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The Role of the Church in Providing Comprehensive Services

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by **Ellen Cook**

The role of the Church in ministering to families that have members with disabilities is a simple one: Be There.

Be there with young parents devastated by a diagnosis. Be there with retired parents agonizing over placement of an adult child in a group home. Be there as families search for religious training and involvement for children who are mentally retarded. Be there during the recurring times when family members struggle to reconcile the long held ideal of a good and caring God with the heartbreaking, tiring, frustrating reality of a child who may need constant watching, taxing physical therapy, extensive pat-

terning drills or absolute and total care around the clock.

The shared experience of families with members who are mentally retarded seems to indicate that level of expertise, formality of approach far less important than the presence of another person who can enter into the family's situation, sharing it, feeling it, owning it. The tenor of faith and God concepts of individuals and families grow out of the historical and contemporary community of faith in which a combination of graced experience, formal teaching and human interaction combine to lead people to reflection, inspiration, spiritual belief and growth. Faith and hope come in part from the fabric of human experience, from the willingness of believing people willing to share their journey and

their story with others. Individual and family faith then provide a "meaning giving" context for experiencing and interpreting life. The believing community is the place where this faith can be nurtured, affirmed and supported. Major unexpected events, especially traumatic ones, challenge and threaten basic faith understandings, methods of processing reality and even membership in the community of shared belief. It is the obligation of the community to be its best compassionate, believing and supportive self when members are faced with major life challenges such as the birth, diagnosis, nurturing or death of a family member with serious disabilities.

Who is this Church, this community? The people from a congregation

The parishoners who provide care while parents with an autistic child have a rest are just as much ministers as the chaplain who sits and prays with a family while a baby with hydrocephalis has an operation.

who provide respite care while parents with an autistic child have a rest are just as much ministers as the chaplain who sits and prays with a family while a baby with hydrocephalis has an operation to have shunts put in. Each level of the institutional church and each person within it may have a contribution to make and each level is in a unique position to enable ministry and services.

At the global level, the Church can use its world leadership position to point out fundamental principles such as the tremendous value and giftedness of each individual and the right of each person to appropriate instruction and meaningful participation in the systems and rites of Churches denominations. World Council of Churches conferences and publications as well as Vatican documents and statements are examples of this.

At the national level, the Church can work on consciousness raising, on disseminating models of education programs, worship formats and inclusive language while insuring that judicatory units or dioceses have the personnel and structures to work toward full participation. The American and Canadian Bishops Pastoral Letters on the handicapped and the establishment of a National Catholic Office for Persons with Disabilities shows the fruits of work on the national level as do the excellent publications of the National Council of Churches Task Force on Developmental Disabilities.

Regional bodies and leaders can sponsor events and programs

that will foster awareness, provide a vision for local congregations and develop resources for people in the field who are teaching, leading worship, and working toward integration of people with disabilities in educational programs, outreach, worship and social events. In Wisconsin, a statewide meeting and workshop on the Church and Persons with Disabilities was attended by 200 people. It was organized by a Commission of the Wisconsin Conference of Churches. In the same state a province committee of the Roman Catholic National Council of Diocesan Directors of Religious Education is working on guidelines for sacramental preparation and celebration with mentally retarded children and adults.

Local congregations have the human resources to say "yes" to families directly. "Yes - someone will care enough to share the journey, to struggle with questions that have no immediate answers, to find a way for a person who is mentally retarded to be an equal and functioning part of the believing community." Clergy and non-ordained members are called to formal ministerial outreach and to the healing ministry of human presence.

The challenges to these levels of Church have their roots in the rights and giftedness of individual members who are physically or mentally disabled. They have first of all the right to a place in the believing community, and this basic right has implications.

A community that is inclusive is

1 All Church members need to be introduced to appropriate denominational teaching about who God is, how God functions in individual and community life and how one can know and serve God better. Teaching and learning of this type need not be dependent on reading or writing or other cognitive skill. Isaiah provided a beautiful non-cognitive example of the experience of God in a gentle breeze and other examples abound. In fact, mentally retarded people who can call clergy and teachers to fundamental and relevant faith questions and to using effective educational methods. Sound, basic and rooted theology and good methods are a benefit and gift to the larger Church community.

2 Part of life for believers is sacred ritual, which lifts human experience to God and in which life is touched by God. Ritual action and symbol and rite belong to all community members. Full access might mean modified use of symbol, explanation of actions, or an open attitude on the part of congregation members. A goal here could be the fullest possible understanding of and participation by all members in ritual worship of the community.

3 Religious belief challenges Church members to grow and to reach out. Disabilities, including mental retardation, do not excuse believers from the challenge of moral growth or the satisfactions of reaching out to others in service. Each believer is called to ministry and to the satisfactions that result from making a meaningful contribution to someone's life through action, financial contribution, prayer, or presence.

Role of the Church

one in which some or all members are aware of the needs of disabled members. These needs include interaction with others in a social setting, growth in religious experience and understanding, prayer and participation in ritual progress toward individual moral potential and orientation out to others in service.

This is not a community that

- denies religious instruction to children who cannot read
- allows parents of a ten year old who has behavior disorders to draw the conclusion that their child will never have a place in any church service
- approaches people who are mentally retarded only as people to minister to but never as people capable of ministry
- quietly tolerates parental statements that a capable twelve year old girl who has Down syndrome is not capable of benefiting from any type of church involvement
- assumes that the community worship needs of people in large state institutions are automatically taken care of by one overworked chaplain
- considers disabilities equal to illness or moral flaws
- ignores usual acceptance and outreach to new parents when a baby is found to have a serious genetic condition.

No one predetermined program or approach by a Church community will be able to address the diversity of needs that may be present in a family under stress because of a member

with special needs. The family of an infant who needs many surgeries, constant watching, frequent resuscitation and special feeding methods may have strong basic needs that must be met almost immediately. The Church may be in a position to address these needs or refer the family to individuals or agencies that can help. There

is a hierarchy

of needs and

h a v i n g

enough sleep,

energy and

compani-

ship to survive day to day are basic

but essential ones. These would differ

greatly from the needs of the parents

of a healthy child with Down syn-

drome whose daily life is running

smoothly but who need prayerful

opportunity to reflect on the challenge

their child has brought into their lives

and on how God has been present to

them in the experience. The Baptist

parents of a 25 year old sexually

active, moderately retarded woman

who lives in a secular group home

will have different expectations of

their church community than the

Catholic parents of a mildly retarded

seven year old who wants their son to

receive First Communion with other

children his age.

The needs vary. The ability of the

Church community to respond varies.

What does not vary is the obligation

of the community to respond or to be

present somehow. Ministry and ser-

vices to families with special needs are

not qualitatively different than min-

istry and services to other families.

Individual and collective prayer,

Ministry and services to families with special needs are not qualitatively different than ministry and services to other families.

human presence in time of stress, outreach to family members, referral to community agencies, establishment of special religious education programs, mainstreaming of people with special needs in existing programs, respite care groups, establishment of church sponsored group homes, involvement in advocacy and programs and homi-

lies aimed at

raising some

congregation-

al conscio-

ness about the

disabled and

their place in the church are just a few

of the methods that have been used to

respond to family needs. No one

should expect the church to meet all

social service, educational, residential,

or therapeutic needs, but families

should expect some response to their

spiritual and community needs from

their local congregation.

In order to develop appropriate

approaches, Church leaders must first

be aware of the situations of families

within the congregation and must

have a vision of full participation of all

members in the life of the Church

community. This is not a question of

whether the Church will respond to

needs but rather of how the Church

will respond. The following questions

highlight the unique role that

Churches can play in families which

have members who are disabled.

What can the Church uniquely do

that cannot be done by other

groups, agencies, or institutions?

Only Church can offer a faith con-

text for the processing of difficult life

events, a meaning giving approach to

reality. Further, the Church has unique contributions to make in the spiritual life of individuals and families, offering formalization of sacred moments in liturgical celebration, a framework for moral decision making, pastoral guidance, models of prayer and a spirit directed community of belief and support.

What is the Church definitely called to do in response to the needs of families with disabled members?

The Church is called to make its educational, liturgical, social, and outreach programs and functions as available as possible to all members. Accessibility can be physical (removing barriers to entrance and participation), psychological (assuring level of comfort for all involved), or social/educational (making events as understandable and meaningful as possible given the abilities of those who participate). The Church is called to accept, pray, educate, celebrate, hope, offer a vision, minister and be ministered to.

What might the Church consider doing in response to family needs?

The response to this question is limited only by the resources and creativity of Church members. Some possibilities are individual or group advocacy, parent support groups, sponsorship or adoption of group homes, development of disability awareness events and adult social clubs.

What should the Church definitely not do?

The Church must not ignore difficult life events, be paralyzed out of ignorance, inflict guilt, intervene without an understanding of the family situation, judge parents or families, assume mentally retarded people have no potential for spiritual growth, isolate or alienate people in need, think that it has all the answers or promise "cures" for mental retardation.

What can the Church undo that has been done?

Many families are alienated from Churches because of perceived rejections or offenses by clergy and community members. Even when parents

have not been able to articulate their needs, they have kept their expectations that the Church should reach out and help them. It may not be too late for the Church to help alienated parents and disabled individuals reflect on the needs they feel, express their needs and hopes and work with leaders to find a way the Church can begin to address those needs.

Believing communities and families can get together to develop a vision of full participation and can work toward making that vision a reality. Much progress is being made as parents articulate needs and as Churches awaken to the concept of the believing community as a union of individuals, each with gifts and limitations, who together can be both signs and builders of God's kingdom on earth. Comprehensive services and ministries come from churches that are aware of family needs, from a strong faith vision in a community, from a willingness to use a congregation's gifts and resources and from a view of each person as someone with potential for faith, growth, and ministry.

This article was delivered as part of a Retreat Symposium Sponsored by the American Association on Mental Deficiency Religion Division on May 27, 1985, in Philadelphia.