for MS and for AIDS. For many children, the goal was to bring about universal physical access. Others considered the possibility of obliterating disability stigma. Some try to live peacefully with their friends while others wish for an end to all war.

Some volunteered thoughtful suggestions about how to end smoking through health teaching

of family members in some cases and through public education or regulatory laws in others. As noted by Alain Gagnon's father, "He was telling me again last night [that smoking is bad for my health]." Alain Jr. keeps himself informed about current research findings about tobacco use. "Cigarettes. Lung cancer. Lip cancer. Lots of people talk about quitting. It's not really the people. It's just, can't quit. Once you're on it, you're stuck there." (Alain Gagnon Jr., age 11).

Penny and Tom Chapman see social action to create accessible transportation as a form of social justice for their father, and for many other disabled people. "We have the handi-transit now. They used to never come down our way. The wheel trans wouldn't come this far. I thought that was really unfair. There's a lot of people I know in wheelchairs and there are others that have MS. So I know it wasn't fair." (Penny Chapman, age 11).

Sandra Taylor (age 14) knows about the difficulty her mother experiences when she is on the street with her scooter. Sandra's hopes for the future include a physically accessible world where the curbs would be altered for wheelchair access.

Paul St. Denis donates time to MS Society projects. He envisions a cure for MS and life threatening diseases. "I wouldn't mind someone finding a cure for MS. A cure for all diseases you could die from, like AIDS or cancer, but also MS. I would hope that everything goes through. No problems. I went to the hospital where there was a Christmas Party for the MS

people." (Paul St. Denis, age 13).

Willis Mills wishes away MS, but makes contingency wishes in case MS does not disappear. Like Penny Chapman and Sandra Taylor, he hopes for improved access for all disabled persons. "Well, if I had some wishes I'd probably wish that there was no such thing as MS. But I also wish that there was more scooters because people you know get tired and they need some way to get around. So use a scooter, don't get tuckered out. I wish that everyone feels better." (Willis Mills, age 8).

Willis Mills also hopes to eradicate air pollution which is emitted from a nearby industrial smoke stack. His concern is largely based on his own smoke allergies, although he is also concerned with plant life and the environment in general. Willis explains his position with a flair for metaphor and drama. "I wish that big national cigarette over there would stop. It's driving me nuts. I'm talking about the smoke stack - the giant cigarette. It's smoking. I wish that was gone. I wish there was a cigarette that you could smoke that made you actually healthier. You should see it over there. I'm surprised those trees can even grow down here. You see the smog here. Sometimes you can barely see through it. It's often that I have to hold my breath because I'm allergic to smoke, even cigarette smoke." (Willis Mills, age 8).

Finally, Willis tries to transform social peer relations at school into the more harmonious world he believes should exist. "I don't like people

fighting. I only fight if the kid is on top of me and I can't move an inch. There's [a particular student] that's always picking on me. He hasn't succeeded. I usually out run him. I told on him a few times. He grabbed onto my shirt. I either drag him with me to the teacher or I shake him off." (Willis Mills, age 8).

We see here children thinking beyond their own needs, with concern for others in terms of curing major illnesses, creating universal physical access, reducing pollution and practicing peaceful coexistence.

Familiarity with a Parent's Disability as a Source of Hope and Spirituality

Given the uncertainty, increased chores, stigma, and reduced income often associated with parental multiple sclerosis, children in this study have reason to be dispirited and to feel vulnerable. How then can we explain evidence of such personal strength indicators as hopefulness and spirituality in children with parental disability? Based on this small number of interviews, one basis for children's spiritual development appears to be an intimate understanding of multiple sclerosis, acquired through a disabled parent's proximity and disclosure. Jillian Workman provides this lesson. "You have to know someone who has MS. My Mom is always telling me, 'Nobody knows what it's like unless you have it or unless they know someone.' You can talk big of it. You can say 'Well, it's nothing.' My Dad [who doesn't live with us] always says to my Mother, 'You can walk around. Leave the

wheelchair alone. Leave the walker.' Because my Dad thinks it's all a big joke. Right! My Mom...if she ever tried to walk around the whole basement without her walker or wheelchair or cane, she would fall. She would hurt herself. You should always know things about MS." (Jillian Workman, age 9)

Thus, children become familiar with their parent's conditions. Spirituality has also been associated with searching for clues that confirm the feasibility of hope and with appreciating even the smallest positive experiences (Wright & Shontz, 1968; Miller, 1992). Some children in this study learned to identify indicators of incremental improvement, even when that change was minimal. For example, Penny Chapman justified her hopeful attitude about her father's physical condition, based on his extended time tolerating a wheelchair. "He's been better in the last few years. Like, being able to do more things. He can stay in the wheelchair a lot longer. He used to be able to stay in it for about two hours. Then he started getting really tired and sore. [Recently] when we were watching the baseball game, he stayed in his wheelchair four and a half hours." (Penny Chapman, age 11).

The hope Penny displays is for small increments in physical condition, but improvements none the less. The focus of her hope demonstrates her knowledge about the disease, based upon her lived experience in observing her father's illness.

Conclusions

Experiences in living with MS and acknowledging disability

appear to form the basis on which hope emerges. Penny and the other children described in this paper also verbalize a clear sense of themselves in relationship to their parents and to others in a larger, beneficent world in which they can make some positive difference.

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Notes

(1) The MS Society's emphasis historically on research and its solicitation of children to take part in the Read-A-Thon Program is not without a potential dark side (Blackford, 1993). After 50 years of neurological research funded by the MS Society, no cure exists, so that research funds could be framed as a means to support the employment of research physicians, or a commodification of children. Certainly, these funds are not earmarked for supportive programs for the children who raise the funds.

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Perspectives

Imagining a History that Illuminates Disability and Spirituality

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The very best works of history are works created through imagination. Sometimes an author's imagination seems inspired: the writings of First Isaiah and the Gospel according to John are representation of this category. In other works one can see the vision of a master historian: Henry Adams' account of the early American republic, for instance, is poetic in its use of irony and statistics. For the most part, however, historians get in touch with their creative imaginations by grappling with those works that seem to embody conventional wisdom. Revisionism animates imaginative analyses: one cites the conclusions of one's elders so as to destroy the argument and replace it with a new thesis - for some other untenured person to attack and revise.

This strategy, of course, presupposes that there is a masterpiece to attack, a major historian whose findings no longer satisfactorily explain what we want to know. It is easy to make one's reputation writing a revisionist history of the U.S. civil war because there is always some new "spin" that necessitates a reworking of familiar evidence, a challenging of ideas that seem now irrelevant. Blazing new ground, paradoxically, tends to be a less fruitful way to make a name: other scholars are not

interested in what you have found, unless you show that this area is rich to be explored. In the case of cross-disciplinary work - where an historian must combine two interests - the challenge becomes geometrically daunting.

Such is the case in imagining what a history that conjoins disability and spirituality might be. In preparing this commentary, I did what historians in the computer age are wont to do: I checked all of the data bases in the University of Michigan catalog. I found no work, in English at least, that seemed to fit the bill. From my own research into the history of aging, I had some ideas about what I might find. I remembered that Carole Haber had stressed Cotton Mather's disabilities in his later years - afflictions that kindled even greater faithfulness to God's will. Not that spirituality necessarily increases with age. Tom Cole suggests that G. Stanley Hall wrote Senescence because of a spiritual crisis. These two examples were useful, but they merely seemed to be suggestive.

Perhaps the way to proceed was to scan the scholarly literature under each major heading. If we confine ourselves to historical works, the yield is disappointingly small. Most histories of disability take an institutional approach - they describe the care of the blind, handicapped, or mentally ill, or they trace the evolution of federal, state, and local provisions for the needy. They rarely let the disabled speak for themselves. As a result, we rarely hear our subjects voice their spiritual yearnings or

anguish. Conversely, studies of spirituality, in the fragmented way that historians try to divide their turf, typically fall into the categories of the history of religion or, alternatively, into cultural history. In this instance scholars would read a lot of theological treatises by men and women who may have been disabled in some way or another. But that fact of disability would be so recessive as to be useless for our present purposes. So what are we to do?

A sensible tack would be to focus on either a patently "disability" case study where the "spiritual dimension" could be teased out or to start with a spiritual dimension and then focus on those historical actors who were disabled. Let us consider each in turn.

Although biographies are not fashionable these days among professional historians, I would select a well-known figure who was creative during a long, productive career. Ideally, my subject would become disabled sometime during the second half of his or her career and that person would have left letters, essays, or other commentaries in which the ways in which their disability nurtured and thwarted their creativity, especially in ruminating on their place in the larger universe and in relationship to the Ultimate Reality, would be made manifest. Possible subjects are May Sarton and Henry Wadsworth Longfellow. So is an author familiar to readers of this Quarterly: Arthur Frank who manages to refer to the sacred and the profane in his allusions to Scripture and his accounts of his own illnesses and the

disabilities that beset others.

At the other direction, I would recommend that people probe Scripture, not just the accounts of blind people and lepers, but in particular the ways that members of the early Jesus movement empowered the disabled to join their fledgling faith community. (For this, the Book of Acts and the Pauline epistles would be useful.) I then would focus on latter-day groups, such as the Shakers, whose dwindling numbers in the twentieth century made it very important to rely on everybody's capacity to make some sort of contribution.

It is quite possible, however, that the first study of the relationship between spirituality and disability in past times will be prompted by a frantic call to an historian to provide some sort of historical perspective to a very contemporary issue such as the fate of aging nuns or monks in cloistered communities. Should that happen, then we can count on the historians to try to ground the "problem" into a particular set of historical circumstances. To the extent that a broader story emerges out of the fact, we will be well on the way to imagining a new form of historical inquiry.

Disability, Spirituality, and Religion: An Anthropological Perspective

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The question of disability, spirituality, and religion from an anthropological perspective,

is an intriguing one. It is also one that has received almost no attention in the anthropological literature.

Let me begin with a sweeping generalization. In the broadest sense, anthropologists seek to answer two basic questions: what is universal to all peoples and what are the particular/unique adaptations that distinguish one culture from another. These two questions are in fact linked. Anthropologists spend a good deal of time examining unique or discrete cultural adaptations, with the hope of establishing universal patterns. Specific cultural adaptations are seen as manifestations of more universal human behavior. For example, marriage patterns among groups X, Y, or Z may be very different from those of their neighboring ethnic or tribal groups, but they are in fact reflections of all societies' need to establish a culturally recognized family that will provide a social and economic support for its members and children for the next generation.

Given this perspective, I would initiate a discussion about disability, spirituality, and religion by turning to existing ethnographic sources with two major questions.

First, do all religions address issues of disability either specifically in their teachings or by implication in their practice and/or outreach? If so, are there some themes that appear to be present in all cultures? In fact, based on what is already available in the literature, I would note, that among the universal issues that seem to revolve around disability are the following: a) all

religions seem to provide some explanation for why certain people (and not others) are born with or acquire a disabling condition be it through reincarnation, violation of taboos, God's will, etc.; b) all religions studied to this point seem to have specific roles that individuals with a disability may or must play, both within the religion and within the society as beggars or objects of charity, holy people or sources of inspiration, etc. Often these categories are rather confused. For example, in Western Christian historical thought, children and adults with a disability often are thought on the one hand to be cursed by God and on the other to be particularly pure and holy. c) Finally, all religions are tied closely with a larger social order and so in a very real sense religious beliefs and practices toward disability seem to have serious ramifications in the broader community.

The second question asks if there is a link between the nature of society, religion, and the expectations of both society and religion towards individuals who have a disabling condition. The question is already partially answered in the anthropological literature. Certain types of organized religions tend to appear in concurrence with certain types of social organizations. (A religion may spread far beyond its point of origin, of course.) However, we know that specific types of religions are tied to broader social patterns. For example, small scale, tribal religions tend to be polytheistic (a belief in a number of deities) and tend to arise in

small-scale egalitarian societies where there are few "roles" to fulfill. Monotheism is a highly centralized form of religious belief which usually arises in more complex, hierarchical societies. In such centralized societies, the role of the individual in regard to the state will be significantly different from that in smaller scale societies. Centralized societies such as kingdoms, empires, and more recently democracies also tend to have much larger populations with individual filling already defined roles and responsible to the state for participation as citizens, the payment of taxes and often military service. In small scale societies persons with a physical, psychological, or intellectual impairment would be more likely to be viewed as individuals and be accorded a full and meaningful place in the community. Conversely, larger, more complex societies with their divisions of labor and more narrowly defined role responsibilities are more likely to consider persons with disabilities as being ineligible for certain roles and thus more subject to the label of "social burden" and thus relegated to life as a beggar or as a recipient of charity.

Finally, the link between disability and spirituality and religion can also be looked at on a more personal level. There has never been a culture reported in the anthropological literature that did not have a religious tradition. Indeed, there has never been one reported that does not have a complex religious tradition. What is the link between religious beliefs either as

explanatory models or as articles of faith and the individual? What role does this play cross-culturally in the lives of some individuals with disability? How do individuals with a disability reconcile often harsh religious attitudes toward disability with their own spiritual needs?

Where would one go to further investigate such ideas? The current ethnographic literature would be a start and there is a good deal written on the major religious traditions, although actual practice toward individuals with a disability will almost surely be different from the religious ideals. However, I suspect, real progress in this area will only begin when actual field work is pursued or, put another way, when anthropologists begin to ask individuals with a disability in cultures around the world to reflect on their own experiences and share their own insights on these subjects.

Religion, Spirituality and Disability: A Health Services Research Agenda

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Data from many studies indicate that the great majority of Americans, including Americans with disabilities, believe in a god or spiritual being. Yet the impact of religion and spirituality in the lives of people with disabilities and their family members has been insufficiently investigated.

Research in this field has

been based primarily on anecdotal reports and qualitative analyses, with little quantification and comparative study. Moreover, the focus of most research to date assumes a strictly beneficial effect: that religious/spiritual beliefs and values are assistive in coping with the "adversities" of physical and mental disabilities. While such studies and assumptions can be useful, they are not definitive.

Perhaps the most methodologically rigorous investigations having at least an indirect bearing on the question of religion and spirituality and disability are those that have been undertaken in the field of psychosomatic medicine. At some distance from the psychosomatic literature is the superabundant lay "self-help" literature, replete with books such as *When Bad Things Happen to Good People* (Harold Kushner), *The Road Less Traveled* (M. Scott Peck), and *Love, Medicine & Miracles* (Bernie Siegel).

A recent national conference may signal a move toward more and better studies on religion/spirituality and disability. On May 1-3, 1995, the National Center for Medical Rehabilitation Research convened a meeting in Bethesda, Maryland, on "Roles of Religiousness and Spirituality in Medical Rehabilitation and the Lives of Persons with Disabilities." A worthwhile background paper distributed to conference participants (Lynn Underwood Gordon, "Role of Religiousness and Spirituality Among Persons with Disability: Applications to Daily Living") offers a conceptual model, an overview of the literature, and a

bibliography.

With all due immodestly, I offer the following personal list of proposed questions for research as a complement to the foregoing:

(1) How, if at all, do people who identify themselves as holding "religious" or "spiritual" beliefs differ from those who do not in their psychological and social reactions to the onset of disability in themselves or in their family members? Similarly, in their long-term response to the disability and its consequences?

(2) How do religious/spiritual beliefs influence one's intellectual response, i.e., the explanation one offers to oneself and others for the occurrence of disability? (3) Do people from various religions differ in regard to the foregoing? In what ways? How can these differences be explained? How might aspects of their respective religions belief systems and rituals account for identified differences?

(4) How, if at all, do religious/spiritual differences translate into objective differences in clinical outcomes?

(5) What roles do religious institutions and "communities" of co-religionists play in one's formal and informal support systems?

(6) What formal disability related services do religious organizations provide?

(7) What are the negative effects, if any, of religious and spiritual beliefs? For example, do some religions promote stigmatization of individuals with physical or

mental disabilities? Or do they universally serve to ameliorate stigma?

(8) What happens to people's religious/spiritual beliefs and practices following onset of disability? For example, do some people withdraw in anger and disenchantment from their prior religion affiliations? Do others "become" religious? Why?

(9) What role do religions play in promoting or deflecting people from traditional (i.e., generally accepted medical model) providers and treatments? With what implications, for better and/or worse?

(10) What formal role do religious organizations play within the health system? For example, do religious hospitals and nursing homes address special needs or particular segments of the disability community?

(11) What practical effects do providers' religious beliefs have on their practice patterns? With what implications for the people they serve?

(12) What problems, if any, have religious/spiritual institutions and communities created for people with disabilities. For example, how have people with disabilities been portrayed in religious writings and visual arts? With what effect?

(13) What changes, if any, are occurring in the relationship between religion/spirituality and disability? Why are these changes occurring?

(14) What effects do religious beliefs have on one's response to health practices and providers? For example, on compliance behaviors, such as taking medications? On

postponing treatment? On finding qualified assistance? On becoming accurately informed about one's disability?

(15) How do religious and spiritual beliefs promote or impede functionality, self-sufficiency, one's sense of "suffering," one's optimism and related efforts to maintain or improve one's condition?

(16) What, if any, are the objective benefits of prayer? Do these differ from those of the "placebo effect?"

Finally, most importantly, I propose that more sophisticated and quantitative research designs, and more adequate resources, be applied to studying these and related questions.

Disability Studies Among the Asian Religions and Philosophies

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Disabilities have been known and recorded in the civilizations of South Asia and China for some 4,000 years. Although much disability material exists in the religious, legal, medical, educational, and traveler literature of the region, studies published in European languages have been few. Nonetheless, hopeful signs are appearing. In recent decades inter-religious studies have emerged, along with Asian cultural studies and academic exchanges. Disability has achieved academic standing as a topic. As more scholars seek promising fields to explore, the interface of Asian religions and philosophies with disability may prove attractive. The present

review sketches some needs, interests, and issues of the field and mentions some work that has been undertaken.

First, some hors d'oeuvres: existing translations provide important glimpses of Asian disability history. For example, in one of the Buddha's incarnations, as a baby prince, he was horrified by the judicial severity of the king. The babe could not countenance unethical behaviour, so he resolved to remain deaf, dumb, and motionless. As he grew, courtiers tried an audiological test. They cut spy-holes in the curtains around the prince's bed and while someone suddenly blew a conch, they checked to see whether the child was startled. Later, the courtiers tried norm-referenced tests tempting him successively with milk, fruit, toys, or animals according to the different ages at which they said a child usually reacts to such stimuli. Whatever one may think of reincarnation and the historicity of such tales, the disability assessments ideas were clearly recorded over 2,000 years ago in Muga-Pakkha Jataka Bk. XXII, No. 538 (1).

The Analects of Confucius (2) are normally read for their influence on Chinese cultural philosophies rather than for etiquette with blind visitors. When blind music-master Mien came to visit, Confucius intimated where the steps were and guided him to the sitting mat. When all were seated, he told Mien who was present and where they were placed. Someone asked later if this were a recognized procedure and was informed that it was (Book XV, 41). Politeness to her blind bridegroom caused the princess

Gandhari to blindfold her own eyes (3). This might not appeal to feminists now, but in the times of the great Indian epic Mahabharata (Adi Parva, Sect. CX) it won great respect and continues to inspire modern Indians.

Disability in Asian religions is much more than a fascinating academic pursuit. As disability is targeted globally for prevention and remediation (or alternative, as disabling social structure are unmasked and denounced) change agents find themselves in conflict with traditional beliefs and concepts which too often are seen as purely negative. Clearly, religious beliefs are a major factor in shaping thoughts and attitudes among the bulk of the South Asian population. Yet in the literature of community-based rehabilitation - a favoured development strategy of the 1980s - one finds dismissive comments about the attitudes of target populations toward disabled people which are said to be based on "false" beliefs, e.g., that disability is a punishment for sins either in the present or past life. It is then usually suggested that these "false" beliefs should be replaced by the facts, i.e., modern "correct" beliefs.

Few western-educated people now believe that disabilities are punishments from unseen forces such as ancestors to whose spirits one has been disrespectful; yet it seems a little arrogant to dismiss religious and traditional beliefs without making efforts to understand just what is believed, how it fits into the believers' general world view, whether beliefs are undergoing

changes, and how far they might be held concurrently with the belief-pictures of medical science. The defective gene theory of some disabilities remains largely a belief in unseen forces unless one credits the interpretation placed on the pattern of dots seen under a microscope by people in white coats. The white-coat theory, in which ancestors send harmful material to a random but statistically calculable proportion of their descendants, is obvious nonsense judged by the belief systems of a large part of humanity. The "reason" offered by the white-coats looks more like fatalism, i.e., it lacks any reasonable explanation of cause and effect that could be influenced by one's conduct, present or past; whereas, to the white-coats, it is the "primitive" beliefs which appears fatalistic. There is room for much more study of the practical effects of such conflicting causation beliefs.

The Asian religions and philosophies appear to teach a measure of dispassion toward suffering or disability with disabling conditions presented in some respects as having little or no ultimate significance. Within religious world views that have continuing relevance for 3 to 4 billion people, one may even welcome a measure of disfigurement and dependency to counter the delusions of youth, beauty, and independence. At the same time, it would be a mistake to view the religious traditions of Buddhism, Hinduism, Islam, and the Chinese philosophies as containing clearly demarcated messages about the nature of disabilities including appro-

priate and inappropriate social reactions to persons with disabilities. For example, a recent introductory study (4) lists items from the historical treatment of disability in contexts of Hinduism, Buddhism, and Islam which might be viewed as positive by "right-thinking westerners" as well as elements that would be negative or difficult to many westerners and some easterners. Yet such lists merely whet the appetite. They are not the "the teaching of Buddhism or Hinduism about disability." Great temerity is required even for a learned person within one religion to describe its current interface with disabilities let alone for an outsider to try. Nevertheless, some work is under way toward formulating accounts of what disability has meant and may now mean within the Asian religions.

Several European groups are taking an interest. In Germany, the Arbeitsgemeinschaft Behinderung und Dritte Welt (Disability and the Third World which is coordinated by Jordanian Musa Al Munaizel) has begun a series of articles on disability and religion in its newsletter (5) and has a group specialising in the Islamic world. Since 1991 Ken Parry at Manchester (6) has run a regular seminar on religion and disability with a variety of speakers. In the Netherlands members of two allied groups, Foundation Comparative Research and the Study Group on Transcultural Rehabilitation Medicine, supported production of C.F. Vreede's Guide to ADL (7) and Arthur Vreede's bibliography on traditional disability concepts, attitudes, and practices (8).

The ADL guide concerns rehabilitation "as though people's beliefs mattered" informed by long experience in Indonesia and studies in Indian religion and philosophy. Another Study Group member, Deliane Burck, produced a model study of beliefs and practices in the context of an African community-based rehabilitation project (9).

Further organisations probably exist with relevant studies in progress. Work on non-western culture and disability, with pertinence to religious belief, by Nora Groce, Laura Krefting, Sylvia Walker, and their various colleagues will already be familiar to DSQ readers. Publications of the International Exchange of Experts and Information in Rehabilitation have added usefully to the literature (10). Benedict Ingstad and Susan Reynolds Whyte recently edited a fascinating collection covering disability beliefs in a wide variety of cultural contexts (11). A forthcoming tome edited by Gary Woodill will include some considerations of religion and disability (12). On a different plane, a few religious networks such as that of L'Arche International conduct daily practical studies of living together in community with severely disabled people. Some of the Indian L'Arche communities involve people of three or more faiths who find that L'Arche's "house rules" (the Beatitudes of Jesus) are acceptable to their religious traditions (13). A network of Baha'i adherents has been active over some years in developing Third World disability services with some informal recording of

experiences (14). The World Council of Churches disability contact post, now held by Korean theologian Ye Ja Lee, is open to dialogue with other faiths (15).

Some isolated studies have appeared that are useful, but which may not be part of an ongoing disability-related work. For example, Ariel Glucklich made a scholarly report on disability provisions in the Dharmasastra (16). Tunisian Kamal Tarzi wrote thoughtfully on mental handicap in Islam (17). Hyun Younghak linked the experience of crippled Korean beggars with a theology of suffering (18). Akiie Ninomiya discussed historical and religious attitudes toward disabled people in Japan (19). Subodh Chandra Roy's thesis (20) recorded the historical treatment of blind Indians. He noted a distinct set-back as the Vedic period gave way to the Upanishadic, when an emphasis on transcendental values led to a withdrawal from social interests and activities, to the detriment of blind people (pp. 260-61).

China studies are developing rapidly, but few authors have described the beliefs or cultural philosophy underlying disability activities. Brief contributions have come from Gustafsson (21), a perceptive visitor (pp. 198-203); and from Dai-Hua Shen (22) who discusses cultural values in disability service (pp. 243-46). The philosopher Qiu Renzong (23, 24) discusses ethical issues in the disability field. Some of his conclusions would be unpalatable to many westerners because Renzong writes what he thinks rather than trying to please westerners. Others from developing countries are often

defensive in the face of western cultural domination presenting only a sanitized version of their religion and culture and reinforcing the barriers between the small "modern" sector of their country and the masses who actually practice the religion.

This lightening sketch must conclude with apologies to authors whose valuable work may inadvertently have been omitted and to scholars and believers who feel that great profundities have lightly been skated over. There is indeed a challenging, multi-faceted, and richly rewarding field of human experience here awaiting study.

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Midsection: Issues

The Church and Disability: A Trinity of Issues

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Why has the Church neglected to do its homework in the area of disability and chronic illness with respect to

biblical studies, systematic, historical and practical theology, especially pastoral care, liturgy, and preaching? Why, in 1995 and several years post-ADA, are we just beginning to work on these issues? Worse, why has the Church resisted doing this work, and why does it continue to do so? For many of the years of my work on disability issues and their relationship to the Church, I saw the list of problems becoming more extensive and the issues getting more complex. But just as the seemingly chaotic pieces of a kaleidoscope suddenly fall into a pattern, so too did these issues become organized into three major categories, each with a different protagonist. They are: personal, theological, and institutional.

I have used a wheelchair for 18 years and so will use myself as a case in point. What does it mean to the average person to encounter me? Whatever else it may mean, it is to be reminded of his/her own vulnerability and the vulnerability of those whom they love. To be reminded, at however deep a level, that they and theirs are but a traffic accident, a fall, a dive into a too-shallow pool, away from being - in their language - a cripple, or, worse yet, a "helpless cripple." To be reminded that even in their sleep in the safety of their homes, a sinister disease can creep in and begin chewing away at nerve and muscle tissue, undetected until it is too late. They see me as loss, as options no longer available, as life's hopes and dreams aborted. Life as existing, not flourishing. And ultimately, as a harbinger of their own final vulner-

ability, death.

It is at this point that the lines blur between the personal and the theological issues because there is still present in the kind of thinking described above more than a trace of that old "stuff" of the Scriptures, the pre-scientific world of a three-tiered universe (God and heaven above, earth in the middle, and waters/the deep/hell below). It is a world which knows nothing of germ theories of disease, of genetics, of birth abnormalities. Everything that happened was caused by God. Those who bore the disfigurement or deformity of birth defects or the results of later disease or injury are seen to bear a stigma, a sign of God's punishment and rejection. These are a sign of estrangement from the Holy One and those who bore it are marked as Other, not as Holy Other, of or pertaining to the Divine, but as the opposite end of the spectrum, shunned, unholy, untouchable Other. Even as sophisticated as we claim to be today, there is a great deal of that ancient world which effects even the most logical of us. Germ theories and accidents notwithstanding, God is seen to have caused - or refused to prohibit - the disease or accident. This has to be my fault and I need to confess, repent, and/or open myself to God's reconciling, healing power. But then the able-bodied person is forced to examine his or her own life, which means a recognition of their own sins and shortcomings and a simultaneous awareness of how vulnerable they therefore are before this fearsome Divinity who can disable at will. These

are frightening, even terrifying questions which totally upset our equilibrium; it is no wonder that we shun them.

The second series of issues is centered on theological questions about the identity and the purposes of God. In short, we are faced with another form of the theodicy problem: God is all-loving, God is all-knowing and all powerful, yet evil, disease, and disability exist in the world. An all-loving God would not want to see God's people ill or injured. An all loving God would never punish God's people with something so terrible, would God? An all-powerful God would stop the accident from happening, minimize the injuries, or send a miracle to effect a cure. And if our God is not all-loving and all-powerful, then what kind of a God do we have? Or what are we to understand about God's love, God's might? Are not the very hairs on our heads numbered and known and valued by God? How could that loving protection permit my need of a wheelchair or my constant pain?

The last group of issues involves the institutional Church and the fact that we live in a consumer-oriented society where marketing is of prime import. The Church acts out of a mind set which says that laity, especially the un-churched, want the best value for their investment, whether it be of dollars, time, or energy. For the Church and its evangelism efforts, it would then stand to reason that persons with disabilities pose a problem. How could the Church ask a person to be baptized, be faithful in attendance at worship, see that their children

are in Sunday School each week, bring something tasty to share for potluck suppers, pledge or tithe, and, oh yes, your "reward" might be to end up like this woman. No, the Church needs Beautiful People in order to promote itself in a marketing economy.

Is there Good News in all of this? You bet! And it's from the People of God themselves. Somehow, despite all the categories of issues just named, many people know better. In my experience, again and again, I have seen confirmed the laity's understanding of the integrity and authenticity of the paradoxical symbols which I embody: Good Friday and Easter. Most people are self-aware enough and wise enough to know that their lives are lived more in Good Fridays - or in the dread of the next Good Friday they will have to endure - than they are in Easter. Many have had only an occasional glimpse of Easter. Even the most fortunate look over their shoulder or listen for the shoe to drop which tells them that the noon-day sky is about to darken. Thus, for them, my Good Friday embodiment and Easter life and faith ring true, far beyond what "Join our fellowship and only good things will happen to you and yours" can signify.

I pray that the Church will dare to be bold, to take the leap of faith which allows it to confront personal, theological, and institutional issues in such a way that, together, we can all be people of the Easter Faith regardless of our abilities and disabilities. The Church is, after all, the Body of Christ. To lose or cut off or shun any of its members is therefore to

disable itself.

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Conference on Spirituality and Disability Held by NIH

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The last taboo in rehabilitation is finally coming down. Whereas sexuality is now an acceptable, if not comfortable, topic in rehabilitation circles and substance abuse among people with disabilities is finally being addressed, we can turn our attention to the spiritual part of our being. Many of us claim that this is the key to our success in life and our source of strength, yet it is rarely, if ever, discussed. The National Center for Medical Rehabilitation Research, part of the National Institutes of Health, together with the Fetzer Institute, a foundation that is dedicated to the study of the relationship of the physical, mental, emotional, and spiritual dimensions of life, initiated a forum for this discussion by

holding an invitational conference on "Roles of Religiousness and Spirituality in Medical Rehabilitation and the Lives of Persons with Disabilities" on May 2-3, 1995, in Bethesda, Maryland. It was two days filled with exploration, controversy, and heated debate.

Three perspectives were represented at the conference: researchers from geriatrics or medical rehabilitation, chaplains and rabbis, and people with disabilities who were academic researchers, clergy members, and/or advocates. Following are some highlights of the points of convergence and controversy from this author's perspective as a rehabilitation researcher, woman with a physical disability, and advocate for disability rights.

There is a substantial difference between spirituality and religiosity. Discussions of definitions surfaced early in the conference and everyone was in agreement that spirituality is related to perceptions of the transcendent, while religiosity is related to the group behaviors and social institutions that arise around those perceptions. Religiosity is more easily quantifiable in terms of creed, ritual, and social behavior. It has, therefore, more often been the subject of research than spirituality, which by definition defies measurement. There is a critical need to apply qualitative research techniques to the study of spirituality and the spiritual (as opposed to social) aspects of religion.

The religious behaviors of persons who are elderly have

little to do with the religiosity or spirituality of people with disabilities. There is a sizable body of literature, though mostly of poor quality (uncontrolled designs, narrowly defined parameters, white male samples, etc.), related to religion and geriatrics. This area was well represented by researchers at the conference stemming in large part from the fact that the Fetzer Institute and the National Institute on Aging had just conducted an invitational conference on the topic two months earlier. It was with no small amount of ire, however, that participants with disabilities responded to notions that findings in that domain are transferable to ours. One psychiatric researcher stated that aging and disability have in common a loss of control over life. This reflects a serious lack of understanding among traditional academic researchers of disability as a context for living throughout the lifespan. There is a wide range of emotional responses to disability that, when combined with the ordinary demands of physical and emotional survival as a child, adolescent, or adult, create an enormously complex life situation. It is simplistic to claim that the effect of spirituality on response to disability is analogous to the tendency of people to become more religious as they approach old age. Similarly, studies of religious coping in chronic or acute illness may not be transferable to disability, which is generally a more multidimensional, lifelong phenomenon.

Are we spiritualizing medicine or medicalizing

spirituality? This question, posed by Carolyn Vash, a clinical psychologist with a disability, captured the fears of many that the medical model of disability that we have been struggling for decades to dissolve is now invading the study of spirituality. By forcing spirituality into categorical units and predictable behaviors, we may be setting up yet another way for people to be labeled and stereotyped. Many of us who found resonance with transcendental influences from the East, prefer to strive for a modification of traditional medical and research practices that will enable the discussion of spirituality as a part of life and create new mechanisms for understanding how spirituality influences the response to disability by the individual and society.

Spirituality and disability as a topic for research is highly problematic. Discussions of research methodology revealed many problems that can arise in the study of spirituality and disability. Even when using qualitative techniques, which are much better suited for this topic, interpretations of data must consider the individual's age at onset of disability, cultural attitudes toward disability, possible effect of cognitive impairment, involvement of family in the interview process, rights to privacy, and constraints placed on the conduct of research by rehabilitation hospitals.

Religious institutions and actions by clergy often seriously violate the rights of people with disabilities. Testimonies given by Ginny

Thornburgh of the National Head Injury Foundation and the Rev. Nancy Lane, an Episcopal priest with cerebral palsy, revealed that church facilities are in large part inaccessible and attitudes of clergy and religious communities tend to be paternalistic and discriminatory. Exemption of religious organizations under the Americans with Disabilities Act leaves advocates with little leverage to make change. Rather than being as inclusive and welcoming as many churches claim to be, they sometimes restrict participation in their activities by people with disabilities in subtle and overt ways.

There is debate over whether all rehabilitation clinicians should be encouraged to address the spiritual needs of their patients or whether this should be the domain of chaplains only. There was considerable heated discussion of the incorporation of spiritual counseling into the practice of occupational and physical therapy and nursing. There was agreement that it is beneficial for all clinicians to be sensitive to the spiritual crises or needs of the people they work with, but disagreement over the degree to which spiritual counseling can be appropriately delivered by an untrained individual. Serious concerns were raised over the individual's right to privacy and the emotional vulnerability of some persons in early stages of comprehensive rehabilitation.

There is an urgent need for a better understanding of the effect of spirituality on living with disability. All the persons with disabilities

participating in this conference experienced a strong influence of spirituality on the way they have dealt with their disabilities. The point was reiterated many times that virtually nothing is known about the phenomenon. There is a strong call to investigate the role of spirituality and religion in the lives of people with disabilities, interventions that may help resolve spiritual crises that arise in response to disability, and the efficacy of spiritual services in medical rehabilitation settings.

Disturbances from Afield: Mind Over Matter Does Not Keep Body and Soul Together

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My field is the Academic Study of Religions (Religious Studies) and my interests and work fall into the third of the areas delineated by Eiesland in her article in this issue of the Quarterly. As she clearly enunciates, the methods and theories engaged by scholars in this area are drawn from the humanities and social sciences. However, there are some valuable differences which set Religious Studies apart from any one of the other humanities or social sciences. These differences have to do with method, observation, theory, and interpretation and the particular ways in which the discipline privileges some aspects of evidence over others in the interest of insight. The purpose of addressing these

issues in this context is to widen the future interaction of religious studies and disability studies.

Let me begin with the words necessary to the current discussion: religion, religious, religiosity, spirituality, theology, religious studies. Few seatmates on airplanes make distinctions between spirituality and religion or between theology and religious studies, but, in the field, careers and reputations are often advanced or diminished in the process of distinguishing one from the other. Consequently, speaking about religious studies and disability studies together requires some active engagement in the vocabulary of field. To that end let me declare my use of terms in this essay, at the same time saying what this essay is not. It is not about any particular established religion although I draw content from many. It does not directly address practice such as dance, prayer, healing. (Ritual liturgy, piety, religiosity). I am not writing theology which is a primarily western endeavor, usually linear, often systematic. Nor am I going to explore the lives of recognizable saints with recognizable disabilities or the spiritual and/or inspirational insights of individuals (spirituality). All of these have been done, are being done, and need to continue to be done.

Why Religious Studies?

I am prepared to make the claim that no discipline is more adept than Religious Studies at addressing the study of race, class, gender, or disability. Furthermore, I believe bene-

ficial understandings can be attained from the combination of religious studies and disability studies. At the same time a caution against academic imperialism and colonization may be in order.

Three contributions which Religious Studies might make to the study of disability come from the internal construction of the discipline itself. These methods of inquiry and presuppositions are more than ad hoc. Religious Studies, as now constituted was born postmodern and multicultural in the 1960s. It is among the youngest of the academic disciplines and yet its heritage is among the most ancient. One notable difference between Religious Studies and some related fields is the former's admission of otherwise inadmissible evidence. In Religious Studies empirical evidence includes intangible experience, something often inadmissible in a field which adheres more closely to traditional scientific methods. For example, dreams, visions, or supraordinary occurrences are often treated as valid data for analytical purposes.

A second variant lies in theories of interpretation or hermeneutics. Interpretation in Religious Studies is characterized by a reflexive attitude: why these questions, problems, formulations? Triangulation, or the combining of quantitative and qualitative methods is often assumed and so Religious Studies invariably identifies the sum as great than any particular combination of the parts. I am not suggesting that Religious Studies is alone in this, but only that it is integral to the field.

The third potential contribution is more complex and can be probed by examining the phrase, "keeping body and soul together." This is more than a statement about the tensions of economic impoverishment and no discipline struggles more with the detrimental effects of body/mind or body/soul dualisms than the field of Religious Studies. But Religious Studies carries an alternate legacy as well. Something akin to what Adrienne Rich calls "thinking through the body" (Rich, Adrienne, Of Woman Born: Motherhood as Experience and Institution, New York: W.W. Norton, 1976, passim) has longstanding currency among religion's thinkers. Known to and subsequently rejected by anthropologists and religionists is something called "participation mystique." This concept, first described by Levy-Bruhl, provides a way of experiencing and identifying with what is initially encountered as "other." Joseph Campbell links this idea inextricably to religion when he says: "It has been one of the chief aims of all religious teaching and ceremonial, ...to suppress as much as possible the sense of ego and develop that of participation." Campbell is making the point of "indissociation" between subjective and objective aspects of experience. (Campbell, Joseph, The Masks of God: Primitive Mythology, New York: Viking Press, 1959, p.85)

Let me be more explicit about the correspondence of "thinking through the body" and participation mystique. What Rich is pleading for is thought rooted in bodily experience. What might be called thought

from down under in which neither body nor mind is completely object or subject. She is not suggesting that thought or mind be brought into conformity with the socially constructed body, but rather for a continuum of subject and object which is quite like Levy-Bruhl's idea of participation mystique.

Viewing this phenomenon as a primitive or pathological identification needing to be made conscious, outgrown, or cured does a disservice to an ancient talent. A West African proverb instructs: "I am because we are. We are because I am. I am We."

Academic study has lost a sense of commonality yet purports to be multicultural and interdisciplinary. How in the world do we dare study difference without first cultivating some sense of persons as "we"? I believe Religious Studies provides clues about how to reveal, cultivate, and promote such thinking and identification. Unlike Jung and other critics of participation mystique I have no fear that the ego or individualism of western scholars will be swallowed up by the "other" if we cultivate this sort of thinking.

Furthermore I see this ancient concept renewed in the postmodern cyberworld as the notion of virtual reality. While virtuality can be regarded as fainthearted fake, benign approximation, the "next best thing," outright deception, and all increments in between, I mean to insinuate that virtuality provides unique opportunities for cross cultural viewing. In virtual reality, virtual experience is available. When I play virtual basketball I

experience myself as the player on the screens. Observers cheer "as if" at an actual game. When the shaman "becomes" the eagle god, he experiences himself as such. Those around him both remember and forget that he is the local shaman and the otherworld god.

Through virtual experience we can put to rest assertions such as only women can teach women's studies; only people with disabilities can do disability studies. Why? Because the possibility of shared experience is present. I want to argue that once this concept, so important to religious studies, is understood it de-otherizes that which is studied and makes common experience accessible.

Reasonable Caveats

We risk tribalizing the actual experiences/lived realities of people with disabilities by theorizing about disability. The argument is plain: I/we have suffered as a result of an actual situation in life, therefore, using my life in any theoretical, non-concrete way denies the pain, difficulty, discrimination I have suffered in this "real life." Writers Adrienne Rich and Susan Sontag both experience negative criticism for using lesbianism (Rich) and illness, especially AIDS (Sontag) as metaphors. No doubt these criticisms will continue, nevertheless, the possibility exists for disability and Religious Studies to remain grounded in or originate from an experiential base. This is what I mean by keeping body and soul together.

Future Explorations

Let me suggest a few areas

of study which combine Religious Studies and disability studies and which might contribute to the pursuit of meaning in these combined fields. They are mentioned here simply because I can imagine exploring them in future work.

The Boddhisatwa as the Broken or Wounded healer.

Disability as desirable; religious practices which disable: footbinding, scarification.

How do we learn to expect/desire only what we are capable of?

Are there "natural deviants?"

People with disabilities as plot devices by means of which the gods "show off."

Why was heresy among New England Puritan women determined by whether or not they had given birth to "monster children?"

How do we learn what is attractive?

Purity and danger: Disability, otherness, and obscenity.

My next undertaking will focus on the last two topics, founded, as I have argued, in experience. My three year old grandson, Marley, was playing happily with several children in a room full of balls at a local play area. A little girl of about the same size and age was playing along side, laughing and giggling. Both children were submerged in balls. When they came up for air the little girl had her back toward Marley and they laughed and played for some time until he reached out to touch her. She turned, looked at him and began to shriek in indisputable terror: "Get away! Get him away. He looks funny." Marley has Down's Syndrome. Is

different dangerous?

Disability from the Point of View of Religion and Spirituality

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Robert has been working on the office computer system for a few months now. He is there part-time while he attends Gallaudet University. Robert is likeable and well-dressed, and very competent at what he does. He is also deaf. One day his supervisor approaches him. "I have been thinking about this. I am a Christian. Robert, if you had more faith, you would be able to hear!"

Rosalie visits a church for the first time. Because she is deaf, but can do pretty well with her hearing aids, she sits in the front. When the healing service begins, she is asked to come forward. Feeling pressured, she does. The minister prays loudly, covers her ears, and asks the Lord to heal her. She is stunned, but wants to be polite. The next week, when she visits the church again, she leaves her hearing aids off. Now Rosalie can understand almost nothing, but she does not want to disappoint all the people who prayed for her.

Both of these stories were told to me by students in my capacity as a teacher of philosophy and religion at Gallaudet University. My training is in the academic study of religion, not as a religious professional. I

searched religious literature for information on disability. I was disappointed. Disability is rarely talked about in religious writings and practices, most often in "miracle" stories.

These two stories illustrate the general attitude of a kind of religion toward people with disabilities. In explaining this, I will focus mainly on Christianity, since that is the majority religion here in America, but these attitudes are found throughout the religions of the world.

Robert and Rosalie were both puzzled by their experiences. What should they have said? What is an appropriate response to such intrusive behavior? My personal response was anger. I was furious that a "religious" person would presume to know the state of another person's faith. I was angry that Rosalie was pressured into a prayer service that she really was not interested in. Frankly, I especially wanted to punch Robert's boss in the nose and throw a pie in church. But, since we were in an academic setting, Robert, Rosalie, and I tried to understand what was such disrespectful behavior. A few themes emerged.

1. The disabled are thought to be morally responsible for their own imperfect physical condition. Human beings need to make meaning out of their lives. Events and conditions need to have a purpose and an explanation. The idea that there are random events that affect us, but which we cannot control is very difficult for people to accept. If you are starting from a religious perspective,

things such as having a physically imperfect body must have a religious cause. The thinking runs like this: "I have a strong faith in God. My body is functioning and healthy. Therefore, my strong faith must be causing my health. I see someone who has a body that does not function well. Therefore, this must be caused by a lack of faith, or the sins of the fathers, or bad karma."

This need to explain everything has roots in human consciousness, the need for continuity, the need to answer the question "Why?" It is also based on the fear of anything different or unknown, which leads to the next theme.

2. Disabled people are feared by non-disabled people and are therefore explained away and marginalized. Fear is a powerful motivating force. When some able-bodied people see disabled people, it scares them. Somewhere they say to themselves, "This could be me! I couldn't tolerate that (wheelchair, sign language, guide, whatever). It would require too many adjustments and changes from me, and it might mean that God does not love me." This is usually on a deeply unconscious level.

On a conscious level, they might think "It could never happen to me." This is magical thinking based on fear. In order to deny that fear, these people then come up with an explanation of why the other person is disabled. This can often be a religious explanation. God made that person disabled as some kind of punishment. If I can be good, God won't do this to me. I can avoid that kind of suffering."

Of course, this is also avoidance of emotional, mental, and spiritual growth.

3. Disabled people are healed in miracle stories and these are often taken literally to mean that all disabled people should and would want to be healed in this way. The parables of Jesus in the Christian New Testament give many examples of Jesus healing people. Whether or not such miraculous healings occurred, we know that Jesus often spoke and told stories on many layers of meaning at one time. A story about a mustard seed is about faith, not gardening. A story about a camel walking through the eye of a needle is not a riddle, but about the proper attitude toward wealth and eternal life. So, too, we might understand these healing stories as having another layer.

In Mark 7:31-37, Jesus heals a man who is then able to hear and talk. This is a story about being open to God, not just a story about a deaf man who hears. It is not the few that the literal story applies to, but the many who can understand the need to be healed of a heart or a life closed to God. A literal understanding of these healing stories may pressure disabled people into seeking healing to become "normal." But the Bible also emphasizes free will. We are not pawns in a giant chess game, but intelligent beings created in the image and likeness of the Divine. It is difficult to understand how some people could presume to take away the free will of disabled people in determining their own values and making their own choices. Inhibiting another persons's

free will is not a biblical attitude.

All three of these themes leave much to be desired. After many years of listening to stories like Robert's and Rosalie's, I would like to propose some alternative ways for religion and spirituality to approach disability.

Life is for learning. Some people are taking the honors course. Life is a school room and each of us is taking a unique course of studies. No cheating is allowed. I cannot cheat and try to take your tests and tell you how to live. If I am paying attention, I have enough of my own homework to do. In religious terms, God has designed for us a life to learn what our soul needs to know. Lessons about patience, understanding, looking at people's inner qualities instead of external conditions, courage, compassion, generosity are taught in the schoolhouse of life. They are not lessons unique to one particular group of people such as people with disabilities. They apply equally to all of us.

It is never appropriate to compare the courses you are taking with someone else's course of study. You are given what you can handle or maybe simply what challenges you. Just remember that some of us must have signed on for an accelerated program and have forgotten that we did so. This explains why some lives seem so much harder than others. But of course the rewards are also great. Who are the most spiritually inspiring people you know, rich, beautiful movie stars or ordinary people who have faced adversity with

courage and style? Just remember that in spiritual matters things are not always what they seem and God has a notorious sense of humor.

When given the choice, choose love over fear. The human ego is an amazing thing. The ego is so handy for organizing and accomplishing things. On the other hand, the ego can take over and try to be such a perfectionist that it finds the slightest lack of control too frightening to face. Fear, and denial of fear, and then projection of our own fear onto others as judgement of them is, one set of ego defense mechanisms.

If you wish to serve your spirit instead of your ego, choose love instead. Love expands where fear contracts. Love makes life more fun, while fear hides in the corner. Love takes risks with people while fear is stuck in what it already knows and expects. "Love is but a song we sing, and fear the way we die. You can make the mountains sing, or make the angels cry...." You can learn a lot more with love than with fear.

Everyone's life needs healing. Healing stories are inspiring because they give us hope. These stories do not apply only to people with obvious physical or mental problems, but to every human being that ever lived. Every human being who has ever lived has experienced suffering. There is no escaping this. Every human being at times has shown lack of compassion for others, and could use healing in their heart. Every human being has been afraid of other people and has been cruel as a result of this fear, and needs forgive-

ness for this mistake. Every human being feels separate from God and every human being could use a healing of that relationship.

When it comes to healing, it is most often our lives that need the most work, not our bodies. For those who wish to pursue hopeful avenues of physical cures, that is a very individual decision. Anything is possible, but sometimes it seems that the laws of the physical world mean that the body simply can not totally heal. In fact, we all will experience a "failure" of our bodies on the day we die.

Healing our lives is a possibility open to all of us right now. Robert does not necessarily need more faith so that he can change the physical structure of his ears. He is a strong, competent, self-respecting person who is proud of himself as God made him. After the confrontation with his boss, Robert did need to work on forgiving such stupidity and ignorance so that he would not be poisoned by bitterness and resentment. Like all of us, Robert also needs more faith to be able to live a life of increasingly expanded compassion for and service to our fellow human beings.

Rosalie is a kind, outgoing person who is loved by all who know her. The healing that needed to be done here was of the minister, who thought he could presume to know what someone else's free will might choose. And Rosalie needed to heal her need to please others instead of standing up for herself and what she wants. In the years since this event in the church, this is exactly what

she has done. She now is employed in a position of great trust and is raising a foster daughter.

Healing our lives is a challenge, yes, but the rewards are immediate. The spiritual path you choose to follow, whether the teachings of Jesus that call us to love one another or the Jewish understanding that we serve God when we help our fellow human beings or the Tibetan Buddhist teachings on the compassionate heart or some other religious tradition, is up to you. One basic principle is shared by all these teachings though. Love is always more powerful than fear and if you use love to guide your life, you are healed.

**Embracing Those Unwelcomed:
The Role of Christian Initiation
in Excluding Persons with
Disabilities from Participation
in Public Worship and Community
Life**

The Reverend Ms. Valerie C.
Stiteler

While I still was a student minister, a young couple in the parish where I was working became pregnant with their first child. Six months into the pregnancy, the mother developed toxemia. As a result, their son was born three months premature and with multiple disabilities.

The child lived for three weeks. In that time, he came to be loved by his family. When he died, his family grieved as deeply as they would have if he had lived a much longer life. The couple was heartbroken.

Sunday morning came and the

senior pastor asked me to do the pastoral prayer in the service. Pastoral prayers are usually constructed in a way that they capture all the joys and sorrows of the worshipping community in one moment of the liturgy. What I did not realize - and I do not think the pastor did either - was that the same Sunday we were mourning the death of this child, we were also celebrating the life of another child with the sacrament of baptism.

This was a very painful pastoral moment for me. How could I give myself over to the sorrow of one family losing a son while expressing joy for the birth of another healthy boy? Neither family was free to release their emotions and be supported by the worshipping community. I felt helpless during the prayer and I believe it was very hard on everyone present that morning.

Putting aside that the senior pastor used poor judgement in not rescheduling the baptism, there are some more disturbing elements of this story. I do not know if the dead child was baptized. If he were, it happened in the hospital and was never honored by the worshipping community. It is very possible he was not, since he was in an incubator in the intensive care unit. There was no formal funeral for him, even though he had been given a name and was grieved over by his family. The most unsettling aspect of this episode for me was that after he died, no one ever spoke of him again, even after his parents gave birth to a baby girl.

When studying how people with disabilities enter Christian worshipping communi-

ties, it is important to start methodologically with the religious oral (1) tradition of the disabled community itself. Acknowledging that the disabled community has its own storytelling abilities and its own oral tradition regarding religion challenges us to recognize that people with disabilities have their own record of religious history coming out of experiences of oppression and inclusion. Almost all theological discourse - either pastoral or academic - is done from the church's perspective of including people with disabilities "into" or "back into" the worshipping community.

Using the oral religious tradition of people with disabilities as a measure for liturgical praxis allows us to validate that people with disabilities are a minority (2) with commonly shared life experiences and culture. It credits us with the possibility that we have a unique experience of the Divine which is not being articulated within faith communities. (3) Our spiritual formation requires the acknowledgement of our need for theological and liturgical symbols expressive of our faith beyond the rites of healing and reconciliation. (4)

Christian theology states that through baptism all people are welcome into the worshipping community, but the oral tradition of the disabled community says this is not so. Many people with disabilities do not feel welcome at worship. Encouraging attendance by making churches architecturally accessible has failed in most worshipping communities. "Not

only are many of the Church's physical structures inaccessible, but our liturgy, attitudes, ceremonial, and doctrine (our social structures), preclude full participation in Church life." (5)

Baptized Christians who are disabled tell me they feel hated for being disabled and they are constantly told that if their faith was stronger they could be healed by God. They feel stared at and rejected by others in the community.

This hostility is widespread and also involves the families of disabled Christians. One disabled man told me that when he was born, a well meaning woman in his church walked up to his mother and asked her what sin she had committed to be punished with a blind child. This behavior is so hurtful to people with disabilities and their families that they turn away from God and their faith communities.

The World Council of Churches document known as Baptism, Eucharist, and Ministry states: "The Christian baptism is rooted in the ministry of Jesus, of Nazareth, in his death and in his resurrection. It is incorporation into Christ who is the crucified and risen Lord. It is entry into the new covenant between God and God's people. Baptism is a gift of God and is administered in the name of the Father, the Son, and the Holy Spirit.... Baptism is a sign of new life in Jesus Christ. Baptism is participation in Christ's death and resurrection. By baptism, Christians are immersed in the liberating death of Christ where their sins are buried; where the old Adam is crucified with

Christ and where the power of sin is broken. Thus, those baptized are no longer slaves to sin, but free." (6)

The B.E.M. document clearly defines baptism as the only initiation rite for entrance into the Christian religion. It demonstrates that - although there are several theological traditions regarding baptism - the two dominant theological norms are cleansing away sin and spiritual rebirth. Since the participation of people with disabilities has only received recent attention (7) among Western Protestant (8) churches, and since disabled people claim to feel unwelcome at worship, is it possible that these two primary theological norms within the rite of baptism are promoting the exclusion of disabled people from worshipping communities? This article is intended to be only a heuristic survey, but there is enough evidence to begin a conversation.

People with disabilities have long been defined as the "charity cases" (9) of the Christian Church. Disabled people are kept out of the worshipping community by the community members' fears of "difference." (10) Effort is also made to preserve the identity and integrity of a given worshipping community by associating human disabilities with religious "stigma" (11) as marks of sin.

One person even went so far as to say to me that disabled people themselves prefer not to be part of the worshipping community because of the shame they feel regarding their disabilities. This kind of statement provides a clue for us that disabled people's

spirituality is expected to be based on suffering (12) and this conflicts with the baptismal doctrine of initiation as spiritual rebirth.

Spiritual rebirth occurs when God acts in the rite of baptism to create a permanent spiritual change within the person. The individual is freed from the effects of sin and incorporated fully into the Body of Christ. The new life offered in Christ is transformative and is often indicated by the giving of a white robe, the anointing with oil, and participation in the eucharistic meal.

The transformative nature of spiritual rebirth is usually illustrated by the healing stories present in the New Testament. Raymond Brown, for example, speaks of the healing of the blind man in John 9 as a baptismal account. (13) This parable is a powerful one for disabled Christians because it is a direct statement from Jesus that blindness is neither a cause or an effect of sin. If Brown is correct that this is a baptismal account - even if only allegorically - it demonstrates how the baptismal motif of spiritual rebirth is problematic for people with disabilities.

The Gospel tradition claims that Jesus ministered to the poor, those in prison, and had an active healing ministry. The response of the oral religious tradition of the disabled community to Jesus' healing ministry as illustrated in John 9, however, points out that the disabled people in the New Testament - unlike the poor and prisoners - only became members of the community after they were healed.

Spiritual rebirth as a sign

of the bodily transformation to wholeness - either spiritual or physical - and restoration back into the worshipping community denies the person's disability as part of his or her Divine creation. One of the strongest scriptural statements we have acknowledging disabilities as part of Divine creation is in Exodus 4 when God states that disabilities are a consequence of Divine creative power. God tells Moses, "Who makes humans dumb, or deaf, or seeing, or blind? Is it not I, the Lord? Now therefore go, and I will be with your mouth and teach you what you shall speak."

The transformative action of spiritual renewal in baptism is paired with the washing away of sins. This theological norm is even more problematic for people with disabilities because it is directly linked to the levitical laws regarding the maintaining of purity within the worshipping community. Aidan Kavanagh states the following regarding the Hebraic ablution rituals surrounding purity and impurity which predate Christian baptismal practices: "impurity was by contact with such numinous realities as blood, corpses or tombs, animals defined as 'strange,' or with persons suffering from certain diseases that were manifestly loathsome no matter what the subjectivity of the sullied person might be. Yet the focus of the matter rested not on the impure object but on the effect contact with it had upon the person, who was ipso facto rendered unfit for any relationship with God or, by extension, with his people. Ritual uncleanness resulted simultaneously in what we today would

recognize as civil and religious excommunication....

"...the nature and function of the impurity can be discerned in the rituals designed to avoid it (as in the rituals of food preparation and diet) or to overcome it. The latter in particular were largely rites involving water, sometimes specified as running water. Their development was especially rapid in the New Testament era as the codification of earlier practices was undertaken by rabbinical schools. For them, with the washing of bodies must go the cleansing of hearts." (14)

I contend that even though Christian theology does not claim that maintaining ritual purity is a consideration when developing Christian initiation rites, it is still a major part of Christian theological and liturgical consciousness. The levitical sanction against the presence of disabled people at worship was ingrained in early Christian worship practices (15) and is still operating in the emotional consciousness of many members of the Christian community today. Evidence of this consciousness is reflected in the language and imagery used in baptismal rites.

The consciousness of ritual purity is most present in the use of water to represent the cleansing of sin and anointing for healing. The B.E.M. document makes this startlingly clear: "As seen in some theological traditions, the use of water, with all its positive associations with life and blessing, signifies the continuity between the old and the new creation thus revealing the significance of baptism, not

only for human beings, but also for the whole cosmos. At the same time, the water represents a purification of creation; a dying to that which is negative and destructive in the world. Those who are baptized into the body of Christ are made partakers of a renewed existence." (16)

Based on the preceding argument, one may wonder why if so many disabled people do not feel welcome in Christian communities, why are so many of them baptized? Bear in mind that when baptismal practices were developing in the first century, they were unified rites signifying the conversion of adults consisting of the convert's education, baptism with living water, anointing with oil and then admittance to the eucharistic meal. (17)

Current liturgical practice broke up the initiation rite so that - even though eucharist still remains as the only repeatable aspect of baptism (18) - baptizans seldom receive eucharist at their initiation into the worshipping community. This practice was partly influenced by the baptism of children which was fully developed by the third century. (19) Eucharist is often now delayed until confirmation when an adolescent can make a personal profession of faith. (20)

Baptized Christians with disabilities are rarely seen at eucharist which is now the sign of community participation even in churches that practice monthly or quarterly communion. Many disabled people either do not attend worship at all or have the eucharist brought to them in their homes. Full

participation in the eucharist is now the "true" symbol of incorporation into the community, not baptism.

In order to recover baptism as a welcoming initiation rite for Christians with disabilities, I want to propose some additional methodology to use with the oral religious tradition of our community. James F. White presents a helpful tool for our exploration.

He describes his measure of liturgical praxis as the "liturgical circle." (21) This circle begins by observing worship customs, determining the theology they articulate and then revising the liturgy with the constantly renewing theology.

This is a functional approach. This method derives theology from the sacraments rather than imposing upon the sacraments an abstract theology that fits some better than others. (22) This, coupled with our oral tradition, will allow us to begin assessing whether baptismal theology itself is promoting the active exclusion of people with disabilities from the worshipping community or if the forms of the rite along with its metaphors and imagery are creating a hostile social atmosphere within Christian communities. More careful study of the Christian historical traditions regarding the baptism of people with disabilities will elucidate the influence of theology on the role Christians with disabilities have within church communities.

One other method we could employ in examining the value of current initiation rites for people with disabilities is exploring how Jesus Christ acted

(23) toward people with disabilities during his ministry and then valuing their response as participants in their own salvation instead of as just subjects to be acted upon. To what extent do the healing stories reflect the emphasis that either Jesus or the Church placed on baptism as a healing sacrament?

The development of the baptismal traditions are not as codified as current literature may lead us to believe. (24) Through critique of the roles people with disabilities have been assigned throughout church history, we may find groundbreaking material which will help us to honor ourselves as disabled Christians with gifts to offer the Church through our presence in community.

Peter - the child I spoke of at the beginning of this article - was unwelcome in his church community. I doubt that he is even remembered by many of the people who were in the church at the time of his birth and death. Even though he was unwelcomed by his community, he is still remembered by his family, by me, and most especially by God.

The challenge is before us all to make a welcome place for everyone in our church communities. Those people with disabilities who want to worship in Christian community deserve the freedom to participate in ways that express their uniqueness as people of God. Providing architectural access alone is not a true "welcome." Disabled people need to be embraced by the community. We need to be accepted and honored for who we are as Christians and members of the church community.

Notes

1. I do not mean solely the literally "spoken" tradition of storytelling with oral language, but the collective life experiences and images held by the disabled community regarding organized religion.

2. Harlan Hahn, "The Politics of Physical Differences: Disability and Discrimination," Journal of Social Issues 44, No. 1 (1988): 39.

3. Valerie C. Stiteler, "Gathering Together: Forming Faith Communities among Persons with Disabilities," Disability Issues 14, No. 7 (July 1993): 1.

4. James F. White, Introduction to Christian Worship, Revised Edition (Nashville: Abingdon Press, 1990), 181. White writes: "Protestants have paid a penalty for the loss of healing as a sacrament, partly by the outcropping of bizarre and spectacular efforts to minister to a basic human need: the desire for God's help in restoring health." This theological premise contributes significantly to the exclusion of disabled people from Christian community life. Most of the literature regarding disabled people in the Church is found in discourses on physical and spiritual healing.

5. Christopher Newell, "Reflections on The Church and People with Disabilities," St. Mark's Review (Winter 1990): 26.

6. World Council of Churches, Baptism Eucharist and Ministry: Faith and Order paper #111 (Geneva: World Council of Churches, 1982), 2.

7. David Briggs, "Churches Cut Back Ministries to Disabled," The Patriot Ledger,

13/14 August 1994, 36. It is interesting to note that in 1981 almost every American Christian denomination had ministerial programs for the disabled community and as of October of 1994, all but two major denominations have closed their ministries to the disabled community.

8. The Western Roman Catholic Church and the Eastern Orthodox Church have been addressing issues regarding ministry to people with disabilities for centuries. The attention, however, has been focused largely on the eligibility of receiving the Eucharist by people who are deaf or mentally retarded.

9. Susan Hanaford, Living Outside Inside, A Disabled Woman's Experience: Towards a Social and Political Perspective (England: Canterbury Press, 1985), 30.

10. Sara Fischer, "No Inclusivity without Accessibility" The Witness, 73 (December 1990): 19.

11. Erving Goffman, Stigma: Notes on the Management of Spoiled Identity (New Jersey: Prentiss Hall, Inc., 1963), 1.

12. Esther C. Stine, "The Disabled, the New Community and The World," Church and Society (January-February 1979): 10.

13. Raymond E. Brown, S.S., The Gospel According to John (I-XII), Introduction, Translation, and Notes, vol.29, The Anchor Bible, second edition, (Garden City, New York: Doubleday and Company, Inc., 1985), 380.

14. Aidan Kavanagh, The Shape of Baptism: The Rite of Christian Initiation (New York: Pueblo Press, 1978), 6-7.

15. Sara Fischer, "No Inclusivity without Acces-

sibility," The Witness 73 (December 1990): 18.

16. World Council of Churches, 7.

17. Kavanagh, 9.

18. White, 218.

19. Ibid., 196.

20. Ibid., 180.

21. James F. White, Sacraments as God's Self-Giving: Sacramental Practice and Faith (Nashville: Remington Press, 1983), 10.

22. Ibid.

23. White, Introduction to Christian Worship, 169. Liturgical scholars debate whether or not Jesus commanded the institution of baptism, or if the more correct methodology when evaluating the scriptural tradition regarding baptism is to evaluate Christ's actions.

24. Ibid.

Viewing Christian Theology Through Evolving Disability Lenses

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Care of the invalid, the crippled, the halt and the blind was viewed as a charitable duty; the giving of alms sufficed to quiet the harsh realities of such tragedies. But evolving miracles of medical science and rehabilitation techniques have drastically altered the scene. Each year hundreds of thousands of people rescued from premature death by these evolving interventions hope to find welcome and inclusion; to take their rightful place within their religious communities. Too often they find the ancient

conceptual lenses through which good people view disabilities distort their potential and fail to see that each of us are essential in building the Body of Christ on earth. There is need to re-grind those theoretical lenses and end the patterns of exclusion and fear.

FIRST: There is need within our theological thinking for a paradigm shift from a medical model, which sees people with disabilities as "patients" with "special" needs, to a political-socio-economic alternative which conceptualizes the environment as the "handicapping" factor.

SECOND: A more relevant definition, that: "Disabilities are the expected, moral and anticipated result of the risks, stresses and strains of the living process itself," needs to be articulated. This new perspective views disabilities as an expectation within every social group rather than as an individual tragedy. Therefore universal design moves to the top of the church's agenda, since none must be excluded from the circle of concern.

THIRD: The symbol of the Cross is essential in the faith life of all Christians. But we are also the Easter people, who look beyond Good Friday to the sunrise of Resurrection when Christ revealed the power of the human spirit to prevail. The familiar theological view that those with disabilities are joined with Christ in suffering can be extended to view each rehabilitation as a minor recapitulation of His Resurrection. Thus we confirm we are all a part of His Body.

FOURTH: Pity limits, shames and never elevates the

person toward whom it is directed. It is an unwanted and unwarranted projection of society's fear and discomfort. Respectful compassion and mutual recognition of our shared fragility must replace it if we are to be united as church. Those who utter the phrase, "There but for the grace of God go I," often fail to recognize the verdict they apparently are leveling against those whom they pity.

FIFTH: This fifth alteration in our conceptual lenses is pivotal if we are to fully celebrate the lives of our brothers and sisters who are disabled. For if we grind a new conceptual lens which views the natural occurrence of human vulnerability and fragility as a vital part of God's plan, we see beyond past fears and loathing of that status. Until we can view this trait as valuable to the health of any social system, we will lack motivation to alter our current patterns of inadvertent exclusion and separatism.

Our vulnerability, which has been encoded into our gene pool, can be the catalyst which brings us into community and church with renewed recognition that we need each other and our god. When He tied the gift of life to the trait of vulnerability, He may have given us the essential incentive to counter our tendency toward disregard of our mutual need for each other. Our interdependency strengthens us as community. "My weaknesses and strengths combined with yours are what community is about." Each time one feels needed and essential to another, the threads of interaction are reinforced and the fabric which holds us

together as church and society is powerfully strengthened.

Spirituality and Religiosity: Thoughts from a Rehabilitation Perspective

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Religious beliefs and spirituality are potentially powerful forces in the lives of individuals who experience a disabling event or the onset of a disabling process. Religion and spirituality are generally considered significant support sources in time of trouble. But do spirituality and religiosity foster rehabilitation?

In the popular movie "Forrest Gump," Lieutenant Dan - a strong, healthy male who suddenly finds himself an amputee - vividly portrays the experience of reacting to a profound physical loss. Lieutenant Dan is intensely angry that Forrest and medical expertise have conspired to make him survive as a less than physically whole person. As a military man, he had reconciled himself to the possibility of death, but he had never envisioned himself living the rest of his life with a permanent disability. Like many individuals who incur a disability, he goes through the classic stages of the grieving process. Depressed and angry, he scoffs at those who urge him to "find Jesus" and tries to dull his pain in alcohol and commitment-free sexual liaisons. Forrest Gump, always uncomplicated and unassuming, remains a

nonjudgmental friend to his Lieutenant and matter of factly offers him an opportunity for renewed self-esteem as his business partner on a shrimping boat. When Lieutenant Dan at last assumes expected social roles again - indicated by his use of a prosthesis and his engagement to be married (both of which might be considered rehabilitation markers) - Forrest observes that "it looks like Lieutenant Dan has finally made his peace with God."

For a long time following Lieutenant Dan's battle injury, the notion of a righteous God was incompatible with his view of his own life as ruined - especially a life ruined through no fault of his own and contrary to the plan he had made for how things should have worked out. He had to painfully make his way back to a point at which his life as person with a disability had meaning and order, but this process was itself a rehabilitating experience.

Other people who become disabled, however, accept their situation by maintaining that God "knows best." While this facilitates disability acceptance, if disablement is viewed as "God's will" there may be little to motivate the individual toward rehabilitation. This effectively makes rehabilitation impossible because rehabilitation cannot be "done to" an individual. Rather, it requires the individual's active participation: "Rehabilitation is both a physical and mental effort in which the individual uses his residual capacities to compensate for his losses (Chyatte 1979:28).

At the same time, spiritu-

ality and religiosity can furnish a tenacious optimism that aids the rehabilitation process. As one patient noted who was interviewed in our studies of chronic dialysis patients, it helps to "believe that God is going to do a lot of positive things for you...." Sources to which individuals look for help in improving their health and functioning can be grouped into three categories, according to Selvin (1978): "mystical sources (God, faith, the healing process, luck); rational sources (doctors, nurses, therapists, diet, exercise); personal sources (yourself, your family, your friends)." Optimal rehabilitation outcomes are likely to require reliance on all three. When asked to explain how he had managed to adapt to life on chronic dialysis after developing renal failure, for example, one patient said, "We just worked with the Lord and the kidney machine."

One final thought: A frequent "spiritual" theme in personal accounts of coping with chronic illness and disability is heightened appreciation for life, e.g., the many beauties and mysteries of nature of "the inexplicable variety of human love, thought, and expression" (Newmann, 1979). Slowing down and "taking one day at a time" is a recommended mechanism to reduce stress and promote life satisfaction, regardless of an individual's health status. This "spiritual dimension," an ingredient of both successful living with a disability and successful living in general, is therefore consistent with a widely accepted definition of rehabilitation, i.e., "to

maximize an individual's residual capacity for optimal function in the usual environment."

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Religion and Disability: A New Wave

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Religion and disability--is not a familiar combination among disability professionals. Perhaps it is the word "religion" that turns on the caution light. Maybe, seen side by side, the two words suggest a clash between church and state. Or, maybe the word religion conjures up images of churches, temples, and synagogues that exclude by virtue of their structures--structures that are both physically and attitudinally daunting. But, the scene is changing.

In 1980 the University of Dayton's Center for Ministry with Disabled People (then MORES) undertook a project to identify the religious needs of Dayton area people who were disabled. The overall need of these people with physical, visual, and mental challenges was to participate in the total life of the place of worship. People who were deaf and used American Sign Language were not so concerned about participation in the total faith community, but rather focused on signed worship services and religious education.

In the ensuing years, many congregations began to reach out to people previously excluded because of inaccessible facilities and the rigid sanctuary structure. Sunday school classes began to welcome students with mental retardation - some in separate classes, others in regular classes. More religious education and worship materials were published specifically for the visually impaired member and the slower learner. Gradually, organized religion responded to the reality of the world situation: people who are challenged by a variety of limitations do exist in our society and are searching for spiritual access in the religion of their choice.

Below is a list of various aspects of how organized religion and issues of disability intersect along with a brief analysis by the author of the current situation in each of those areas.

Church Building Access:

Increasing number of ramps; some increase in other necessities such as restrooms and social halls; little access to altar.

Religious Instruction:

Separate curriculums available in many Christian denominations; inclusion and necessary instructional adaptations are beginning.

Signed Worship Services:

Many mainline Christian churches offer one or two sites per community; larger cities offer church for deaf, but in few denominations.

Braille and/or Large Print Worship Material: Revised Standard Version of Bible available in braille; some worship services/readings provided in large print by individual congregations or by publishers.

Seminary Education for Ministry with Disabled People and Families: About eight accredited seminaries offer a separate course for this ministry; about thirteen address this type of ministry in another course.

Active Clergy Who Are Disabled: One national organization exists to support ministers who are disabled.

Seminarians Who Are Disabled: An increasing number of people with disabilities are enrolling in seminaries.

Taken as a whole these items give rise to a number of important questions in the field of religion and disability. They also identify issues more commonly associated with parishioners or congregants with disability, issues particular to individuals called to ministry, and those common to both.

When we look to what religion has had to say to people who live with challenging limitations, we find that most of the literature about disability ministry has focused on the

topics of access and exclusivity. Even here discussions and concerns usually were limited to the notion that if buildings were made accessible and if the attitudes of parishioners change from fear and awkwardness to hospitality, then all would be well within the disability community. As Stanley Hauerwas of Duke University says in Religion and Disability (Sheed & Ward, 1995): "Through the prism of worship, Christians discover mentally handicapped people as brothers and sisters in Christ. . . . Through their willingness to be present in church, they provide the church with the time to be church. We thus learn that we can take the time for someone who does not talk well to read the Scripture. We can take the time to walk slowly together to the Communion table when one of our own does not walk well or at all. We can take the time to design our places of gathering so that they are open to many who would otherwise not be able to be there." (pp. 60-61)

But a new wave is coming-- and it combines the questions of who speaks about the role of religion in the life of people who are disabled and just what does religion have to say to people who are disabled? These finer points of the questions about religion and disability are being addressed gradually by people who live with a handicapping condition. Over time, they themselves are becoming the leaders in this field because they are professionals in ministry. For instance, the book The Disabled God by Nancy L. Eiesland (Abingdon 1994) sets the topic of religion and disability within the context

of liberation theology. The author living with a life-long disability, writes about her theology of a disabled God: "At the resurrection, the disciples understood the person Jesus for who he really was. Only through the lens of resurrection could they understand the meaning and significance of the life of Jesus on earth. In the resurrected Jesus Christ, they saw not the suffering servant for whom the last and most important word was tragedy and sin, but the disabled God who embodied both impaired hands and feet and pierced side and the imago Dei." (p. 99)

William Blair, a Presbyterian minister whose three-wheeled chair is a familiar scene in Birmingham, Alabama, is co-editor of the Journal of Religion and Disability. Blair considers disability and religion through the lens of a theology of "steadfast love." In And Show Steadfast Love (Presbyterian Publishing House, Louisville, KY, 1993), he writes: "The core philosophy of Christianity is one of love. Indeed, all our spiritual well-being as Christians rests in the assurance of God's enduring, steadfast love for us. We are comforted, humbled, and inspired by hesed--the love that brought Christ to us, and we often find it difficult to follow the example of love God has given us."

The rise of leaders such as these raises important questions about the future leadership of the disability movement within organized religion. The advocacy movement within religion has been lead primarily by people without disabilities, but with experience and compassion

for the issues of justice for people who are disabled. With the advent of new, vital leadership by people who are disabled, what will the role of the previous leaders be? Partnership will be the most conducive to progress as people realize the necessity for a multifaceted approach. The National Council of Churches Committee on Disabilities is beginning to develop its own policies on this question with a first step to be a mentor approach: people with disabilities are invited to key events so that they can learn the internal workings of church organizations.

The changes within the field of disability and religion can be highlighted with the prepositions To, For, and With. Formerly, we ministered to people who were objects of charity; then we ministered for people who needed our service. Now we minister with people who live and participate in the churches, the temples, and the synagogues of America.

Missing Characters in a Gospel Story

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Those of us who are Christians often use the story of the paralyzed man from the town of Capernaum to highlight Christ's interest in those who are handicapped by inaccessible facilities as well as to serve as a Gospel base upon which to build a hominy. The story is familiar: "Some people came

bringing him a paralytic carried by four men, but as the crowd made it impossible to get the man to him, they stripped the roof over the place where Jesus was; and when they had made an opening, they lowered the stretcher on which the paralytic lay. Seeing their faith, Jesus said to the paralytic, 'My child, your sins are forgiven.' Now some scribes were sitting there, and they thought to themselves, 'How can this man talk like that? He is blaspheming. Who can forgive sins but God?'" (Mark 2:3-8)

This text is used to encourage outreach to include everyone, including those with disabilities. But what of those elements missing from this brief script?

Who made up that crowd clustered around the door? They must have been intrigued by Jesus for they were unwilling to give way to allow the entry of the disabled man and his friends. What conclusions for our contemporary church might we draw from their behavior? What was their role before and after the events included in the story? Did they realize they had blocked the door or sense any obligation to have moved aside to allow the man and his companions entry into the house? Here we can only wonder, but we witness unfolding events in our world today.

What role might the man himself have assumed? Did he insist upon being taken to meet this man he had heard about? Did he think he had a right to be present in this crowded place or was he somewhat embarrassed that his colleagues made such a mess and flurry about getting him into the room. Had he and

his friends talked of his need to share the experience of hearing the Good News from this strange teacher from Galilee? Had they hoped to alter his life by providing him with this opportunity? Was the paralyzed man the passive recipient of the blessing he was about to receive or an active part of the encounter? From the story it seems Jesus was moved by his friends' faith. Was that because the man lacked such an expectation? And how did he feel upon being told, "My child, your sins are forgiven." We all experience failures and self-recrimination but what sins might have justified the "punishment" of this particular individual? Or was that what Jesus meant?

And what of his family? Was he someone's son or father; had he filled an essential role in the family which had been disrupted when he became paralyzed or had he been dependent all his life? At that time and in that place such a significant disability would have presented almost insurmountable challenges to those around him. Was he brought to that roof over Jesus' head out of love or desperation? Had the pattern of caretaking become ingrained in the family culture? Would they welcome his altered role as healed? We know that within contemporary families there is sometimes a need for a scapegoat: someone to blame for failures to move on with life. What alterations were essential in his family's constellation when he was no longer dependent?

And what of those scribes who sat in judgement and raised questions about the legitimacy of this simple sign of Christ's

healing power? Do they mirror those authorities in our contemporary world who question the value of the lives of those who live with disabilities? Surely Jesus acted out of concern and with little attention to the protocol of the day.

There can be little question that disabilities are a familiar challenge to many families. A Louis Harris and Associates survey of a few years ago indicated that one family in three includes a member with a disability. And these individuals' relationship with their parish is often complex and painful. Too often when families find a loved one excluded from a church service or program, the whole family fades away, unnoticed and unmissed. The connection between our religious communities and those with disabilities must be examined and discussed. We know how to build inclusion into our secular world. We must do no less within our religious environments.

If bars are more accessible than altars; if movie theaters are more welcoming than churches; if television producers are more concerned about creating programs accessible to the blind and deaf than our liturgists; if publishers of pulp fiction are more dedicated to production of books in accessible formats than religious printing houses; then we might be seen as a part of that crowd, clustered about the door and oblivious to the need for all to be present to the Good News.

What Does ADA Mean to U.S. Churches

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Although religious organizations and those entities which they control have been excluded from some aspects of the Americans with Disabilities Act, primarily in the area of public accommodations, most mainstream religions have a tradition of adhering to a moral obligation to serve those whose secular freedoms are now covered under the civil rights umbrella of this law. In fact, both the Old and New Testaments include instructions to care for the vulnerable and weak.

Those sections of the Rehabilitation Act of 1973 dealing with facilities receiving federal funds and establishing requirements to accommodate those with disabilities did not exclude religious entities nor did the Fair Housing Act Amendments of 1988 nor the Voter Accessibility Act of 1985. Therefore, those religious entities which provide social services funded through federal assistance and those churches with various housing projects have been required to comply since those earlier laws went into effect. In addition religious facilities utilized for voting are to be monitored by civil authority to assure access for the elderly and disabled voters.

However, during negotiations with the Bush administration some churches concerned with governmental "interference" in their operations requested

and received assurances from the Bush administration that they would not be compelled to comply with the public accommodations requirements of the new law. There was no such exclusion from the employment sections.

Title I of ADA requires that all religious organizations with 15 or more employees meet the standards set forth by the regulations compiled by the U.S. Equal Employment Opportunity Commission through job restructuring, appropriate accommodations and job descriptions which clearly state the essential functions required to do a specific job. Applicants for a job with a religious entity are protected from pre-employment inquiries about disabilities, although the potential employer may ask questions about the applicants ability to perform those tasks established as essential to the job.

In order to avoid unlawful behavior at any stage of the process, it is well to have job descriptions which clearly state what must be accomplished, not how it is expected to be done. With such clarity at hand an interviewer or supervisor can refer to elements considered essential, rather than becoming confused by diversity of function. Focusing on capability and experience in fulfilling essential tasks simplifies a process which might otherwise seem confusing and complex. The National Catholic Office has prepared materials which will assist those within its network to create appropriate job descriptions and be familiar with the sorts of questions which can be legally asked. We also have prepared a sample employment policy statement which we

strongly recommend be a part of the official documentation of various offices. (See the resources section.)

One other section which merits attention, even in this brief overview, is Title II, which deals with public services. It does not specifically exempt a religious entity if it engages in a public program which offers services. These might be a meal site for seniors or nursery program for children, an adoption agency, a shelter for the homeless or an office which provides a counseling service. Since state and local entities are required to comply with ADA, it follows that such programs run within religious facilities must be accessible.

Such a brief review of religious organizations' obligations under ADA can only sweep over the surface of the issues. However, it must be noted that ADA has forever altered the expectations of the 49 million people it covers as they approach their houses of worship and the services provided. Just as we assert certain freedoms are within our "Constitutional rights," without knowing exactly what that historic document guarantees, so it is with ADA. It is less important what this historic document requires of U.S. churches than how far it has raised the expectations of those 49 million people covered. Never before have so many disabled people and their families come to their houses of worship with such high expectations. If we are to continue to minister to Christ's flock, we must exceed the minimal requirements of the law and match the expanding expectations of those who

previously faced barriers in fulfilling their God given potential.

Resources

The National Catholic Office for Persons with Disabilities's (NCPD) newly revised 215 page pastoral guide to access and inclusion has just been published. Opening Doors to People with Disabilities answers questions asked by pastoral workers, bishops, pastors, people with disabilities, family members, catechists, and providers of social services. Currently available at the introductory price of \$10.00 plus \$4.25 shipping and handling, it can be ordered from NCPD, P.O. Box 29113, Washington, DC 20017.

The NCPD has also published a guide to accommodations for the ten million Catholics in the United States who are classified as disabled. The guide is titled A Loving Justice: The Moral and Legal Responsibilities of the U.S. Catholic Church under the Americans with Disabilities Act and was presented recently to Rev. Msgr. Dennis M. Schnurr, the newly appointed Secretary General of the National Conference of Catholic Bishops and the U.S. Catholic Conference (NCCB/USCC). He commented: "For all those who seek to build inclusion into our parish buildings and activities, this publication will prove a valued resource. In addition to offering answers to the most common questions about the Catholic Church's

legal and moral obligations under federal law, it includes statements from our religious leaders calling upon us to welcome and include all His people with loving concern."

Edited by Janice LaLonde Benton and designed by M. Luisa Velasco, this 58 page guide was reviewed by USCC's Office of the General Counsel. While not a substitute for legal counsel, it provides practical answers to a multitude of questions.

NCPD was established in 1982 to promote and foster the 1978 U.S. Catholic bishops' pastoral letter which calls for inclusion and welcome of those with disabilities within the Church and society. It accomplishes this task by working with those leaders called by their bishops to develop programs and plans for inclusion at the parish levels and through other national level Catholic organizations. It develops and distributes resources to assist in this mission.

A Loving Justice: The Moral and Legal Responsibilities of the U.S. Catholic Church under the Americans with Disabilities Act is available at \$7.50 single copy, \$6.50 for multiple copies, plus additional charges for handling and mailing. Order from: National Catholic Office for Persons with Disabilities, P.O. Box 29113, Washington, DC 20019, Tel: 202/529-2933.)

Booknotes

Baldwin, Stephen C. Pictures in the Air, The Story of the National Theatre of the Deaf. Washington, DC: Gallaudet University Press, 1993, 142 pp.,

\$24.95 hardcover.

Since its origins in the late 1960s, the National Theatre of the Deaf has presented more than 6,000 performances in all fifty states - a record unmatched by any other American professional touring acting company. Since its first European tour in 1969, the NTD has performed twenty-eight foreign tours to thirty-two countries in five continents. During the course of its brief twenty-five year history, the NTD has won numerous awards for artistic excellence; more importantly, however, the company has met the objective of its founders and demonstrated that an acting company of deaf actors who used American Sign Language could become a professional, artistic, and financial success.

Stephen Baldwin, who has his doctorate in theatre history from the University of Texas, is a teacher, actor, and playwright. Deaf himself, Baldwin is well-qualified to trace the history of the NTD from its shaky origins (1959-1967) when its supporters, actress Anne Bancroft, playwright Arthur Penn, psychologist Edna Levine, and Broadway set designer David Hays sought federal funds which would demonstrate the capabilities of deaf performers given an opportunity to work with theatre professionals. Moreover as a writer active in local deaf community theatre, Baldwin is personally acquainted with nearly all of the deaf personnel who have been associated with the NTD.

As such, he clearly lays out the performance chronology and identifies all of the major players, artistic and administrative, important to the

success of NTD. Baldwin also clearly explains the difference in what he calls a theatre for the deaf and a theatre of the deaf. Historically, the deaf community has a strong tradition of sign language theatre composed of volunteer companies and scripts of interest to the deaf community. Unfortunately, these theaters for the deaf have never been commercial successes and have never attracted non-deaf audiences. The NTD changed this pattern. As a theatre of the deaf, deaf actors who use American Sign Language, NTD aimed, through the direction of its original and current director David Hayes, to attract primarily hearing audiences to its performances. Initially, this caused some hostility by some deaf audience members who has difficulty comprehending the theatrical signs or story lines of NTD performances; however, Baldwin alleges that this has passed and that the deaf community now understands and accepts the social and educational value of the NTD.

Baldwin also clearly describes the importance of the decision that the NTD would be a touring company. Even though the company would establish numerous training and educational programs at its headquarters in Connecticut, the heart of its success lay in the fact that the company went out to America, as well as other parts of the world, and demonstrated the artistic merit of sign language and capabilities of deaf performers.

Two weeks prior to its first television appearance on NBC, the Alexander Graham Bell Association, through telegrams to the network and members of

the U.S. Congress, objected to the signs on television as "anything more than an artificial language, and a foreign one at that, for the deaf...." If the NTD did nothing else, it put the lie to the Bell Association oral proponents and allowed hearing audiences to understand the linguistic power of American Sign Language.

Baldwin's history of the NTD is almost too good to be true. Admittedly a success story in American theatre and the deaf community, Baldwin's analysis is not very critical. Although he mentions that there have been very few deaf administrators at the NTD, he has not pursued this aspect of the story. For example, there is very little discussion of the role of Bernard Bragg, a major deaf actor who became a part of the NTD from its inception. His focus is also very narrowly confined to the deaf community. He makes no effort to relate NTD to the larger disability movement and recent efforts by disabled advocates to seek employment for disabled actors or to remedy stereotypical images of disability in Hollywood and Broadway.

These are, however, minor criticisms. Baldwin's primary objective was to provide a basic historical description of the National Theatre of the Deaf. He has done this and anyone who is interested in theatre history, deafness, or disability should add this monograph to their collection.

(John S. Schuchman,
Gallaudet University,
Washington, DC)

Webb-Mitchell, Brett. God Plays Piano Too: The Spiritual

Lives of Disabled Children.
Crossroad, New York, 1993, 191
pp. \$21.95 softcover.

God Plays Piano Too by
Brett Webb Mitchell is a good
read for anyone interested in
improving the connections
between families with a disabled
child and faith communities.
Collecting stories from people
with disabilities, Webb Mitchell
writes resoundingly that
disabled people are looking for
the same response from the faith
community as non-disabled
people.

The author brings a rich
work history to this topic: as a
music therapist and a minister,
Webb Mitchell chose the story-
telling mode because in sharing
stories we learn both who we are
and whose we are. Stories put a
face on abstract concepts and
are the basis of our ability to
understand and experience God.

Three concentrations of
information emerge from this
book. The first is the author's
personal growth in understanding
the primacy of the person.
Then, readers learn what is
wanted from the church, and
finally, what the church can
learn.

Through living with and
working with disabled people,
the author comes to see them as
people with unique combinations
of abilities and limitations
rather than as "victims." This
book grew out of his desire that
their stories be heard and
understood and that their
contributions be celebrated.

The birth of a child with a
disability demands revamping of
the dream of the family. The
family needs support from many
fronts, one of which is the
faith community. What support
the church has to offer is

threefold: 1) Presence as
trusted friends: family members
need a space with people who
have no agenda for them. Out of
this listening presence will
flow the practical supports
needed by the family. 2) A
forum to ask the hard questions
of God: Who is responsible for
disabilities? How is a disabled
child made in the image of God?
The questions pivot around
suffering and pain in the con-
text of a God who loves us. 3)
Church as sanctuary: The church
can be a place where children
with disabilities are seen as a
whole people, regardless of what
they can and cannot do.

In turn, families with a
disabled child offer lessons to
the community. What disabled
children teach their parents and
siblings is the ability to put
aside personal wants in service
to another. By their very
presence, they speak volumes
about church being a compas-
sionate space. Families with a
disabled member teach about care
and commitment. The faith com-
munity learns what it means to
be committed to a family, no
matter what.

Where people with disabili-
ties are, there is diversity.
Diversity is critical for
parishes to flourish because it
reminds us of our being loved
for who we are and not what we
do, a core teaching of religion.
Sustaining this diversity, how-
ever, is difficult because we
naturally fear differences.

God Plays Piano Too is an
excellent primer for readers
interested in strengthening the
bonds between families with a
disabled child and their family
community.

(Mary Jane Steinhagen,
Catholic Charities Advocate, St.

Paul, MN).

Webb-Mitchell, Brett.
Unexpected Guests at God's Banquet: Welcoming People with Disabilities Into the Church.
Crossroad, New York, 1994, 184 pp., \$17.95 softcover.

Unexpected Guests is an excellent follow-up to God Plays Piano Too. This book is filled with practical suggestions on creating welcoming, inclusive communities.

The book is built around a parable found in Luke 14. In this story all of the guests invited to a banquet find reasons not to attend. The host's desire to have this banquet impels him to send servants out to invite people previously overlooked. Disadvantaged people, certainly those with disabilities in early Jewish times, became the invited and welcomed guests. This parable presents an idea about the nature of the kingdom of God.

Luke 14 presents several clues about whom we can expect to find in God's kingdom. An obvious lesson is that membership is not based on money, fame, or deeds, but on accepting the extended invitation. Then the banquet celebrates the importance of the presence of all people there. Finally, the story drives home the value of recognizing and responding to the invitation.

With this theological underpinning, Webb-Mitchell describes why churches have been slow to invite and welcome everyone into our congregation's feast. He names the problem as one of images. Non-disabled people have nurtured the image of disabled people as "suffering

ones" and as people less than human.

One chapter details a brief history and theological reflection of the place and presence of people with disabilities. Truths which emerge from the historical overview are that people will always have disabling conditions and always have faced a world which wants to transform them into something other than who they are. In closing this chapter, the author writes that including people with disabilities is essential to the life of the faith community because they are children of God and children of the Church who the Church should not choose to be without.

The author notes that our task is to discover and take seriously the needs and concerns of the "unexpected guests" in our congregations. Conversation with disabled people and their families will give basic knowledge of what's been missing and of who's been missing because their needs have been ignored. By seeking out that information, the church community is tacitly acknowledging its need for transformation from a "community for myself" to "myself for the community," where each person's heart is open to all others without any exception.

What follows then are four chapters dealing with practical issues congregations face as they learn to invite, welcome, and finally celebrate the presence of the "unexpected guests." The activities suggested range from the simple and silly to more intense and involved interactions; however, all have the bottom line of creating a community where

everyone is seen as contributing.

In committing ourselves to creating a more welcoming community, we, as church, will become more imaginative in learning new capabilities in all aspects of congregational life. As church we will become more patient and tolerant of differences; we will become more resilient and less threatened by the new and different. As church, we will become more intimate and supportive.

Paired with his God Plays Piano Too, Webb Mitchell has written a set of guidebooks for people interested in building, inviting, welcoming, and accepting faith communities.

(Mary Jane Steinhagen, Catholic Charities Advocate, St. Paul, MN).

Kowalewski, Mark R. All Things to All People: The Catholic Church Confronts the AIDS Crises. State University of New York Press, 1994, 167 pp., \$14.95, hardcover.

All Things to All People follows up on the results of a dissertation which developed out of the author's interest in how religious institutions "balanced their traditional prohibitions against homosexuality with their desire to care for the sick...." Kowalewski concentrated on the Los Angeles Archdiocese examining selected documents of Catholic officials, attending religious services for gay men, and interviewing priests who had expressed an interest in ministering to AIDS patients at the request of their chancellery.

A glance at the preface of this book, published in June 1994 although based on data from the mid-1980s, suggests this is

less an exploration of the disabilities or even the medical aspects of AIDS than of the aspects of Roman Catholicism which Kowalewski finds burdensome: "Theologically, I am critical of assertions of hierarchical power in the Roman Catholic church over against the legitimate place of the laity to inform the church's moral discourse." (Previously a practicing Catholic, the author converted to the Episcopal Church during the process of this study finding there greater acceptance of his orientation.)

A basic flaw of this study is the author's narrow definition of the "AIDS Crises." AIDS is conceptualized as a gay man's killer with little effort to connect this modern day plague to other populations in other places around the world. Even in 1985 the AIDS crisis could be defined thus only if its encroachments in Africa were ignored. This narrow definition was not appropriate for a religion as universal in its outreach as the Catholic Church.

In the United States in 1985, 73% of those with the diagnosis were gay men while 17% were drug users and only 1% were heterosexuals. By last year the percentage of heterosexual with AIDS had risen to 10% while gay men constituted 44% and drug users 27% of the growing numbers of those affected. In 1985 women made up only 7% of the total while this number had risen to 18% by 1994.

Those individuals infected with the AIDS virus today can expect to live 12 years or more, but those extended years bring assorted "disabilities." However, the author failed to address critically relevant

questions of how the largest private provider of both medical and social services in the United States addresses the health and maintenance needs of these individuals, no matter their sexual preferences, who look to Catholic institutions for assistance.

Kowalewski cites scant information reflective of rapidly changing knowledge and sophistication about the disease. Of the more than 125 references listed, only 5 are recent. While the author refers to a 1992 report on legislative proposals which discriminated against homosexuals published by Catholic News Services's "Origins," there is no indication this article was motivated by concern about "gay bashing." One might also expect to find the weighty and detailed report of the international conference on AIDS held in Vatican City in November of 1991 attended by thousands of scientists and other concerned professionals from around the world, but it is not included. This gathering, hosted by the Pontifical Council for Pastoral Assistance to Health Care Workers, addressed exactly those conflicts which Kowalewski attempts to dramatize.

Kowalewski has constructed a series of chapters on decision-making, power, and the structure of the relationship between gay men with AIDS, the Los Angeles priests who serve them, and the totality of the Church. These passages could serve as boiler plate for exposes revealing that the magisterium of the hierarchy "fails" to respond to tugs upon its structural integrity.

Those sections of this book

reporting on the interviews with 32 priests seem the most germane to the topic at hand since it is at this point that the Catholic Church "confronted" the gay men of Los Angeles who were dying of AIDS. These priests, struggling to add heart to the teaching of the magisterium, were balancing the necessity of a consistent ethic when pastoral duties called them to comfort and offer redemption. Some dying men were angry, others frightened. Some wanted to know if there was a place for them in heaven. Churches are for sinners and those who seek Christ's healing blessing find it there.

Repeatedly this reviewer was reminded of an explanation of how the two branches of the Roman Catholic Church in the United States, the National Conference of Catholic Bishops and the U.S. Catholic Conference, operate: The structure is rather like a two headed elephant. It moves very slowly with considerable thought and a tremendous need for coordination of all its parts.

The stability of such a structure, impervious to shifts in popular opinion or current politically correct rhetoric, may seem an anathema to some. To others it may be like the North Star: a constant reference point on one's horizon, the only steady component in a shifting environment where one is buffeted by sudden shifts in the secular wind.

(Mary Jane Owen, National Catholic Office for People with Disabilities)

Battin, Margaret Pabst.
Least Worst Death: Essays in Bioethics on the End of Life.

New York: Oxford University Press, 1994, 305 pp., \$18.95 softcover.

This book brings together a series of previously published interrelated and overlapping essays in bioethics by philosopher Margaret Pabst Battin. Her essays range from 1980 to 1994 with half appearing in the early 1990s. All the essays either presuppose or evaluate the distinction between killing and letting die. Battin's title captures the contradiction patients, practitioners, and families face as death occurs primarily from degenerative diseases within an imperfect health care system. The least worst death is the realistic death for us to aspire to have, not the good and easy "natural" death. Thus Battin devotes considerable attention to what makes for the least worst death and how our health care system largely precludes pursuing the good death.

The book begins with what Battin proposes as an overriding moral question: How will we all die? She proposes that right-to-die issues are increasingly politicized because of changes in 1) the cause of death and therefore the way we die and 2) the way we think about death. Battin sets the stage for what follows by introducing major ideas and events about right-to-die issues and the quality of dying in the political context of the last half century in the United States. She divides the book into three major sections, "Withdrawing and Withholding Treatment," "Euthanasia," and "Suicide." In my view, Battin's main contribution lies in her detailed discussions in the

first two sections of the book. A major strength of Battin's work lies in her sophisticated grasp of the complexities of end-of-life medical conditions and the intricacies of the American health care system. Her chapter on euthanasia in the Netherlands nicely forces the reader to conclude that any cross-national comparisons must examine social and existential meanings, institutionalized practices and structures, and economic statuses. Unlike Americans, the Dutch have long-term relationships with physicians, full insurance, home-care and do not suffer from impoverishment, racial prejudice, and homelessness. Much of her discussion of suicide is aimed directly at her interest in right-to-die decisions for those who suffer from terminal diseases. However, Battin also examines why the Christian opposition to suicide is much stronger than that of other religions. She shows that Christianity celebrates choosing death by heroism, but does not define it as suicide. Her discussions of the moral dilemmas about assisting in suicide are lucid and useful. Medical and mental health practitioners will find her discussion of questions they should ask in regard to assisting in suicide worth the price of the book.

Despite her title, Battin's treatment of the contradiction between desiring and choosing a good, natural death and getting an institutionalized, technological death remains more suggestive than definitive. She is aware, however, that some ways of dying are easier, more peaceful, and more conscious than others. Battin puts

forward five major arguments that have gained increased attention and support from ethicists and lay persons. They include: 1) the distinction between killing and letting die is not so straightforward as the public imagines, 2) when there is a difference between actions of killing and letting die, questions arise whether, in fact, there is a moral difference, 3) each case needs to be decided on its own merits, 4) the circumstances of American health care may make recognizing physician performed euthanasia more problematic than physician-assisted suicide, and 5) right to die problems will become the major social issue of the next decade.

Battin certainly is correct when she argues that the distinction between killing and letting die is not straightforward. Clearly, what withholding treatment means is experientially and morally relative. Is deciding to take an end-stage renal disease patient off dialysis a form of killing or letting die? Does simply the source of that decision, patient rather than say, spouse and physician, result in whether withdrawing dialysis is killing or letting die? When we consider intention as well as source then the possibilities also include suicide. Battin is also correct about the moral difference between killing and letting die. Morally the difference does lie in case by case circumstances. Allowing someone to die may mean subjecting that individual to terror and discomfort. For example, is it morally defensible to force a seriously impaired dying baby to die while

screaming for food and water because we have a moral preference for "allowing" babies to die rather than ending their misery?

Consistent with most ethicists from philosophy, Battin looks at right-to-die dilemmas from an individual basis, echoing the medical model of the focus on a single patient and practitioner. Her emphasis on a case by case approach breaks down earlier philosophical reliance on adherence to either deontological and utilitarian ethical positions. Yet focusing on the individual minimizes or leaves out other important considerations such as the concerns of those for whom the patient's life or death is central, the symbolic meanings of quality of life and of level of civilization in society.

Throughout the book, Battin seems to shift her position between essays, not just the focus of her gaze. The final essay written in 1980 takes the position that suicide is a fundamental right. However, in her 1983 essay she argues that active euthanasia or suicide in any way need not be among all the alternatives to achieve the least worst death. In her 1992 essay on the risks of abuse with voluntary euthanasia, she again avers, "control over one's death as far as possible is a matter of fundamental human right." If her position shifted, then reversed or even became more fully articulated over the years, it would have helped to have had short integrating introductions to the chapters, or least to the sections. On the positive side, Battin acknowledges that we already practice euthanasia commonly,

but not always morally because medical costs drive the action, not autonomous decision. She also honors autonomy as a safeguard against the slippery slope.

Battin argues that right-to-die concerns will become the major social issue of the next decade - possibly, probably not. They may follow and exemplify, however, larger concerns in the United States such as the rights of the individual vs the state and priorities for national spending. Nor am I as sanguine as Battin that degenerative diseases in late life will continue to be the major cause of death in the future. Her analysis is on target now. But will it hold for the future? How long? Might it more accurately reflect the size of generational cohorts than relative cause of death, per se? Then, too, increasing resistance to antibiotics and the development of deadly new viruses may bring the twenty-first century a return of uncontrolled infectious diseases. Should the US continue to create world-wide environmental degradation as well as economic decline of its middle and working classes, disability from degenerative diseases likely will affect more people more quickly and harshly. If so, the death rates of middle aged adults would noticeably increase. Correspondingly, economic decline may well bring more health care rationing, in turn, resulting in greater disability and death. Paradoxically, my point here echoes Battin's 1987 contention that rationing health care to the elderly does not simply let them die, but more likely abandons them to prolonged illness

followed by death.

These concerns aside, Battin's essays are thoughtful, pertinent, detailed, and well-written. She has made a solid contribution to the growing field of bioethics. I recommend her book to anyone who is a serious student of right-to-die questions in their various forms.

(Kathy Charmaz, Sonoma State University)

Nelkin, Dorothy and M. Susan Lindee. The DNA Mystique: The Gene As a Cultural Icon. New York: W.H. Freeman and Company, 1995, 288 pp., \$22.95 hardcover.

Efforts to map and sequence the entire human genome are now in progress as part of the Human Genome Project. These efforts, coupled with a general increase in molecular genetics research, has made new information - and misinformation - about human genetics widely available. Researchers claim to have discovered genes for alcoholism, homosexuality, and obesity; news reports describe DNA fingerprinting techniques used in criminal trials; reporters promise "designer babies" in our future. Indeed, we are bombarded daily with images of DNA related to all aspects of our lives. As genetic information becomes a means for explaining the root of all manner of human behavior, the idea of culture as separate from biology is rapidly fading.

In The DNA Mystique, Dorothy Nelkin and M. Susan Lindee explore popular examples of this shift in emphasis toward biological explanations, introducing us to the DNA of popular culture. Using images and ideas

from movies, legal cases, comics, news, parenting advice literature, and other popular cultural forms, they document the pervasiveness of the gene as cultural icon. Popular depictions present DNA as the central element that makes us who we are; Nelkin and Lindee refer to such depictions as "genetic essentialism." Genes supposedly responsible for such a wide range of human attributes as violence, femaleness, fashion sense, messiness, obesity, intelligence, and infidelity fill the arena of popular culture. Nelkin and Lindee term this emphasis on the genetic causes of human behavior "genetic determinism."

The gene as represented in popular sources has powerful non-biological meaning; it has taken on mythical proportions, a "secular equivalent of the soul - the immortal site of the true self and the determiner of fate" (p. 193). The authors claim that DNA, like the Christian soul, appears sacred: "The gene has become a way to talk about the boundaries of personhood, the nature of immortality, and the sacred meaning of life in ways that parallel theological narratives" (p. 41).

As issues of race, gender, and sexuality are publicly debated, genetic ideas often are used to define differences and justify social inequalities. Nelkin and Lindee begin to document this process by providing examples from popular media sources. For instance, they describe a government official's blatantly racist statement that African-Americans are "conditioned by 10,000 years of selective breeding for personal combat and the anti-

work ethic of jungle freedoms" (p. 115). They also cite a magazine article's feminist dismissing pronouncement that as far as differences between males and females are concerned, "the old nature-versus-nurture quibble has finally been settled - and nature now appears to be the winner" (p. 109). They present a tabloid cover's homophobic response to news of a "gay gene" discovery that proclaims: "Simple injection will let gay men turn straight, doctors report" (p. 122).

Nelkin and Lindee make a compelling case that DNA has important cultural meaning distinct from its basic biological fact. In characterizing this cultural meaning, they surf through the realm of popular culture to collect the sources which are the subjects of their study. However, the authors do not develop any particular topic in depth and in the end the book leaves the reader with an overwhelming, eclectic group of references which is neither comprehensive nor focused. Nonetheless, the array of images and ideas presented provides a good guide to the range of popular forms reliant on genetic determinism.

In chapters seven and eight, the authors relate genetic determinism to contemporary cultural emphasis on culpability and blame and examine the institutional consequences of genetic determinism. Readers engaged in disability studies will find these chapters of particular interest. Disability rights activists have responded in various (and sometimes conflicting) ways to research seeking genetic explanations for disabilities.

As Nelkin and Lindee point out, some "hope that the discovery of genes for depression and other mental conditions will reduce the social stigma of being different" (p. 174). Some fear eugenics: identifying genes related to various disabilities or "predispositions" to conditions could lead to social pressure, if not social policy, aimed at discouraging reproduction by those people identified as carrying "defective" genes. Some fear that an emphasis on genetic causes for disabilities may undermine development of treatment and social supports for people with disabilities. For if genetic "flaws" will be eliminated, no accommodations need be made for people with disabilities.

Nelkin and Lindee argue that the genetic determinism conveyed in popular sources is most likely to serve as a justification for already existing social inequalities. In addition, they warn that many institutions increasingly will use genetic traits and "predispositions" to make decisions about hiring and firing, teaching, job placement, criminal conviction, and insurance. The book's justified warning of the dangers of genetic screening and testing is supported by Nelkin's earlier work with Laurence Tancredi (1994), which provides an overview of the misuses of diagnostic testing in the health care system, the workplace, schools, and legal institutions.

A chapter devoted to the U.S. eugenics movement of the late nineteenth and early twentieth centuries warns of the social implications of genetic determinist thinking demonstrating the connections between

popular depictions of the "germ plasm" (then a description for hereditary material) and public acceptance of reproductive regulation for "eugenic" purposes. The authors contend contemporary popular images of genes and genetics are strikingly similar to earlier depictions of the germ plasm and they fear that such depictions of the gene in contemporary culture make renewed eugenics likely. As in the late nineteenth and early twentieth centuries, contemporary "[s]tories of genetic essentialism and biological determinism facilitate public acceptance of the control of reproduction for the common good" (p. 171). And Nelkin and Lindee demonstrate that current economic and social problems are, at least in part, being discussed in terms of genetics.

What is the attraction of genetic determinism in contemporary U.S. society? Nelkin and Lindee argue that "the status of the gene - as a deterministic agent, a blueprint, a basis for social relations, and a source of good and evil - promises a reassuring certainty, order, predictability, and control" (p. 194). Genetic explanations are an easy way to deal with difficult social problems. The authors offer several suggestions for DNA's emergence as a cultural icon. First, genetic explanations for social problems can be used to justify social inequalities. Second, "the gene" has shown itself to be a flexible concept, serving many different agendas, even simultaneously. Third, genetic explanations echo the enduring (if somewhat contradictory) "American values" of looking to the individual as the location of

social problems and seeking moral redemption for events beyond individual control. Finally, genetic explanations are appealing because they raise hopes about the possibility of treatment for disease.

These suggestions seem plausible; however, Nelkin and Lindee offer little evidence to support their proposed explanations. This oversight is part of a more general problem with the book. While the authors effectively document the images of DNA in contemporary U.S. culture, they fail to address the influence of these images. The DNA Mystique makes no attempt to gauge the impact of popular images of DNA on how individuals make sense of genetics. Nowhere in the volume is anyone asked about their views on genetics or cultural representations of DNA. We are left to wonder how parents respond to the advice literature which explains children are born with certain inalterable abilities and tendencies. Has parenting changed due to the shift from environmental to biological emphases Nelkin and Lindee document? Media and popular cultural forms do not necessarily mirror popular opinion. For example, in her study of cultural understandings of immunology, Emily Martin (1995) describes widely contrasting conceptions of the body, health, and disease in media images and in the individuals she interviewed. While the media has continually depicted the body as being "at war" with disease, interviewees overwhelmingly rejected such metaphors for immunity.

It would be interesting to explore how people understand

the DNA of popular culture Nelkin and Lindee have so extensively described. Only with this information could we truly begin to understand the meaning of DNA in contemporary society. Do scientists and medical professionals talk about DNA as explanatory and culpable vis a vis social problems thereby reflecting acceptance of the cultural images described in the DNA Mystique? Do lay people share the media excitement about genetic "discoveries?" Do moviegoers really believe the essentialist advertisement for the film Tainted Blood which claims: "Some girls are born smart. Some girls are born beautiful. Some girls are born killers" (reproduced in Nelkin and Lindee, p. 86)? Clearly the frequently occurring ideas about and images of DNA documented in Nelkin and Lindee's book reflect an important aspect of our culture; through studying these representations alone, however, we cannot know how popular culture influences popular opinion about genetics.

Despite its shortcomings, The DNA Mystique provides an important introduction to popular representations of genetics, and the work is particularly useful to those engaged in disability studies or activism. The book cleverly connects disparate sources to demonstrate the extent to which ideas about DNA and genetics have infused U.S. culture, and Nelkin and Lindee make a compelling case for paying particular attention to a new cultural emphasis on the explanatory powers afforded DNA in a world where previous definitions of identity are coming under question.

References

Martin, Emily. Flexible Bodies: Tracking Immunity in American Culture - From the Days of Polio to the Age of AIDS. Boston: Beacon Press, 1994.

Nelkin, Dorothy and Laurence Tancredi. Dangerous Diagnostics: The Social Power of Biological Information. Chicago: The University of Chicago Press, 1994.

(Nancy Martin, Department of Sociology, Brandeis University, Waltham, MA)

Announcements

August 15-20. The Association for the Sociology of Religion meetings will be held in Washington, DC. Theme: Community, Globality and Research Paradigm in the Sociology of Religion. Contact: Peter Beyer, Program Chair, Department for the Study of Religion, University of Toronto, 123 St. George Street, Toronto, Ontario, Canada M5S 2E8, (416) 978-2395; FAX (416) 978-1610, e-mail: pbeyer@epas.utoronto.ca.

September 13-16. The American Psychological Association, in collaboration with the National Institute for Occupational Safety and Health (NIOSH), the U.S. Department of Labor (DOL), and the U.S. Office of Personnel Management (OPM), will convene the third interdisciplinary conference in Washington, DC. Theme: Work, Stress, and Health "95" Creating Healthier Workplaces. Deadline for proposals is January 13, 1996. Contact: Lynn A. Letourneau, American Psychological Association, 750 First Street, NE, Washington, DC

20002-4242, (202) 336-6124; FAX (202) 336-6117.

October 2-4. Scientific Basis of Health Services. International Conference, London, England. Contact: Sally Welham, Office of Director of Research & Development, NHS Research & Development, Department of Health, Richmond House, 79 Whitehall, London SW1A 2NS, England; 071/210-5556, fax 071/210-5868.

Call for Manuscripts: Social Thought has been retitled Social Thought: The Journal of Religion in the Social Services. Joseph J. Shields, Associate Professor in the National Catholic School of Social Service, will serve as editor of the journal now to be published by The Haworth Press, Inc. As a quarterly, the journal will publish scholarly papers which focus on topics pertaining to institutional and noninstitutional religion in relationship to the development and delivery of social services. The journal welcomes papers dealing with sectarian and non-sectarian approaches to spirituality and ethics. The journal is also interested in philosophically oriented articles which deal with innovations in professional paradigms, world views, conceptual frameworks, and the philosophy of social work. Articles submitted should be written in APA style and not exceed 20 pages, exclusive of bibliography and tables. Contact Joseph J. Shields, Editor, Social Thought: Journal of Religion in the Social Services, The Catholic University of America, National Catholic School of Social Service, Shahan Hall, Washington, DC 20064, (202) 319-5458, FAX (202) 319-5093.

The quarterly journal Rehabilitation Education set an August publication date for a special double issue (volume 9, issues 2/3) on Spirituality, Disability and Rehabilitation. Single copies can be ordered from the publisher for \$12.00 prepaid, including postage and handling. Order from Elliott & Fitzpatrick, Inc., Georgia Southern Press, P.O. Box 1945, Athens, GA 30603, (706) 548-8161, (800) 843-4977, FAX (706) 546-8417.

The table of contents for this special issue is as follows: Introduction to the Special Issue, Carolyn Vash and Henry McCarthy; Part I, Cultural and Theoretical Perspectives on Spirituality, Disability and Rehabilitation: (1) Integrating Spirituality into Rehabilitation in a Technocratic Society, Henry McCarthy; (2) A Theology of Anger When Living with Disability, Nancy J. Lane; (3) Metaphysical Influences on Disability Attitudes, Carolyn Vash; (4) African Indigenous Healing and Cosmology: Toward a Philosophy of Ethnorehabilitation, Lisa Lopez and Dennis R. Maki; (5) Pragmatic Spirituality: Enablement in Traditional Africa, Robert W. Nicholls; Part II: Living with Disability: Impact of Spiritual Views and Values: (1) Buddhism and the Spiritually Challenged, Winfield Clark; (2) To Stand on Holy Ground: A Jewish Spiritual Perspective on Disability, Michael Levy; The Defining Light of Vedanta: Personal Reflections on Spirituality and Disability, Margaret A. Nosek; (4) Be Still, Migel Elie; Part III: Rehabilitation Education and Practice: Finding the Place for Spiritual Views and Values:

(1) Understanding and Reversing Rehabilitation Counseling's Neglect of Spirituality, Henry McCarthy; (2) Mindfulness in Rehabilitation Practice, Education, and Research, Martha Lentz Walker and Robert Burke Walker; (3) The Impact of Differing Belief Systems Between Native Americans and Their Rehabilitation Service Providers, Carol Locust; (4) The Energy Model: A New Approach to Rehabilitation, Roberta B. Trieschmann; (5) Choice, Carolyn Vash; Gray Matter: Cosmological Rehabilitation, Robert Gregory; Book Reviews: Ethics in rehabilitation: A guide for rehabilitation professionals by T.L. Blackwell, W.E. Martin, and V.A. Scalia (1994), Cynthia Langford; The power of the mind to heal by J. Borysenko and M. Borysenko (1994), Suzanne Meyer.

Notice: Professors Nancy Eiesland and Don Saliers of Candler School of Theology, Emory University, have received funding for a conference and edited volume on Christian liturgy and people with disabilities. They are seeking persons who are currently working biblical, pastoral, ritual, and liturgical themes and issues in religion and disability studies. Please contact Nancy Eiesland, Candler School of Theology, Emory University, Atlanta, GA 30322; (404) 727-6322; email neiesla@emory.edu.

Society for Disability Studies

Zola Scholar Award: The Society for Disability Studies (SDS) is pleased to announce its Irving Kenneth Zola Emerging Scholar Award competition. Papers may be submitted by graduate students and new faculty or researchers in the area of disability studies. The award includes: certificate of recognition, cash award of \$200, place on the program to present the award-winning paper at the 1996 SDS conference, and SDS conference registration fee waiver. Papers will be judged on: (a) significance of the topic, (b) advancement of knowledge, (c) quality of research design, (d) analysis of findings and their implications, (e) organization, and (f) clarity of writing. The submission deadline is: January 8, 1996. Send three (3) copies of your paper to: Gary Kiger, Department of Sociology, Social Work, and Anthropology, Utah State University, Logan UT 84322-0730. Phone: (801) 797-1235 (V/TTY). E-mail: GKIGER@WPO.HASS.USU.EDU (questions only). Please send papers only, no theses or dissertations.

The Society: The Society for Disability Studies is a nonprofit scientific and educational organization. It is a multidisciplinary and international organization composed of social scientists, scholars in the humanities, and disability rights advocates concerned with the problems of disabled people in society. The purpose of the Society is to bring together people from diverse backgrounds to share ideas and to engage in dialogues that cut across disciplinary backgrounds and substantive concerns. The Society is committed to developing theoretical and practical knowledge about disability and to promoting the full and equal participation of persons with disabilities in society.

The Society for Disability Studies annual meeting is usually held in June of each year. Likely themes for disability studies papers or panels are topics such as policy, history, sexuality, law, culture, methods, politics, media, literature, pedagogy, gender, self image, cross cultural studies, family, advocacy, activism, and related topics.

Further information on membership and the 1996 annual meeting can be obtained by TDD at 617-523-3682 or by voice at 617-523-3429. The mailing address is: Society for Disability Studies, c/o Department of Public Management, Suffolk University, Eight Ashburton Place, Boston, MA 02108-2770 USA.

Dues for membership in the Society are based on income and are as follows:

Less than \$15,000	\$15.00
\$15,000 - \$30,000	\$25.00
\$30,001 - \$45,000	\$35.00
Over \$45,000	\$45.00

Subscription information: Disability Studies Quarterly comes out four times a year. Each volume is the same as a calendar year. Although the Quarterly is associated with the Society for Disability Studies, the subscription price for the Quarterly is not included in the dues for the Society. However, members of the Society are entitled to a \$5.00 reduction in the Quarterly subscription price. The prices for a one year subscription are as follows.

Individual	\$35.00
Institution	\$45.00
Student	\$20.00
Low Income	what you can afford
International	\$50.00*

*The price for international subscriptions excludes Canada and Mexico. Subscription prices for Canada are the same as for the US even though the mailing costs are higher than domestic rates. International subscriptions can be obtained by the exchange of newsletters and/or publications relating to disability.

Please specify if you wish to receive the Quarterly on disk, in Braille, on tape, or by email over the Internet. There is no additional cost for an alternative format.

SPECIAL NOTICE

Since Irv Zola died many persons wondered about the future of the Quarterly. Disability Studies Quarterly will continue. For the calendar year 1996 (and longer if necessary) I will be the editor of the Quarterly. The Steering Committee feels confident that subscription and other income will provide sufficient funds to pay for its publication. We are receiving some support from Suffolk University, but we need much more.

Please consider making a donation to ensure that the Quarterly will continue during this transition time. For persons (or organizations) who can afford large contributions, please make one now. All donations are welcome, however. Make the check payable to Disability Studies Quarterly and write on it DONATION. Send it to David Pfeiffer, Department of Public Management, Suffolk University, Eight Ashburton Place, Boston, MA 02108-2770, USA. Thank you.

David Pfeiffer, Editor

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