

# Mennonite Advocacy for Persons with Disabilities

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**SUMMARY.** The Mennonites, who emerged as a distinctive group from the radical wing of 16th Century Reformation, have emphasized four themes in their response to persons with disabilities: love, service, peace and justice, and community. Early ministry with children and adults with disabilities occurred within the context of family and close-knit rural community life. Work after World War II developed based on the service of Mennonite conscientious objectors in institutions for the mentally ill and developmentally disabled. Programs from then to the present developed an array of services including providing resources to congregations, operating group homes and residential facilities, and providing support to regional and church-wide arms of the church. Recent developments have focused on reorganization after changes in organizational structure and reduced funding. [Article copies available for a fee from *The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <<http://www.HaworthPress.com>>* © 2006 by *The Haworth Press, Inc. All rights reserved.*]

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From the early days when Mennonites emerged as a distinctive group from the radical wing of the 16th Century Reformation known as Anabaptism, four interlocking themes formed the core of the Mennonite response to persons with disabilities.

1. An unconditional and redemptive *love* for people with special needs, based on the Biblical mandate to love all people, especially the poor, the sick, and the hurting.
2. A mandate to *serve*, acting in the name of Christ to minister healing and hope to those in need, first within the community of faith and then to the larger world.
3. A commitment to be agents of God's *peace and justice* to the earth, bringing healing to individuals, families, and nations and treating all persons with dignity and respect.
4. A sense of *community*, in which young and old, rich and poor, and those with more and less abilities could live together, experiencing God's love in an environment of safety and mutual regard, each for who he or she is.

As Mennonites increasingly engaged in the mainstream of American life starting in the late 19th and on through the 20th century, these four themes formed the basis for a Mennonite response to the needs of persons with disabilities and their families. Following World War II, Mennonites began specific ministries and organizations to express their faith in relationship to persons with disabilities, first in their own circles and then in the larger communities in which they lived.

Mennonites and Amish Mennonites (most of the latter joining or merging with Mennonite conferences in the late 19th century, leaving only the "Old Order" Amish that we know today) started migrating to North America in 1683. From then on, through most of the first half of the 20th century, the themes of love and community prevailed.

The few references that exist about the presence of persons with disabilities in the midst of mostly German-speaking Mennonite communities indicates that such persons were accepted as a part of the fabric of rural community life and put to work on the family farm doing whatever they were able to do. If there were special needs in the family due to the presence of a person with disabilities, those needs would have been handled as a matter of course by the mutual aid system administered by the deacon of the congregation.

During this time, Mennonites were largely unaware of any movements around them to care for persons with disabilities or mental illness

in large institutions such as asylums and hospitals. It was natural for Mennonites who saw themselves as separate from the English-speaking world to simply care for their own people and not worry about those outside their communities. That all changed with the coming of World War II.

After experiencing considerable tensions and even persecution as a result of refusing to fight in World War I, Mennonites had joined with Brethren and Friends (Quakers) to petition the U.S. government to recognize their young men as conscientious objectors to war and allow them to perform vital services to the country that were not tied to the military. The Civilian Public Service (CPS) units established with the coming of World War II became a major test of that policy.<sup>1</sup> Young men were sent into some of the most wretched conditions of the deteriorating institutions for persons with mental illness and disabilities. In some cases, they were joined by their wives and other Mennonite young women. For most of these Mennonite young people coming from relatively sheltered rural environments, the experience was an immediate eye-opener. Certainly, their commitment to be agents of peace by not going to war met up with the test of whether they could perform loving service to even the most “unlovely” members of society.

While the theme of service formed the initial rationale for their actions, the experience also helped to couple the issues of justice and human dignity to the cause of peace as they joined their fellow servants in those institutions to expose the deplorable conditions that prevailed. The national exposés based on the records of these conscientious objectors were a key factor in unleashing reform movements in both the mental health and disabilities fields that followed in the last half of the twentieth century.<sup>2</sup>

Following the war, Mennonite mission and service institutions became involved in mental health ministries. By the early 1960s a number of community-based mental health centers opened under Mennonite sponsorship across the U.S. The work was loosely coordinated at the national level by the establishment of a Mennonite Mental Health Services (MMHS) under Mennonite Central Committee (MCC), an inter-Mennonite relief and service structure started initially in 1920 to channel relief efforts to fellow Mennonites in Russia and Ukraine.

In the midst of this work in the area of mental health, a new awareness of the needs of persons with developmental disabilities also emerged through a slightly different route. As Mennonite families increasingly moved away from the farm and into professional roles in

towns and cities, the presence of a family member with disabilities took on a new dynamic within the family system. Coupled with this shift was the fact that, with advances in medicine, children with disabilities were living longer. Parents and other family members of persons with developmental disabilities began asking the larger church for help in dealing with issues such as family life activities, respite, and financial planning for adults with disabilities who outlived their parents. These families were supported by a growing number of professionals who were entering the field, largely as a result of their CPS experiences in large institutions during and after World War II.

In 1963, the concerted efforts of these families and friends in lobbying church agencies on this issue resulted in the formation by MMHS of a "Retardation Study Committee" which first met in March 1964.<sup>3</sup> That committee soon turned into a "Planning Committee" for a special one-day workshop held in Kansas in November 1964 in conjunction with other MMHS meetings. The focus of their concerns at this point was solely on persons that we now refer to as having "developmental disabilities" and their families.

In 1965, the Planning Committee embarked on its first project, originally envisioned by another group of parents, a special camping program at a Mennonite camp to serve persons with developmental disabilities and their families. This program was unique in that it involved the whole family. There were activities planned for both children and adults with developmental disabilities as well as any accompanying siblings. This provided not only a time of respite for parents, but also the opportunity for mutual encouragement, inspiration, and education in true community spirit. At the same time, families participated together in the retreat experience in a way that allowed "campers" to interact with each other and volunteer staff, and encouraged parents and other family members to not only learn from and support each other, but also see their children function in a different setting. This retreat has been in continuous existence at Laurelville Mennonite Church Center in Pennsylvania and is now called the "Retreat for Families, Friends, and Persons with Disabilities." Throughout the years, additional retreats using variations of this model have also taken place in other parts of the country.

The success of the camping program led to the formation of a "Resource Committee on Mental Retardation" under MMHS. The committee considered other means of educating the church and planning for additional resources and programming. Eventually, the committee became known as the "Developmental Disabilities Council." By the mid-1970s, workshops and "helps for the church" were being created

under the direction of the staff of MMHS. There was also a staff consultant available to assist churches, families with a disabled member, and Mennonite-related organizations serving those with developmental disabilities.

Those organizations grew out of the same ferment as the national advocacy movement. From the start of the committee's work, the emphasis on service led to the consideration of more local community programs to serve persons with developmental disabilities. However, it was generally left to increasingly active local groups of parents in strong Mennonite communities to create the organizations that would care for their loved ones after they were gone. Their concern was primarily that their loved ones would have a wholesome Christian community with proper supports after they, as an increasingly mobile extended family system, were no longer able to care for them. Today, disability services providers with ties to Mennonite churches exist in Pennsylvania, Maryland, Virginia, Ohio, Indiana, Missouri, Oregon, and California with an additional project emerging in Arizona.

Most of these organizations focus on residential services for adults with developmental disabilities. The main model used is that of the group home where four to eight persons live together in a household along with caregivers. In many places, live-in caregivers have been the norm as married couples or groups of two or three single persons live with the residents. This model has worked best when residents functioned well enough to do all their own personal care and had work or day programs to which they could go during working hours. This allowed a caregiving couple, for example, to take at least one outside job between them during those same hours and thus support themselves. For the organizations, this reduced costs.

Typically, such caregivers saw their work as fitting in with the post-war pattern of "Voluntary Service" (VS). VS emerged as one alternative service option for young men of draft age during the period of military conscription that lasted through the Vietnam War era. Young adults in general were encouraged to give a period of up to two years to VS and even young married couples just out of college were involved. For some, VS became a more long-term lifestyle, and caregiving in Mennonite-sponsored group homes became an avenue of service. Even older couples in a life transition or newly retired seniors have participated in this movement.

However, as the draft ended and more young adults went right into college and then into the kind of jobs that enabled them to pay off their college loans, more and more caregivers came from outside of the

church. In many cases, the service providers needed to pay a more standard wage, provide the time off needed to avoid burnout, or go to a modified or full shift rotation to staff the homes. This led to more service providers turning to government funding to provide ongoing residential services.

Some Mennonite-related service providers also have vocational and day activity programs and have been part of a movement to encourage companies to employ persons with disabilities. Typically, these programs also rely on government funding. However, for all of the service provider programs, there are also fundraising efforts within the local communities to make up the difference between what the government provides and what is necessary to sustain a wholesome quality of community life for the persons being served.

In 1978 the role of the Developmental Disabilities Council changed from that of advisor to MMHS to an “administrative” and “policy setting” role. This allowed for the hiring in 1979 of the first full-time staff devoted exclusively to disabilities resources. By this time, MCC, as the parent organization, was more focused on peace and justice issues and this emphasis carried over into the advocacy work for disabilities. Questions were raised as to whether the developmental disabilities work should broaden to include the needs of families and individuals with other types of disabilities, including mental illness.

With designated staff and administrative and a policy-setting board, the advocacy ministries in the '80s were known as Mennonite Developmental Disability Services (MDDS). As MCC itself decentralized its operations and opened regional offices, developmental disabilities committees sprang up in each MCC region. These committees were instrumental in linking the concerns of families in the congregations to the advocacy ministries. Some of these regional committees were active in establishing new service provider organizations in their regions. It is worth noting that in one case, MCC West Coast, a full-time staff position was designated to serve in disabilities ministry. At the national level MDDS provided a coordinating role for these regional committees and also served as a forum for locally controlled service providers around the country to build networks of support and encouragement.

During this time, a parallel national advocacy program developed around the issues of mental illness. By this time, the mental health service providers themselves had become strong multi-service community agencies, locally operated and funded largely by fees and government funding. However, there was not generally a strong connection to Men-

nonite churches and therefore, there had not been much attention paid to education and advocacy around the issues of mental illness at the congregational level. MDDS provided a model for that to happen for mental illness as well through the Mental Health Awareness and Education Program (MHA&EP).

During the 1970s and '80s, MDDS worked diligently to provide resources for families and congregations. A Disabilities Awareness Sunday was added to the church calendar and resource packets of worship and educational materials were created annually. With the assistance of lawyers within the church, guidelines and principles were developed to aid parents in planning for their loved ones after their death. Increasingly, the theme of community came to the forefront as congregations were given models and encouraged to form circles of care for each adult with a disability in order to provide the ongoing community of support that would leave parents feeling at peace about the future. The little booklet entitled "Supportive Care in the Congregation" is still in print. Even though few congregations have implemented all of the details in the plan, it has nevertheless served as a model and inspiration for thinking about these issues from the standpoint of the wider family of faith instead of just the biological family.

With the coming of the last quarter of the 20th century, MCC and the various Mennonite regional and national mission agencies gradually realized that they were administering many scattered health and human service organizations on parallel tracks. Included among these organizations were a growing number of nursing homes and retirement communities, as well as providers of disabilities services. Mission boards particularly wanted to turn over the administration of local service provider organizations to the local community. At the same time, there was a keen desire on the part of many that these local organizations to retain a distinctive Mennonite witness through some kind of linkage with the church structures. In 1988, MMHS was renamed "Mennonite Health Services" (MHS) and given the mandate to guide and serve these local community health and human service providers of all types. This was further encouragement for locally-controlled disability services providers to see their services as related to the national and binational church.

As MHS grew to become a distinctive entity from MCC, its role became increasingly more focused as a resource to the self-supporting local agencies which it served. This led to the question about the relationship of MHS to the disabilities and mental health advocacy ministries. The advocacy ministries were not bound to a local geographic area, serving families and congregations directly throughout the coun-

try. They also relied, for the most part, on donated funds. In the early '90s, as a formal separation was planned between MCC and MHS, the question of the placement of the advocacy programs within either of the parent organizations remained in limbo.

The disabilities and mental illness advocacy programs fell victim to a complex set of forces. Mission boards were clear that their mission was not in administering intricate health care structures and were increasingly focusing on planting new churches and resourcing churches for spiritual outreach both overseas and at home. MCC, with its emphasis on cutting-edge peace and justice ministries that had originally strengthened the advocacy programs, now moved on to other issues. The divestiture of MHS made the MCC governing board reluctant to welcome the disabilities and mental illness advocacy ministries which they assumed were a remnant of the old health care organization administration system. At the same time, MHS felt a need and mandate to serve the local service organizations, relying on their membership dues for funding. The church-wide advocacy ministries, with no steady funding source or administrative structure to benefit from MHS resources simply did not fit into this new scheme.

In 1994, with MHS established apart from MCC, a decision had to be made regarding a "home" for the advocacy ministries. Mennonite Mutual Aid (MMA), a stewardship ministry of the Mennonite Church (and other Anabaptist-related denominations) stepped forward and agreed to sponsor the programs. Accepting these ministries was a "stretch" for MMA as their mission was focused on developing stewardship education and wellness education resources and products. MCC eased the transition by promising a level of funding that would decrease over five years.

Historically, MMA has held the Mennonite Church mandate to provide affordable health insurance to church members. However, as they increasingly faced financial pressures in a complex and constantly changing national health care environment in the '70s and '80s, MMA's energies went increasingly into providing general stewardship products and health awareness and education efforts at the congregational level through a system of congregational advocates. This was coupled with a stewardship emphasis related to its investment products (mutual funds, foundation investments, etc.). The result was that the advocacy programs for disabilities and mental illness were seen as two expansions in MMA's "Stewardship Education" emphasis.

The initial result was a flurry of activity around the development of tangible disability and mental illness "products" that could be marketed

to families and congregations to help offset the costs of this ministry. At the same time, the tradition of mutual aid and donor support made MMA reluctant to move whole-heartedly into a marketing approach. Updated and new materials were produced and the two half-time consultants, hired by MMA to replace the earlier advocacy staff, spent considerable energy getting into conference and congregational settings. In addition, extra efforts were made to connect again with families as a consultant was hired to revive the flagging disabilities retreat at Laurelville and develop new retreats for family members of persons with mental illness.

At the same time, the national committees that had earlier set policy were downgraded to advisory status and then eliminated altogether in a cost-cutting move. MCC regional committees on developmental disabilities gradually faded as well since they were no longer tied back to the parent organization. MMA's volunteer, congregationally-based advocacy system was able to pick up some of the slack of congregational connectedness, but the effect was more diffuse without committees of activists meeting regularly.

Even given these significant changes, the mental illness and disability advocacy programs did adapt to MMA's environment and ran smoothly during the stock market boom of the late 1990s and early into the new millennium. As MCC's subsidies ended in 1999, a meeting was called in early 2000 for MMA, MCC US, and MHS to evaluate the future of the programs. MCC US continued to encourage its regional organizations to have disabilities programs of their choosing, but did not pursue creating anything on the national level, despite the fact that MCC Canada continued to sponsor the disabilities and mental health advocacy programs in that country. MHS reaffirmed its position that the programs did not belong in its organizational structure and MMA agreed to continue to sponsor them without the MCC subsidies.

The clash of the stewardship theme with the earlier themes of love, service, peace and justice, and community finally took its toll. As the stock market turned sour and health care costs continued to put pressure on its revenue-producing insurance programs, MMA decided it needed to focus on its stewardship core. MMA made a unilateral decision and the advocacy programs were eliminated on short notice at the end of September 2002.

Yet, a small group of parents in Indiana, site of MMA's offices, picked up the banner. After making contacts with MHS, service providers, and officials from Mennonite Church USA, the ad hoc committee determined that there was no church agency willing to pick up sponsorship of the advocacy programs even though they all agreed there was a

need for them. So this group of parents called together a larger group of parents, individuals with disabilities, and friends and were empowered to form a new organization to carry on the work.

The Anabaptist Disabilities Network (ADNet) was thus formed in early 2003. MMA agreed to give the fledgling group its remaining stock of disability and mental illness resource materials and provide some initial funding for start-up costs. A national Board was recruited and met for the first time in January 2004. By mid-summer of that year, volunteer efforts were waning and fundraising was going well enough to hire a half-time Director starting in September. MMA continued to be supportive by providing a matching grant to donated funds.

ADNet has continued to distribute resource materials published by MMA, some of which date back to the MCC days. It has continued to publish a periodic newsletter directed to this constituency and initiated new communications through a Web site, a toll-free voice mail system, and a quarterly electronic newsletter for congregations. Presentations have been given in a number of area churches in worship and Sunday school settings.

In 2004, ADNet responded to nearly 90 requests for information and resourcing from individuals, families, congregations, and church-related agencies in 22 states. These requests included booklets on topics ranging from estate planning and "Supportive Care in the Congregation" to essays on "A Christian View of Mental Illness." Also provided were videos from a loan library, accessibility audits, and referrals to Mennonite service provider organizations. ADNet also participates (as did its immediate predecessor) in the loosely structured National Council of Churches of Christ Committee on Disabilities. This connection, along with the increased exposure of the Website, have resulted in other denominations outside of the Anabaptist community also using ADNet's materials.

Future goals for ADNet include better utilization of electronic discussion groups as well as linkages with and the establishment of more local and regional face-to-face support groups. ADNet would also like to build a centralized database by which individuals, families, and congregations could gain ready access to people, media, and organizational resources in the style of a true network. This would include a national network of consultants to congregations on accessibility issues.

ADNet has emphasized the effort of congregations to build community that includes all persons regardless of their abilities. However, just as at the beginning of the advocacy efforts for persons with disabilities, the ministry is again being championed by families and individuals liv-

ing with disabilities and mental illness. This group continues to remind the church that the themes that the church holds dear, peace, justice, and community, apply to persons with disabilities and need to be fleshed out in concrete actions of love and service.

### NOTES

1. This story is told through a PBS film entitled “The Good War and Those Who Refused to Fight It” and accompanying website at <http://www.pbs.org/itvs/thegoodwar/>
2. Sareyan, Alex. *The Turning Point: How Persons of Conscience Brought About Major Change in the Care of America’s Mentally Ill*. Pennsylvania: Herald Press, 1994.
3. From here on, source materials for this article consist mainly of archival papers housed in the offices of ADNet and in the Mennonite Church USA archives, both located in Goshen, IN.