

Pastoral Care with People with Disabilities and Their Families
An Adaptable Module for Intro Courses
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Preface

The following paper is an attempt to share the outline, topics, and content of an introductory module on pastoral care with people with disabilities and their families. I have used this in a variety of settings and courses. This is written in a way that others, hopefully, can adapt it to their own settings, and use parts of it interchangeably. Some of this is further explored in the chapter on "Religious Ministries with Persons with Developmental Disabilities" in The Right to Grow Up. Ed. Jean Summers. Baltimore: Paul Brookes Publishing. That is out of print, but copies of the chapter are available from me.

Readings

There is a wide variety of options. You may have ones that fit your tradition and context. For an extensive bibliography, see Dimensions of Faith and Congregational Ministries with Persons with Developmental Disabilities and Their Families: A Bibliography and Address Listing for Clergy, Layperson, Families, and Service Providers. This is a 170 page resource guide with books, articles, and videos. Cost: \$15. Also in PDF format on The Boggs Center Website.

Introductory Readings I Like to Use:

Nouwen, Henri. "My Peace is not of this World." Article in Weavings on his relationship with Adam at Daybreak, the L'Arche Community in Toronto.

"How to Speak to an Able-Bodied Person." Article

Autism and Faith: A Journey into Community. 52 pp. booklet of family stories, strategies for congregations, reflections by clergy, and more. The Boggs Center. @\$5 each.

Other Resources:

There are a number of effective videos, several which I go back to frequently in an introductory module even though they are older. They illustrate particular theological issues or perspectives. The best introductory video on common courtesy and relationships with people with disabilities is a new one, Ten Commandments for Communicating with People with Disabilities. If there is time, probably the most effective resource for an introductory module would be for people with disabilities, and family members, to come and tell their story...and talk about the role of faith, congregation, and pastor. Another is a short eleven minute video entitled "Believing, Belonging, Becoming," with four short vignettes about congregations who are including people with developmental disabilities. Two of the vignettes are about children; two are about adults. It is available from The Boggs Center for \$10. Check payable to "The Boggs Center."

Pastoral Care with Persons with Disabilities and Their Families

A Plunge Into Pastoral Theology

While most of my experience is in working with people with developmental disabilities and their families, this paper and session will explore the opportunities and challenges which people with all kinds of disabilities present to pastor and congregation. The most immediate is that ministries with people with disabilities brings us face to face, immediately, with theological questions, issues, and assumptions in stark, concrete ways. There are at least three:

First, what does it mean to be human, to be a person, to be whole? How are the labels used to form judgements and stereotypes. Is a person fully described by their label. Is it an attribute, e.g., does a person have a disability, or is a person disabled? While there are all kinds of labels and diagnoses, in our religious tradition, how do we define and describe people. If we say that every person is created in the image of God, what does that mean for the person with multiple disabilities in comparison to, or with, people whose attributes we more commonly value.

Thus, what does "disability" mean? Here, the World Health Organization's three fold definition of disability is very helpful. There are three levels to the definition:

A disability is first of all an impairment. Something biological or physical has happened which causes a difference. It could be an extra chromosome. It could be lack of oxygen at birth. It could be another genetic "defect." It could be environmental pollution. It could be an illness after birth. It could be an accident. There is a physical basis, even though the root causes of many forms of mental retardation and some disabilities are unknown.

Second, that impairment causes some level of dis-ability...the lack of being able to function in assumed, normal ways. Thus, I may not be able to walk. I may not be able to think as quickly or clearly. I may not be able to see. And that level of disability is impacted by context. In some cultures or contexts, the same kind of impairment may be much more dis-oblong than it is in another.

Third, what do we think about the impairment and disability? What is the value judgement placed on that difference? That is the "handicap," just as we use the word in a race or golf game, a socially imposed value judgment about a difference or lack of ability. What do I think about my "impairment or difference." What do others think? And this is where the power of social labels, expectations, and value judgements gets displayed in all its creative and destructive forms. David Belgum wrote a book called by a question that many of us ask What Can I Do About the Part of Me I Don't Like? An old mind twister illustrates the self-fulfilling prophecy powers of labels and expectations. "I am not who I think I am. I am not who you think I am. I often am who I think you think I am."

But now, mainstream that definition. All of us are born with some kind of limitation or impairment. It may be minor, but we are all limited by our physical and biological make-up. Our unique bodies and minds contribute to the kinds of abilities and dis-abilities we all have. I can't do everything I might like to do. And third, it is what I think about my unique self, its abilities and disabilities, that makes a huge difference in my own life, spirit, and soul.

Some differences, obviously, are disabilities and handicaps. Many are the opposite. I was not created seven feet tall, with the capacity to put a ball through a round hoop. If I was, I would stand out in a crowd for my difference...and it would be valued by all kinds of socially normative ways.

Be careful, though, in saying that we are all limited and vulnerable...or disabled. It is often a step in honesty and community to realize that...but the kinds of impairments that some people have to struggle with, the disabling conditions they cause and are caused by the world around them, and

the value judgements on those differences...are not the same. It is only a beginning of a pastoral and theological journey to say "We all are disabled." People with severe and multiple disabilities, however, represent what Dan Gottlieb says is probably "everyone's worst nightmare." Perhaps our most appropriate label, as Harold Wilke pioneered, is that most of us are "TAB's," temporarily able-bodied. Jurgen Moltmann says it another way in an essay on disabilities in his book of sermons called The Power of the Powerless, in which he notes, essentially, that we are all born weak, vulnerable, and limited, and we all die that way. The paradox is that we think we are anything else in between.

If we are created in God's image, then the second theological question raised by people with disabilities, beyond how we define the value of each person, is what does a disability say about our image of God? Is God disabled?, as Nancy Eiesland explores in her recent book. Or to ask it in another way done by a seminarian who once worked with me at a developmental center in Rochester and wrote a paper entitled "God is Black, Beautiful, and She Has Cerebral Palsy." The question quickly gets into the "why" of disability and suffering, the power and will of God in relation to God's love and goodness. (See the classic, When Bad Things Happen to Good People, by Harold Kushner, written from his struggle with his son with a degenerative disease and disability.) But to say it more positively, what would it really mean if we believed the medieval saying that "in front of every person there is a host of angels saying "Make way for the image of God! Make way for the image of God!" How might that impact the way that we treat everyone?

And the third major theological question is what it means to be God's people...to be community...to be the church, where we say, everyone is welcome. If you go to most churches and ask about people with disabilities, they will say "We don't have any." But there are 45 million people in this country with some form of disability, an estimated 1.2 million in New Jersey. Where are they? Who are they? How does our image of God's people, the body of Christ, include people with severe mental retardation, deafness, schizophrenia, Down syndrome, cerebral palsy, or others considered to be "the least of these." As Bishop Leslie Newbigen of India has said, can we really say that the whole body of Christ reaches out to include people with disabilities, or must we say that we are not whole until they are included. How do we include, for everyone's sake, the "lesser parts of the body" which we often think we do not need, much less want.

Illustrating the Questions: A Story and Brief Look at Church History.

Let's go back a bit and illustrate the questions and struggle, beginning with the question many parents, and all of us, face when something happens to a child that we assume to be out of the ordinary.

Use video Mother Tiger, Mother Tiger 12 minute video on one family's response to the birth and diagnosis of a child with multiple disabilities focusing on the mother's response to the question "Why?" It is a very powerful and dramatic video, which needs time for reaction and discussion. Here's how I might do it.

The video illustrates a number of powerful questions and symbolic actions. What got destroyed in the film? (The mother shoots three items.) Three things: the toy man up on the shelf...perhaps an image of God. The picture of a baby...the image of what she expected her child to be. And her own image in the mirror...her own self-image and expectation. Some parents and families have described the process as being like the death of a child and expectations, before a new image and vision arises of what and who their child and family will be.

Now, I could never answer the question "Why?" in the way she did. But that would not be my role as pastor. My role would be to be there, and help a person find the answer that is right for them. It would certainly not be the role as some families have told me, that their minister came and said to them "What did you do that God sent you that child?"

When we look at church history, the alternate responses to the question of "Why?" a disability, or "Why suffering?" is illustrated generally by two extremes.

The first answer has too often been that a disability is caused by evil actions on the part of the parents, or represents evil, or is somehow demonic. There are plenty of scriptural references to that. The word in the Middle Ages was "changeling," i.e., in the middle of the night the demonic forces of the forests had come and "changed" their child for another.

The other extreme has been that children and people with disabilities are somehow angelic, eternal children, God's special child, holy innocents, angels unawares. The problem with that answer is that it does not take a lot of personal experience with people with disabilities, as with any children or adults, to know that "they" are not completely angelic, or innocent.

(Put in your own stories...)

What is needed, in fact, is a balance between the extremes, a doctrine of humanity and personhood that says we are all "evil and angelic," we all have good parts and bad, we all have strengths and weaknesses. The question, Biblically, is not how many talents we have, but what we do with them.

When one begins to look at church history and the development of more inclusive ministries with people with disabilities, there are in fact some general "stages" that parallel, in a "macro" way, what happens in a "micro" way as individual congregations begin to include people with disabilities and their families in pastoral and congregational life and ministry. Remember that the following is simplistic, but can illustrate what has happened over time, both in the life of "the church" and in individual congregations.

Stage One: "They" are outside of God's creation and God's people.

Think of the injunctions in Leviticus about people with disabilities at the altar. Think of the mis-uses of the Biblical injunction that the "sins of the parents are visited upon the children." Remember the pastor who asked "What did you do?" Hear the story of Martin Luther, who suggested that a prince should take his son who "ate, defecated, and drooled, as much as four peasants a day" (We would probably call it "Prader Willi Syndrome) and throw him in the river because the devil sits in his body where his soul should have been. He was a "massa carnis," a mass of flesh, without a soul. Think of the stories of people who use wheelchairs being asked to leave a church when it is full.

And if the stories you know are not explicit, think of the implicit messages that are perhaps more insidious because they are more subtle. The signs say "Everyone Welcome," but everyone may not be able to get in. How do people with disabilities challenge the image we have for what it means to be human and whole, or a member of this congregation. We want the people with many talents, those whole, complete, beautiful, powerful, bright, cool...you name it.

Ministry at this stage is often non-existent.

The feeling level is usually one of fear of the unknown, the stranger, and rejection of those who are different.

Stage Two: Special Ministry to God's Special People

When people begin to say, "Wait, I can't believe that God has condemned these people. They are somehow a part of God's creation, but perhaps need special care and services commensurate with their separate, yet part of, God's creation. It is a step in the right direction, but it still can segregate and devalue. Many wonderful programs in special education, special religious education, special services and others have been helpful, but there are problems.

For one, "special" often justifies segregation.

Second, think about your own feelings about being called "special" in some way. Sometimes specialness is a virtue. Sometimes it is a liability. Women are special. Ministers are special. Too often we put people devalued on a special pedestal.

And when someone calls you that for what you have done, "Oh, you are such a special person for what you do," it is dishonest and dis-empowering. Dishonest because it fails to recognize the mutuality of giving and receiving in community and care. Dis-empowering because it too often means "I am glad you can do that because I can't (or I don't want to.)"

Parents and families of people with disabilities often get stuck in this role as well. To many, they become "such special people" or "heroic" for their care, patience, and compassion. Yet when you listen to the parents, they ache for a chance to "be normal," to be included, to have a break from parenting like other parents do, to not be so isolated.

Ministry at this stage is often "to" or "for" those special people.

The feeling level is often pity, coming out of "a feeling sorry for."

Stage Three: Inclusion. What's Good for Us is Good for Them

After listening to people with disabilities and their families, what you hear most often is "Don't do anything special for us. Do what you would for others and with others. Include us in the life of the church, in pastoral care...do unto us what you would have done unto you." It may mean doing some special things to make that inclusion possible, but it is a perspective that says to both pastor and congregation, "You already have gifts that we need and value, and which will make a huge difference in our lives."

Let's think about it in terms of the family on the film. What could be your pastoral roles? From my experience, the roles are at least four...and it turns out they are basic pastoral roles and skills that are good for everyone.

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 observations on the family.

He said he knew about their daughter. He had been to their house, and seen 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 huge gap in between them, each waiting for the other to make the first move. The family aching for the pastor to say..."Tell me what it's like to be parents and what our church can 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, even when things are not easily or quickly fixable. Presence is also both going there...and welcoming in 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. (See diagram, appendix.) 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 have 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 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 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 shepherd in the 23rd Psalm is also one who 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, 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. *I 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 living."

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 hour a day, seven day a week caregivers, 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 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 too time to attend zoning 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 l'rosh pinah. (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.

Stage Four: What's Good for Them is Good for Us.

But don't stop with the inclusion. What begins to happen, as has already been hinted, is that as congregations reach out to include, the real benefits are to the whole body. We are not whole unless everyone is included. As you work on inclusion, the issues raised become issues not just for the people with disabilities and their families, but for everyone. They are profound issues, as already discussed, about identity, purpose, belonging, what it means to "be church," to be interdependent, to be in community, and the body of Christ. "For he has broken down the dividing walls of hostility between us, and we are called no longer strangers but friends."

Let's take a look at what we can learn from efforts to include people with various forms of disabling conditions:

Physical Disabilities.

When a congregation focuses on accessibility, and physical barriers, the steps often taken (or removed) lead to houses of worship that are more accessible to many people. It is often the people with the invisible disabilities, those with heart conditions and other health problems, who use ramps and elevators. A famous study at the University of Minnesota followed the efforts of the university to comply with federal regulations by doing curb cuts and other efforts to make the campus accessible. They then asked the university community why it was done. The vending machine operators said it was done for them. Everyone with a bicycle said it was done for them. Every parent with a stroller said it was done for them.

A synagogue in Lawrenceville, N.J. built a new building, making it totally accessible. Their use of the international disability sign in their newspaper ads lets parents know that this is a congregation that knows something about inclusion. But after the new building was built, it became

possible for a ninety two year old woman to come back to synagogue for the first time in years, to come regularly for several years, and then to have her funeral from the synagogue, which the family would not have done otherwise. That woman, and her husband, had paid the mortgage on the old synagogue during the depression.

Think of who the congregation shuts out by its architecture. Think of the building as an "evangelical statement to the community."

Mental or Cognitive Disabilities.

(Possible resource to use here: Ten minute video: Same Spirit...Different Gifts. Depicts three different congregations and their efforts to include people with mental retardation and other disabilities.)

When a congregation works on inclusion of people with cognitive disabilities, a number of issues and lessons start emerging.

Worship needs to become **participatory** in new ways. Is there a place for spontaneity in the service?

We were at mass, my friend Florence and I, with a group of volunteers and clients from the developmental center. I was sitting right behind Florence, who was about five feet tall. On this particular Sunday, the usually somewhat stiff priest poured himself into the profession of faith following the homily. There was a bit more response in the congregation than usual, but as he finished with a flourish, Florence stood straight up and applauded, much to my own chagrin. "Don't do anything to threaten your acceptance here," I thought. If I were more honest, the feeling was "Don't do anything to threaten my acceptance here."

And then, several weeks later, I was invited to do the homily. And I went back to that day, and did what we often need to do when the unusual happens. Look at it and listen to it. And the message was, while Florence needs to learn more of the culture of that church, was not her response perhaps the most faithful. If we all said the Profession of Faith in a way that captured heart, mind, body, and soul, an expression of the week past and a pledge for the one ahead, should we not celebrate that effort in faith...??

I don't know what his name was, but he was a kid, in elementary school, from a strict fundamentalist church who had come with his family and other church members to help run the afternoon service at the developmental center. He had a suit on, this boy of six or seven. I had watched his surprise, and others, as all these adults at this service clapped and sang and moved and spoke in response to the leadership. At the coffee hour, he pulled on my coat sleeve and said "Hi."

"Hi," I said.

And his words: "I like this retarded church."

At her confirmation, the young woman with Down Syndrome was asked a series of questions by the pastor:

"Do you love Jesus?" "Yes."

"Do you know Jesus loves you?" "Yes."

And she turns to her mother and asks "Do I have to get a physical for this too?"

Simplicity of Words and Actions.

We talk about the "child-like" behavior of persons with mental retardation, but perhaps a simple, child-like approach to faith is something we learn from? Henri Nouwen once called his friends at Daybreak "people of the heart who teach us to respond from our hearts and together we walk into the heart of God." The insights are often profound:

The Bible reading was that "he gave his only begotten son."

"Gee, I bet he would have liked two or three more."

Florence, as old as the hills, a resident of the institution probably since it had been an "institution for feeble minded young women of child bearing age" came to the Maundy Thursday service, held in the basement ward of the building, with the pool table used for an altar. This was the one service where we did not focus on celebration, but on telling the story, breaking the bread, hearing about someone being beaten, made fun of, left alone, ridiculed. As if to take care of me, she came up afterwards, put her arm around my waist, and said "Well, you know he doesn't have to die anymore."

Mike thought his disability was that he was too short, and that there must be, in this technological society of ours, a machine that could stretch him out. But one day he came into my office to talk, and then to pray. And his prayer was: Oh, Lord-d-d-d, take away the bad stuff in my heart. Take it away...a pause of several seconds..."It's gone. It's gone. Thank you, Lord-d-d, God-d-d for my prayer."

Would we believe in forgiveness so strongly!

The group home came to the church where the recent seminary graduate was assistant pastor. The first Sunday they received communion, Sue went over to the table at which they were sitting during coffee hour. Noting their lively spirits, here's the verbatim:

Sue: You really seem excited and happy today.

Man: I ate in church today.

Sue: Do you know what that is called?

Man: Yea...eating bread and drinking.

Sue: That is what we do. It is called communion. Do you why we do that?

Man: (Shaking head yes, but he says) Yea...you tell me!

Sue: Jesus lived a very special life and showed us in that life how to live and treat others. Jesus died on a cross...

Man: (abruptly interrupts with emphatic annoyance)

No! not that. Tell me the part about us all doing it...I ate with everyone else in church today...tell me the part about all of us doing that together.

Judith came to communion, which we did by intinction, dipping the bread in the cup, and saying,

"Judith, this is the body of Christ. Jesus loves you."

Her response the first time: Oh, yeah, how come?

Her response the next month: "Who told you?"

Her response the next time: "Yes, I know."

When one wonders why a good children's sermon is remembered and commented on by more than the regular one, think of the importance of saying what we want to say in words and images that are simple and direct.

A place to give and to receive. Including people with serious cognitive impairments, or with any disabilities, also means looking for ways they can contribute to the life of the congregation. Think of the hundreds of "small jobs" that need doing. Peter Thornburgh's job was to fill the pastor's water glass. Handing out bulletins. Folding them. Church night suppers. Clean-up days. Something that is a hassle or menial for some may be a hugely important job for others.

Cathy spoke at the end of the conference, telling about her life in an institution, her move to the community, and now her own apartment. At the end, she said in her spastic voice...You know, it is important for you to be nice to handicapped people, but it is more important for you to let them be nice to you."

Chris, in his sixties, a wheelchair user (not victim, or confined to...he would be confined to his bed without a wheelchair) could move one wheel at a time because of his arthritis. Ten feet every five minutes. He came to the service every Sunday. One day, I sat with him, and we sat behind Kim and Theresa who came laying in their stretcher chairs. He turned to me and said, "You know, when you see people like that, it makes you glad you can get around!"

How do we give feedback to each other?

Watch out for rhetorical questions in a sermon, they might get answered.

Anna listened to the fairly standard ten minute sermon by visiting pastor, then stood up at the end and did something most lay people wish at one point or another they had a chance, or the guts, to do: "Now I want to tell you something."

That one is funny, but one of the biggest questions that comes up is that of appropriate behavior in church. Often the atypical behavior gets attributed to the disability, when in fact people with disabilities have often not had the years of participation and practice that "normal" people have had. So part of religious education and congregational inclusion means careful teaching about what is expected and done in a worship service. But it is also an issue of learning how to interpret "difference" in two directions. First, what does the behavior say about what the person is feeling, and how can we help teach more "typical" behavior so people can fit in more easily. But second, what does the "different" behavior teach us about our unspoken expectations and norms in a congregation. Are those boundaries too confined? Are they God's or ours?

Hearing Impairments.

Hearing impairments are the single largest form of disability. And that has profound implications for traditions that focus primarily on the spoken and heard word. There are all kinds of

assistive hearing devices that facilitate hearing. But for people who are deaf, the issue becomes interpreting, the use of sign language. And that pushes us to look at worship as movement, and think about the ways we communicate non-verbally in worship. People with hearing often enjoy watching a sign language interpreter, for it can be a form of liturgical dance.

How do we "incarnate" our words and actions in worship and service?

(Exercise: A Movement Version of the Lord's Prayer. See attachments)

Visual Impairments.

When a congregation works to include people with visual impairments and blindness, then we have to look at the importance of touch and other forms of non-visual communication. Fortunately, large print bulletins are easy to produce in an age of computer fonts, but large print hymnals, tapes, and many other resources assist in this. But at an even more fundamental level, how to reach out and touch others as forms of hospitality and welcome.

Looking at what we begin to learn by including people with various forms of disabilities thus pushes us to look at all the ways that different senses and dimensions are used to communicate the Gospel and the Word. And then, when people with disabilities are also able to use their gifts in contribution to the community and congregation, the original questions get reversed. It is no longer an issue of what we can or should do "for them." You often begin to hear congregations say that "we are the ones being blessed." Or "they are doing more for us." **Thus the operative preposition becomes ministry by people with disabilities.**

The operative feeling is one of real love and mutuality, in which everyone has recognized gifts, and we all both give and receive.

Conclusion: Issues and Implications for Pastoral Care and Theology

Ministries to, with, and by people with disabilities and their families is thus a part of the life of the church and Christian community that has raised, and continues to raise, a number of issues and opportunities for pastors and congregations. Much has changed over the past few decades. The quality and quantity of written resources, models of ministries, awareness, and research have increased dramatically. But there is much left to be done. With the advent of the Americans With Disabilities Act (which was opposed by many in the religious community), "it should not be," as Assistant Attorney General John Donne said, "easier to get a beer in a bar than it is to go to church and pray."

But the issues are not just ones of architectural accessibility, but also ones of attitudes and commitment. From the viewpoints of theological and pastoral education, there is still much to be done. The following are some of questions and issues which need your research and help:

Pastoral Care

Just what is pastoral care, especially in the long haul, with people who are not fixable? What is the role of the pastor when the problem is not the disability or limitation but the attitudes towards it, not the individual but the community. It is a place for preaching, visitation, modeling, and empowering people to speak for themselves.

Theology

What are some of the implications for our theology, our understandings of God, our images of humankind and what it means to be created in the image of God. People with obvious and severe disabilities raise classic theological questions in stark, concrete ways.

Might not "they" help us struggle with them and come up with deeper understandings of the mysteries of creation and God's purposes within it, the dimensions of healing in wholeness and brokenness, and the responsibility of call.

Mission, Outreach, and Evangelism

There are tremendous implications for mission, outreach, and evangelism. The world of people with disabilities and their families is often one untouched by the church. The potential numbers are huge. Can we embody what we say on the signs: "Everyone welcome." Reaching out may mean hearing the pain, anger, and distrust from people with disabilities and their families who have been rejected, used, and/or abused by "religious people" in the past. It means looking at the call to concrete, specific actions that can facilitate and accommodate the participation of people who may need particular supports to be included. A number of theological images and metaphors begin to have great potency:

- *the return of the exiles
- *the call to welcome the stranger through hospitality.
- *the power of "sanctuary," a place of safety and rest, for everyone.
- *the "re-membling" of people who have been excluded or forgotten into, or onto, the body of Christ.
- *the movement of "liberation" beyond words to concrete action.
- *reaching out to whomever we consider to be the "least of these."
- *the parable of the talents, advocating and supporting ways for people with disabilities to use their gifts and talents both in the life of the congregation and in the community.

Whether you and your congregation consider yourself "liberal" or "conservative", the question becomes how your ministry embodies your words in relation to people with disabilities, often a "foreign land" right next door.

Of the many stories and experiences that compel and propel me in this area of ministry, one in particular hits this issue head-on. At a conference, a mother came up to me, talking about the move of their family from one state to another. In their previous home, their daughter (labeled "micro-cephalic and moderately retarded") had been in a supported employment job at McDonalds. After the move, their new community did not have that kind of program, and she ended up back at a sheltered workshop, where, with the power of peer expectations, she began to act "more retarded." They started looking for a church to attend, and, after a number of tries, found one where they tried to involve the daughter in the youth group. But there had not been any preparation or guidance for the youth group, and as might be imagined, something happened or was said that was hurtful.

The daughter came home and told her mother, "I am not going back there anymore."

The mother confessed to me that she got into the role of being a "Mom," and she replied, "But you have to go. We have to go. We are part of God's family. That is God's house. We need to be there as well."

To which the daughter simply said, "Well, it may be God's house, but he's not home."

Religious Education

With ministries with people with developmental disabilities, particularly cognitive disabilities, we are pushed to ask questions about how people learn and grow in the faith. What is religious education and nurture? We are often faced with re-examinations of the power of sacraments and symbols, and re-learn the power of baptism, confirmation, the Eucharist, and others by looking at the assumptions we make about them that are often taken for granted. As teachers, we are pushed to learn how to teach in new and creative ways for people with learning disabilities, and those may turn out to help everyone. And, with the great variety of issues coming from this area of ministry, think of the possibilities for youth and adult education programs that address the issues related to disability, attitudes, inclusion, mission, and support. (There are good videos, materials, and voices to help in that!)

Church History and Polity

How can we learn from church history about the ways that churches at different times and places have included and/or excluded people with disabilities. In this area, like many other, the church has sometimes justified social prejudices and practices, and sometimes acted prophetically against them. We need lots of research to recover the voices which have dealt in this area where people's voices have often not been heard. One of the hardest issues to face in this area combines with the next, i.e., our understandings of call and ordination, and policies on whether or not a person with a disability can be ordained.

Biblical Studies

In Biblical studies, what are the stories, images, and themes that have great impact and power in relation to people with disabilities and their families? What can we learn from exegesis of scriptures that deal with people with disabilities? How can we appreciate scriptural traditions in new ways when read and explored through the hermeneutical lens of "disabilities".

Finally, the promise in this area of ministry is like that in many others in which reaching out in hospitality to the stranger, and working on inclusion of those often on fringe, ends up blessing the host as much as the guest. Henri Nouwen acted and lived that out, speaking of it in many ways. Kierkegaard once said that "the faces of the void become the faces of God." W.H. Auden's lines from "For the Time Being" have renewed meaning for me:

He is the Way.
Seek him in the Land of Unlikeness
And you will meet rare beasts, and have unique adventures

He is the Truth
Seek him in the Kingdom of Anxiety,
And you will come to a city which has expected your return for years.

He is the Life.
Seek him in the world of the flesh.
And at your marriage all its occasions shall dance for joy.

But a retelling of the Beatitudes by some young people with developmental disabilities perhaps says it most clearly:

(Show video: Blessed Be. Eight minutes. Simply a recitation of the Beatitudes with short vignettes and scenes from the lives of some teenagers with developmental disabilities.)

Resources:

Go to the following web sites...

www.aamrreligion.org, with links to other faith networks in ministries with people with disabilities.
www.rwjms.umdnj.edu/boggscenter. And go to our Products. Dimensions of Faith, a resource guide, is on line in PDF Format.

For more information, or other resources named or listed, contact the author:

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