

Excerpt from "Pastoral Care for People with Disabilities and Their Families"

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I. Pastoral Care as Presence

The basic pastoral role. Be there. Be there at crucial and critical times. At a birth. At a diagnosis. At a first struggle with appropriate schooling and services. At critical transitions in an individual and family's life when the impairment and disability, at that point in time, kick up all the questions and then some new ones, such as what happens after school? Who will care after we are gone? Be there. Be willing to ask the questions. Hear the story. **You don't have to have the answers.** You do have to be able to ask the open-ended questions, listen, and hear the lamentations, the anger, the joys, the dreams, the frustrations.

Early in my pastoral work with families with children with mental retardation, (I was a CPE Intern with one of my assignments at a diagnostic and evaluation center connected to the medical center) a family came through with the story I had begun to hear too often in one form or another. For them, their daughter had gone to Sunday School until she was asked to stay behind when others moved on in early elementary grades. Eventually, they had to place her in an institution, but no one ever asked about her, in contrast to the other children away at school. Once, when she was home, they had taken her to church, but the new minister would not shake her hand when they left the service (a sacrament in many congregations!).

I was going to another meeting in the direction of that town and called up the minister and asked if I could come talk to him. I rode my white horse into town to set them straight, paused when I entered his office and saw all the certificates on the wall saying he had more training than I, and then asked him about his observation on the family.

He said he knew about their daughter. He had been to their house and saw her hyperactively "bouncing off the walls". But "they seemed to be a strong, independent family," and never said much about her. "My schedule," he said, "is full of people calling and asking for time to come and talk."

*And for me, as the young chaplain and clergyperson, the sudden image was of 'two parties with small but seemingly huge gap in-between them, each waiting for the other to make the first move. The family was aching for the pastor to say.... "Tell me what it's like to be parents and what can our church do to help" (Or as another family said to me, our minister did wonders simply by helping us see the joy in our child.) And the minister, waiting for the family to say, "Pastor, please help us. " The grace of God, in a pastoral role, was for the minister to be "foolish enough" to ask the questions and enter into the story, even when it felt awkward and foreign, and even when things are not easily or quickly fixable. Presence is also both **going** there...and welcoming when they **come**.*

II. Pastoral Care as Guide

Call it counseling, grief work, resurrection work...whatever, the pastoral role is walking with others in ways that helps people trust you with their questions and feelings, and helps interpret the experience in the light of their individual and communal faith traditions. It is not easy, because this is both pastoral care in crisis situations, and pastoral care over the long haul. It is hearing the questions, and helping people find their own answers. The theological and spiritual issues can be many:

*** Questions about God's will, and God's purpose. Why?** In the book, Helping Your Handicapped Child, George Patterson explores the variety of ways that people can struggle with those questions in the context of the Bible. The crucial issue for a pastor is the variety of interpretations that have Biblical roots and parallels. They are all, in other words, part of faith. And the pastoral tasks are like others in response to "God's will." When, for example, someone says, "The Lord doesn't put more on you than you can bear," is that a statement of hope and purpose that gives meaning, or is that a statement that implies a lot of resentment and anger at God.

*** Issues about responsibility, sinfulness, and control.** We may not believe in God punishing a child because of the sins of the parents, but the irony is that in modern times we make assumptions about our capacity to control pregnancies. What did you do? What could you have done differently? And sometimes, it is in fact human or social behavior that causes the disability, such as fetal alcohol syndrome, disabilities due to environmental pollution, medication side effects like the thalidomide babies.

*** Issues of healing.** What does it mean to be healed? Or to be whole? Talk with people with disabilities and their families, and many will tell you about years of praying for healing, or others will talk about people coming up to them and saying "let me heal you." And even worse, what often happens is the blaming of the victim when it doesn't work, i.e., if my child or my body is not healed, perhaps my faith is not strong enough. I didn't pray right."

Harold Wilke tells the wonderful story of a person with an obvious disability being approached by someone on the street who said "My brother, if your faith was strong enough, you could be healed." To which the man with the disability replied, "My brother, if your faith was strong enough, you could cure me." Which one is more Biblical?

*** Issues of prejudice and attitudes.** Let me illustrate with two stories. One is from Bob Perske, who tells about a father saying to another father, "Can't you see, it's we who tell other people they are a tragedy."

And my friend Donna, a woman labeled as mildly retarded with cerebral palsy, asking me after she heard about a neighborhood rebelling to the possible presence of a group home for people

with disabilities. "When will normal people learn to accept handicapped people the same way handicapped people have to learn to accept normal people? "

It is hard to be a guide when you as a pastor are challenged to go with a family into a land or territory that is very strange and unfamiliar. But your role as guide is not a "fix-it" guide, or a "how-to", but one that walks in the journey, helping to find a way, and interpret the signs and paths.

III. Shepherding

Shepherding is the Biblical name for what service systems call "advocacy." But it is more encompassing. There are several images of a shepherd that have real application here. The one too often used in relation to pastoral care with people with disabilities is that of Jesus rocking the lamb in his arms. That is fine, we all need that willingness to be touched and held, but the image of a shepherd in the 23rd Psalm is also one that goes through the highs and lows, has a "rod and staff that comfort me," someone who fights off the dangers, finds a way through a wilderness of services and red tape, has the audacity to celebrate "in the presence of my enemies," and the hospitality of sanctuary.

That shepherding can happen both within the church, but also with a person and family in the community. It is often ironic that clergy, like many others, feel powerless in the face of a system of special services for people with disabilities, but in fact, by virtue of being a community resource, have great power.

A family in South Carolina told me the story about their minister going with them to their child's IEP (a meeting at the school with teachers, specialists, & a variety of professionals to review individual goals, progress, and direction...an often intimidating session for families). They said, "It was wonderful....we got everything we wanted....they thought he was our lawyer." Funny, yes, but for many people with disabilities and their families, knowing that their pastor and congregation might stand with them as they seek appropriate supports from service systems would be an amazing source of power.

And the other image of shepherd is the one that goes after the one while the ninety and nine are in the fold.

"How many disabled people do you have here?"

"Just one or two or three?"

"What about the one? Where are they?"

"But I don't have time, because of the needs of ninety and nine."

Ministries which search out those who fall between the cracks of systems and congregations is a call to all of us. And realize that when you touch and include the one, you are impacting a whole family, and

often an extended family and other caregivers. / remember clearly the mother who said to me, "*When the church rejected my child, they rejected me. When they accepted my child, they accepted me.*" In the "world of disability services," a story of a congregation that seeks out, accepts, and includes is a powerful witness to faith, just as the negative stories become reasons and justifications for giving up on the church and God.

IV. Community Building: Empowering the Body to Care and Support

The fourth pastoral role is that of simply mobilizing the congregation, friends, neighbors and community to respond, to care, and to support. It is the role of community building, empowering the saints, being a church family.... or whatever image you wish to use. It is too often a neglected pastoral skill in an age that focuses on individualism and one-to-one pastoral care. It is a way of saying "This person and family belongs to all of us." You know the African proverb that it takes a village to raise a child. There is another which says "When there is a thorn in the foot, the whole body must stoop to pluck it out."

The mother got up at the conference on congregational ministries with people with disabilities and said, "In my pregnancy I discovered that my child was going to be multiply handicapped. My priest and church said my child had a right to life. And I also believed that. And he was born. Then they disappeared. He also has a right to live.

There are a multitude of ways that congregations support members. The first step is to look at how you already support one another, and make sure people with disabilities and their families are included, not just in the receiving of support...but in the opportunities to give. Then ask before doing. What kinds of supports are needed? Families often are put in the position of having to ask and fight for inclusion in their own church, and say "I have to do that everywhere else...I don't want to have to do it here."

The possibilities are limitless. Helping to buy a needed piece of medical equipment. Providing respite care for families who are 24 hours a day, seven days a week caregiverw, advocating with community and political issues and services...you name them. One of the most promising models of support these days is called a "circle of support," an intentional way of mobilizing people who are connected, or who would like to help, in the shared tasks of helping a person with a disability and/or family reach their own dreams.

What can happen is that the congregation then learns better how to care for one another.

One of my favorite stories is from Rabbi Walter Jacob, a Pittsburgh rabbi whose severely disabled daughter occasioned his involvement and leadership of an interfaith effort which eventually established a network of community-based group homes. Here is what he says: Through all of this the congregation and hundreds of individuals from it were very supportive. The initial funds for the effort came from members of the congregation and were raised largely with their help. The political battle was waged with the assistance of hundreds who took time to attend zone meetings, help circulate petitions, and spearheaded a letter writing campaign which ultimately involved thousands of letters. Horizon Homes' original director had

his office in my study for the first year. During the two year period, which led to the establishment of the first group home, I spent at least thirty hours a week on this effort. The congregation and its leadership supported this expenditure of time. (His daughter, Claire, then died before moving into the home.) Claire's achievements during her short life were very limited, but what stimulated in others was substantial. Even ma-asu ha-bonim haytah I'roshpinah. (The stone which the builder's rejected has become the cornerstone.)

Just as one can learn about key roles in pastoral care from issues faced by people with disabilities, so is the learning possible in other areas of congregational life. In religious education, programs which seek to include children with disabilities often learn how to be more inclusive of everyone. In visitation and evangelism, we often talk about the "unchurched." How many are people with disabilities and their families? Are they "shut-in's" or "shut-out's?" In designing buildings, do they reflect the soul of the congregation? Is everyone welcome? Can everyone get in and around... and not just to the sanctuary? What about other forms of recreation and social programs that happen in the congregation. In mission and outreach, how can people with disabilities be involved in discipleship, as well as receiving care?

And so, including people with disabilities and their families in all dimensions of pastoral care and congregational life, the key word in ministry is "with". Not ministry "to" or "for", but ministry with others. The key feelings are often compassion and anger the latter at the barriers in architecture and attitude that prevent inclusion. The end product is the gift of belonging, the feeling of being welcome, a part of rather than apart from, and in real ways, new understandings of what it means for everyone to be part of God's people.



Supporting families and equipping the church for inclusive communities.

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