

The Challenge and Power of Location and Role: Pastoral Counseling in the Lives of Children with Disabilities and their Families

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Abstract: Children with disabilities and their families can benefit from effective pastoral counseling by clergy and professional counselors. However, these families may not approach pastoral counselors in traditional ways. Effective pastoral counseling calls for an awareness of the “worlds” of disability and service systems. The field of theology and disability studies is rapidly expanding, alongside inclusive congregational ministries. Pastoral counselors have gifts to offer families and there are a multitude of resources from disability services and supports that can be a resource to clergy.

Keywords: Children with disabilities, Families, Clergy, Pastoral Counselors, Inclusive Ministries, Hospitality, Community, Congregation.

“When they rejected my child, they rejected me. “ (Parent talking about her pastor and church)

“While sitting in worship with my two young children, an older woman asked me to remove my disruptive toddler. She spoke with a condemning tone, one I would soon become immune to. I took my children to the nursery and cried. A few weeks later, I tried to take my children to worship again, but my son was just as disruptive. When I stood up to leave, the pastor stopped me. In the middle of her sermon, she told me to sit down. She told the rest of the congregation that my son was a member of our church and that it was all of our responsibility to raise him and to teach him the ways of God. The tears I am shedding as I write this story are ones of gratitude,

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in contrast to those I shed seven years ago in the nursery of my church” (Anonymous parent in Walsh, A., Walsh, M.B., & Gaventa, B., 2007).

Introduction

When I think of pastoral counseling, I acknowledge that my own stereotypes come into play: I think of person and office, whether such counseling involves a certified pastoral counselor, a clergyperson, or another form of counseling that is called “spiritual” or “faith-based.” In years of ministry with people with disabilities and their families, however, few counseling requests have come from people calling for an appointment or asking to come to my office to talk to me as a clergyperson. Nor have I heard many families talk about going to see a “pastoral counselor” because of issues concerning either their child with disabilities or their whole family. None of that means that pastoral counseling does not, or could not, play a profound role in the lives of families with children with disabilities. The range of spiritual- and faith- questions faced by these families is as large as the diversity of “kinds” of disability. Amid such questions and issues, the potential power of a pastoral caregiver to help and to heal is only matched, in a negative way, by the potential power to hurt and wound. Where pastoral care takes place, and through what kinds of pastoral roles, may not be in the traditional locations of offices and processes of individual or family counseling.

In this article, I claim that children with disabilities and their families may challenge usual understandings of pastoral counseling, especially regarding its setting and form. More particularly, if counselor and faith community are willing and able to collaborate with families and meet them both when and how they come, and where they are (i.e., outside of the usual office setting), then pastoral counseling can serve a unique and unmatched role in helping children with disabilities and their families to grow and flourish.

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I begin by identifying some of the prominent definitions related to disability, as well as some of the challenges regarding the use of language vis-à-vis persons who have a disability. Then I identify and depict some of the key issues faced by children with disabilities and their families through the lenses of some core spiritual and theological questions, followed by a discussion of key pastoral roles in a life span perspective. This perspective is necessary, given that care generally will go beyond the usual time when children become adults. Many families have to continue their roles as responsible, care-taking parents in ways that are not usual for more “typical” parents continuing to love and support their grown children. This chapter ends with an offering of some of the broad range of resources and allies that a pastoral counselor or pastor might access and use in his or her work with a family with one or more children with disabilities.

Talking about disability

The first task is to define our terms, dealing with the complex issues by which disability is discussed and the language that is used. If a pastoral counselor who works with children and/or families or a pastor has not had many people dealing with disability approach him/her, it is not because of a lack of prevalence of people with disabilities. The statistics on the numbers of people with disabilities in the United States vary depending on the source, from 12% (Erickson, Lee, & von Schrader, 2013) to 19% (Wong, 2005), with 12% being the number of non-institutionalized people with disabilities in the United States. The percentage of people with intellectual and developmental disabilities (including autism) is 2-3 % (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011). Take those figures, and then note the parents involved, siblings, and relatives, and the numbers of people directly impacted by disability grow exponentially. To

change the question, who is not impacted by disability, at least at some point in their lives? Or, said another way, the question is not whether one will be affected by disability, but when?

Official definitions of disability also vary. Disability includes people with physical disabilities, sensory (hearing, visual, and environmental, i.e., chemical sensitivity) disabilities, intellectual or cognitive disabilities, emotional disabilities, learning disabilities, and psychiatric disabilities. It also includes disease-related disabilities, e.g., multiple sclerosis and HIV/ AIDS. A disability may be defined as “developmental” (i.e., occurring sometime in the pre-natal or post-natal process up to age 21, e.g., autism, cerebral palsy or Down Syndrome) or as “acquired,” e.g., the result of an accident, such as spinal cord injury or traumatic brain injury, disease, or aging.

There are several operative definitions written into public legislation and policy that are important descriptors. The ADA (Americans with Disabilities Act of 1990) defines disability as a physical or mental impairment that substantially limits a major life activity. The Act protects three classes of people with disabilities: (1) those who have a disability, (2) those with a record of having a disability, and (3) those regarded as having a disability if that perception results in some form of discrimination.

The Developmental Disabilities Act (<http://www.ncd.gov/publications/2011/Feb142011>) defines a disability as a severe, chronic disability of a person which:

- Is attributable to a severe mental or physical impairment or combination of mental and physical impairments
- Is manifest before age 22
- Is likely to continue indefinitely

- Results in substantial functional limitations in three or more of the following areas of major life activity: self care, receptive and expressive language, learning, mobility, self direction, capacity for independent living, and economic self sufficiency.

Developmental disabilities include but are not limited to what used to be called “mental retardation” but is now termed intellectual disability, along with autism, cerebral palsy, epilepsy, spina bifida, and other neurological impairments which meet the above criteria. For the purposes of pastoral care and counseling, the most helpful definition may be that of the World Health Organization whose definition of disability is shifting from a purely medical model to include social context (www.who.int/disabilities/world_report/2011/en/index.html). The WHO defines disability in three levels:

1. A physical or mental impairment, i.e., a description of the physical or psychological cause of the condition. That could be genetic, a disease, an accident, a chemical imbalance, or many more.
2. A disability which results from the impairment, i.e., a change in functioning or adaptive capabilities which results from the impairing condition. The disability may then result from an interaction between impairment and an environment. For example, a person who uses a wheelchair may not be disabled in some environments or life activities, but will be so in others, including, possibly, getting in to see a pastoral counselor or clergy person.
3. An inability to participate in many parts of community life because of attitudinal and/or architectural barriers.

A key trend in definition and classification is away from seeing "disability" in medical terms and towards seeing it in terms of difference and diversity. That has immediate implications for ministry and counseling given the significant attention paid to diversity and inclusion in faith

communities. A person with a disability may or may not be sick. A healthy person also has limitations, or, frequently, some form of impairment and disability. Another trend is that some definitions have moved explicitly towards identifying a disability as a characteristic that results from the interplay of inherent abilities, environments around an individual, and the kinds of supports needed. Thus, for the AAIDD (American Association on Intellectual and Developmental Disability) a child who used to be described as “profoundly disabled” is now a person with “pervasive support needs.” The classification system is known as the Supports Intensity Scale (www.aidd.org) thus describes the level of disability by the amount of supports needed.

One of the main reasons to be careful about the ways definitions, terms and labels are used is precisely because of the stigma often associated with disability and the long history of discrimination, neglect, and abuse against people with disabilities. When confronted with the confusing array of terms and labels, there are two basic counseling strategies: First, use what is called “people first” language (www.disabilityisnatural.org). A disability is an adjective, not a noun. Use terms like “a person with a physical disability” rather than “the disabled.” Stated in relation to one of the premises of this article, a person “has a disability,” not “is disabled.” A disability, like any other personal characteristic, may be a major part of someone’s life, but it does not define him or her totally unless that is imposed. (But even here there are exceptions, especially when the disability is seen as a culture, e.g. “I am deaf,” or is affirmed by an individual claiming that identity as a matter of self definition and pride, e.g., “I am autistic.”)

Second, if a pastoral care giver is not sure how a person with a disability wants to be described, it is best to ask him or her, or their parents, rather than make assumptions. There are a wide variety of opinions and preferences here in both personal and professional arenas. In my Sacred Spaces: The e-Journal of the American Association of Pastoral Counselors (2014), vol.6

experience, most people dislike euphemisms such as "physically challenged" as much as they dislike old and stigmatizing labels such as "cripple," "retard," or "dumb." Even the word "special" has many layers of meaning and interpretations. Some parents are very comfortable with saying, "My child has special needs." Others may hate the word "special" because for them it implies pity and segregation in terms of supports and services. Parents will also get called "special" because others may see them as "heroic" for the love and strength they exude. Some parents don't mind. Others yearn just for the chance to be seen as a so called normal family trying to do the best they can, a family who would love support in both concrete and emotional ways, rather than being set on a pedestal. So when in doubt, ask. Even the question shows sensitivity, and may be a helpful pathway for a counselor into the issues of self-understanding and personal identity. The issues of naming a disability or difference, and how someone wants to be called or have their "condition" talked about, are foundational step stones to a professional and pastoral relationship (Hayes, 2012).

Understanding the complexities of language and labels also helps a counselor be sensitive to one of the huge binds that confront parents and families with children with disabilities. For parents, the diagnosis of a set of previously unspecified conditions as a form of disability may be a relief because, as with other diagnoses, it gives these conditions a name. As noted, though, the label can become more important than the person and also limit what people see and expect. To counter the negative power of labels, current trends in educational and service arenas emphasize talking about a child's strengths and gifts as well as deficits and limitations, and then building on those strengths and gifts for learning and growth. Generally speaking, parents implicitly know those gifts. They love their child. But they also face a society which sees their child's core identity as "disabled" and one in which, in order to get the right kinds of educational or public

supports, the parents are forced to emphasize the deficits and limitations of their son or daughter. Families have described it to me as beyond frustrating to “maddening” and “despairing.” Pastoral sensitivity to that bind and the ironic paradox faced by families is crucial.

“When (where) did we see you?”

Families with issues related to parenting children with disabilities, just as with any family with children, may come to clergy and pastoral counselors for all kinds of reasons. Many may have little to do with the disability per se, because families with a child with a disability and other children face the same kinds of psychological, emotional, and spiritual issues that any child and family may face. Those can be related to or compounded by the presence of disability, but the connection is not necessarily causal. For example, an “urban myth” about families with children with disabilities is that there is an 80% divorce rate. While that is not true (Morstad, 2012), it is the case that being the parents of a child with a disability means facing the same sorts of parenting dilemmas that many other parents face, but perhaps to a different degree, in addition to facing other challenges unique to parents of children with disabilities.

Some of the questions and dilemmas that face parents and families related to disability may very well come to your door and office. They may include:

- A young couple or couple thinking about engagement, but worried about genetic issues in their families that may give rise to a higher probability that they will have a child with some form of genetic disability (Dollar, 2012).
- A couple who has just learned that the child they are expecting will have a form of disability.

- A new parent/family whose newborn child has an unexpected disability or whose young child begins to show problems in their expected growth and development (Becker, 2011; Bolduc, 1999).
- Parents experiencing increasing pressure on their time and parenting skills because of the sheer struggle of caregiving. If they have difficulty finding appropriate social supports, or material supports such as insurance, then stress and fatigue can come out in many different ways (Naseef, 2013).
- Problems in an extended family if there is not the expected support or even worse, if there is blaming, because of the disability.
- Questions that may get raised as a family hopes and plans for the key religious rites of transition, such as baptism, first communion, confirmation, etc. (Walsh, Walsh, & Gaventa, 2007).
- The myriad of issues a family may face trying to find the right educational environment for their child or the right kinds of specialized services. That also pertains to religious education.
- The despair and loneliness felt by children with disabilities and their parents when their child is not invited to birthday parties, has few friends outside of school, and/or is shunned or bullied because of the disability.
- Children with disabilities moving into their teen years when typical questions of identity and social connection become even more heightened by the presence of disability.

- Siblings who may be struggling with their own journey because of the care and attention needed by their brother or sister (http://www.siblingsupport.org/about/copy_of_index_html).
- Parents struggling with their children's behavioral issues and acting out at whatever age and in whatever place, including their faith community. (See the discussion of positive behavior supports later in this article.)
- The huge questions that teenagers and parents face as their child with a disability transitions or ages out of the school system which is obligated by law to include them, to an adult service world where that is not that legal obligation, compounded with all the questions of independence, employment, social roles, and more (<http://www2.ed.gov/about/inits/ed/ycc/index.html>).
- Parents struggling with issues of sexuality and disability being lived out by their children (Melburg, Schwier & Hingsburger, 2000).
- The ongoing question that most families carry with them from Day 1: Who will care for our child after we are gone? (Preheim & Neufeldt, 2011; Etmanski, 2004).
- Transitions out of the home for an adult child, if there are viable options in a time when funding for public residential supports is getting even tighter.
- Mixed in through any or all of these, are reoccurring issues of loss or grief (Gaventa, 2013) and additional grief caused by people and professionals who do not seem to see and understand their child or by those who discount all parental input and opinion.

Over the course of a lifetime, the kinds of questions and issues facing families change. Sometimes families may put off dealing with certain issues when it could be very helpful to address them earlier. Shelly, an adult sibling of a brother with a disability at UMKC and Director Sacred Spaces: The e-Journal of the American Association of Pastoral Counselors (2014), vol.6

of Family Supports, conceptualizes three primary areas of support needed by families (Reynolds, 2012).

Discovery and Navigation Information and Training Support	Emotional Supports Mental health and Self- efficacy	Instrumental Supports Day to Day Needs
<p>Knowledge and Skills</p> <ul style="list-style-type: none"> • Information on disability • Knowledge about best practices and values • Skills to navigate and access services • Ability to advocate for services and policy change 	<ul style="list-style-type: none"> • Parent –to-Parent Support • Self Advocacy Organizations • Family Organizations • Sib-shops • Support groups • Professional counseling • Non-disability community support 	<p>Supports for the Role of Daily Care/Support</p> <ul style="list-style-type: none"> • Respite/childcare • Adaptive Equipment • Home modifications • Financial assistance • Cash subsidies • Short and long term planning with family

One might note that clergy and congregations can in fact be supportive and already are being supportive in every one of those areas of ministry in places around the country. To complement that model, Reynolds and colleagues have developed a lifespan planning outline for the kinds of questions families need to address over the course of a lifetime (Missouri Family to Family 2012). Their outline serves as an excellent resource for clergy working with the complexity of issues and questions that a family may be facing.

When did we hear you?

That lifespan planning outline represents contexts, time periods, and situations in which a family may approach a pastoral caregiver for counseling, or, as caregiver conversely, times in which a pastor might be “on alert” as families enter different stages of their child’s life. Here is one of the challenges of “location,” because it might be that families would never think of coming into a pastoral counseling relationship unless there is a proactive stance of welcome, hospitality, and

caring inquiry into how a faith community and its professional leaders may be of help to a family and child.

What explains the gap between the needs families face and their possible lack of involvement with pastoral caregivers? One key explanation is that the birth and/or diagnosis of a child with a disability puts parents into a complex world of human services that can include specialized medical care, early intervention services, all kinds of therapies, special education, and so on. Unless a family's faith community is on alert to reach out, a family may never think of coming to a pastor or pastoral counselor for help, sometimes simply because they do not have the time. It may be that any number of wonderful parent- and family- support networks become the place where they find the most help and ongoing care from other parents who "have been there." Most states have Parent-to-Parent and other related organizations and, through the internet, one can find a support network of families dealing with almost any kind of disability. Pastoral referral to a parent support network may be greatly appreciated, especially when families are struggling with an initial diagnosis.

However, a second explanation for the gap might be because in all those other assessments and treatments, health and human service professionals do not ask about their spirituality. In this area, a family's faith community especially could be helpful. There is a gradual growth in research, understanding and practices helping "secular" services to recognize crucial spiritual issues for families. Some of these caregivers may recognize ways that faith communities can provide powerful supports to children with disabilities and their families, but that is not standard practice (Carter, 2007). There are also assumed barriers of policy, e.g., when an educational system believes it can never talk about the role of spirituality or faith community because of assumptions about separation of church and state.

Sometimes the problem is simply one of assumptions. A formative experience for me as a young chaplain working in this area of ministry was hearing a family's story about their pastor and church during a multi-disciplinary evaluation process at the first of what are now called University Centers of Excellence in Developmental Disabilities.² The family told me that their pastor had never asked about their daughter. Things had been fine until she had to be held back in Sunday School while other children advanced, and that later, when she had to go to a residential school, no one ever asked about her like they did about each other's kids who went off to college. She had come home for a visit; they took her to church, where there was a new pastor. He had "refused to shake her hand when we left the service." The pain was still real.

I asked if I could approach the pastor, so I called him up and rode a white horse into town to get this fixed. When I entered his office, I saw the certificates that said he had as much or even more Clinical Pastoral Education (CPE) than I had had, plus other forms of training. Losing a little of my own self righteousness, I asked him what he knew about the family that had come to our center. He noted that he had been in their house when their daughter was there for a visit, but they had never said, "Pastor, we would like to talk to you about our daughter," or expressed a desire to talk about issues related to her involvement at the church. He went on, "My pastoral role is under constant demand from people who say, "Pastor, can I come see you about (you name it)?"

The profound image that I left with that day was the gap between family and pastor, each waiting for the other to make the first move. The grace of God, in this situation, could have come through the pastor had he been willing to say, even if he was unsure what to do, "Can you tell me about your daughter?" "How might the church be of support?"

²At least one of these exists in every state. These centers can be a resource for both clergy and families. See www.aucd.org.
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That story is relatively mild, for many families tell stories of things said by clergy that were directly wounding and rejecting. There are far too many stories in the world of disability about questions being asked such as the one in John 9 that assume guilt and sin: What did you do that caused your child to be disabled? Or the question may impugn faith: “If your faith was strong enough, your child could be healed.” Sadly, in many instances, it can come in the form of a pastor or faith community asking a family to leave a congregation because of their child. In 2010, I was at a conference listening to a panel of parents and individuals with disabilities tell their faith stories. Two mothers talked about their experiences, one a family with a son with severe psychiatric and emotional issues, and the other with a daughter with autism. The first family had been asked to leave seventeen congregations; the second, thirteen (Gaventa, 2010). The answers to the question, “Tell me about your spiritual journey, or faith journey, with your child and faith community?” are never lukewarm. They are either stories about how important God and/or their faith community has been or about being deeply wounded. It is not too much of a stretch to call the latter “spiritual abuse.”

Many other families and people with disabilities have faced these kinds of experiences of neglect and/or rejection. The negative stories can quickly become part of the oral tradition in disability networks because of the expectation that a pastoral caregiver or congregation would respond with compassion. In this day and time, the negative stories, in particular can be part of an internet wave in a matter of hours. Other helping professionals and systems in the lives of those families and individuals may have heard them as well, which also explains, in part, the lack of referral or suggestion from them to families to talk with their clergy. Thus, one key alert for clergy and pastoral counselors is that families may carry those personal experiences or have

heard about them. Clergy need to be open, ready, and willing to hearing the anger and pain before trust can be established.

What did we hear?

As noted earlier, families that include children with disabilities may come to a relationship with a pastor/pastoral counselor for any number of reasons, which may or may not involve their child or family member. I would like to suggest a framework to examine and understand some of the core spiritual issues that may be implicitly or explicitly embedded in a family's reasons for coming. The questions are ones of identity, purpose, and community, with purpose being encountered in two ways.

Question/Issue	Theology	Social Values
Identity: Who am I?	What does it mean to be a person? Am I child of God? Created in the image of God? Vulnerability and limits	Independence/dependence Capacity to reason and freedom to choose. Agency/self determination Strengths and deficits
Why am I?	What is my purpose in life? Vocation? Calling?	Employment Usefulness Contribution
Whose am I?	Belonging and part of God's people and creation, whether the "Body of Christ" or the "people of God" or other religious understandings of community and/or family	Inclusion Friendships Right to participate in community Informal, generic, natural supports
Why the disability and can it be changed?	Questions of theodicy, shame Understanding of suffering, healing and cure. Coping with grief, loss, and changed expectations	Causation and Support Plans Genetics/Environment Responsibility Prevention, Rehabilitation, Therapy, Special Education

If one adds to that framework the different perspectives and responses to those core questions that come from differences of faith tradition and culture, then a pastor and/or counselor might be

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able to envision any number of ways core spiritual questions might be embodied and addressed in the lives of children with disabilities and their families. There are so many different cultural understandings of what constitutes a person, independence and self-determination. How do those understandings connect to our Western cultural fears of dependence or a frequent lack of appreciation for interdependence? Does disability represent “everyone’s living nightmare,” whether it comes through the birth of a child or a disability acquired by accident, injury or illness? What does it mean to be a citizen and valued member of society? Can I accept myself “just as I am?” Will others accept me? Our child? Our family? What does God have to do with this disability? Whose fault is it? Does faith help? Is there a place for us at church, synagogue, or temple? Who will help us face the confusing, complex, disorganized, and/or non-existent service system and find the supports our child and our family need? There is no way in this article that to lay out all of the ways that these questions and issues may be encountered and exhibited in the lives of real children and families. For most of them, of course, there are no quick and easy answers, for these are questions and issues everyone faces in different ways most of their lives. My hope, first, is that this framework may help a pastor, pastoral counselor and/or family understand the ways that the particular questions that families face concerning education, health care, human services and relationships within their community are also, through other lenses, basic human, spiritual and theological questions. A pastoral caregiver, working in collaboration with families and other professionals from health, human services, and education systems, may also have opportunities to help those professionals understand the spiritual dimensions of those issues.

Second, the hope is that pastors and pastoral counselors who may know little of the “languages” or “worlds” of disability will realize that they have the same gifts to offer children

with disabilities and their parents/families that they do to anyone else, gifts of presence, guidance, support and care that start from the premise that this child and their family are already parts of God's creation and the people of God. That attitude of welcome, a willingness to travel with families on spiritual and emotional journeys where the answers might not be quick but there is a commitment to figuring it out. The modeling of an unquestioned assumption that they and their child are part of the people of God like everyone else, with strengths, gifts and limits, may be the single most powerful and valuable offering in the lives of children with disabilities and their families.

The core roles

Each clergyperson and pastoral counselor will have his or her own understanding of the gifts they bring to others with whom they minister or counsel. The first basic assumption should be that those gifts and skills could be offered to families with children with disabilities. In my experience, the multiple possibilities in pastoral care and counseling have jelled into four basic roles: presence, guide, advocate (or shepherd), and community builder (Gaventa, 1997). For the purpose of this article, I discuss how these might be present in the ministries of clergy and pastoral counselors working with children with disabilities and their families.

Presence

The basic rule of pastoral care and counseling is, of course, "be there." Be present. Go there. Or pay attention when their paths cross yours. Have an open door or network so that people can get to you. Offer hospitality and welcome. Your relationship, and the place it occurs, is one of symbolic presence of God's care, a power amplified by your capacity to listen, to hear the personal stories, and especially to see and love their child. Tillie Giumento, the Catholic mom

whose quote began this article taught me that long ago: “When the church rejected my child, they rejected me.” When we were subsequently able to arrange for Michael’s First Communion and participation in religious services at Monroe Developmental Center in Rochester, she became my biggest advocate and right hand volunteer in organizing the “coffee hours” after our Sunday afternoon services.

One very concrete question, sometimes literally so, is whether families with children physically can get to where you are. If a child or teen with a physical disability is coming to see you, can he or she get there? Is the space arranged to accommodate a wheelchair or other special equipment? Are there restrooms that are accessible? Is your space, whether at a church, synagogue, mosque, etc. or in an office building, welcoming and hospitable to everyone (Anderson, 2010). Just last week, a woman with a doctorate in special education who has lived her life with a disability shared with our Clinical Pastoral Education group and committee an experience of how she felt totally mistreated by a receptionist and nurse in a doctor’s office. “They never talked to me as a person. All they saw was my chair.” Are others who work with you and your work environment prepared? What might happen if a family needs to come to talk with you, but needs someone to be with their child who comes along, because they cannot find anyone to come to their home? If you are uncertain about what you can do in your space to be more accommodating and welcoming, simply ask the family and child. Or, using the term accommodation, are you willing to meet them elsewhere?

Guide

Each counselor will have his/her own understanding of the ways they use their faith tradition and professional skills to guide another in their journey. The issues may relate to one or more of the three areas of family support as summarized in Reynolds’s framework above. They may also be

issues that are short term, or ones that come from the fact that parenting a child with a disability is a long term journey. Thus, preparation for working with such children and their families may entail having resources available in all three areas identified in Reynolds's framework. If a counselor is not providing the information itself, knowing where to find it or helping a family to look is key. What kinds of connections have you built with area service agencies or schools? Are there members of your congregation who can help, either because they are parents or professionals? Be cautious about referring a family to another referral source if you can, because many spend hours being referred from one service or organization to another.

With that foundation, the primary role of guiding is that which comes with the spiritual and emotional journey being lived out in the lives of parents and their child. One of the first things to do as guide is to model care for, and communication with, the child. Develop your own relationship with him or her. Far too often, professionals of many disciplines talk to families or caregivers of children and adults with disabilities as if they are not present when in fact they are. Modeling a desire to know and love their child will benefit both you and the whole family.

How might the family be dealing with the spiritual and theological questions noted in the framework above? How then do you see yourself as pastor helping people through questions of theodicy, feelings of lamentation, lack of support, issues of guilt, responsibility and purpose, issues of faith and healing, coping with stigma, and more? One potential gift you bring, along with the ways you assist others coping with those same issues, is helping families see that the issues and questions are ones shared by many. A second is that of helping them re-frame scriptural and theological understandings in their faith tradition toward seeing issues in new ways, and to know that revered figures in their own tradition also have grappled with these questions. That reframing may start the moment a family and child encounter you because of the

attitude you bring to hearing their story. It can also be helped by a growing body of books and literature by parents and family members sharing ways that their faith and/or faith communities have been supportive to them that take fresh approaches to how disability is perceived, referenced, and dealt with in scriptural and religious traditions.

Another reframing strategy comes from the WHO definitional framework of disability discussed at the beginning of this article and related trends in thinking about disability. Does an issue come from the impairment, the lack of appropriate supports, a "disabling" environment, value judgments and attitudes about the disability, or barriers to participation? In helping anyone learn to accept and cope with something that has happened to them, does "accepting" a disability mean having to accept the limitations of the environment or discriminating attitudes by others? Is a family searching desperately for some form of cure or dealing with the impact of the latest web-flamed medication or therapy that overpromises? If presenting issues are the relationship between faith and healing, how might a pastoral counselor help a person to see the issues of healing in terms other than "fixing" or "curing?" What needs to be fixed or cured may be, in fact, barriers in the environment and/or discriminating stigma or attitudes in others. One of my favorite reframing stories is that of the person with a disability who was approached by a stranger on the street (a too frequent occurrence in the disability community) and told that "if his faith were strong enough, he could be healed." The person with the disability immediately shot back, "If your faith was strong enough, you could cure me."

Partly by intention, I have avoided framing the emotional and spiritual journeys of families with children with disabilities as a grief process. A counselor's understanding of grief may indeed be very helpful for some families, if those are the presenting issues. For example, when coping with a diagnosis, pastoral counselors may be helping others recognize the death of

expectations about who their child would be and what parenting might be like. A new crisis for a family may kick up earlier feelings of intense grief or add to their experience by “grief given to them” by others.

These are crucial issues, but not the only framework for hearing, understanding and assisting families. When I first began in this area of ministry, the professional assumption was that all parents of children with disabilities suffered from “chronic grief.” That may be true for some, but more than often, my experience has been that families can cope amazingly well, that their lives are filled with joy, hope and love as well as struggle and hard work, and that both parents and child(ren) may be flourishing.

The role of guide can also expand to helping members of a congregation understand some of the same spiritual and theological issues that are often so crystallized in the experience of disability. Informal conversations, sermons, and educational programs related to spirituality, theology and disability are some ways of doing so. Addressing those issues may be crucial as a pastoral caregiver also works as community builder.

Advocate (Shepherd)

The role of guide, when moved from the sanctuary of an office or counseling space, into the public arena, quickly becomes the pastoral role of advocate, or, to use a Biblical symbol, shepherd. In the imagery of the 23rd Psalm, a shepherd helps to provide the sanctuary (the place beside the still waters and in the green pastures, and the table in front of my enemies). The shepherd accompanies in the journeys (through the valleys of the shadows of death), and, with a rod and staff, takes an active role in defending and in clearing the way (through red tape as well as wildernesses). He or she also helps find the place of peace, gratitude and abundance ("my cup runneth over") for the persons with whom they are advocating.

In a preliminary report on research with families with children with disabilities and the importance of their spiritual lives, Erik Carter and colleagues at the Vanderbilt Kennedy Center in Nashville note that a high percentage of families in their study practiced some form of spiritual expression in their home and saw it as a crucial part of their lives. However, many fewer families felt that their faith community had responded well, if at all, to the needs of their child and family. And even fewer felt that the school system or other public services saw spiritual and religious services as a significant resource for both family and child (Carter, 2012).

A first key concern for a counselor in working with a person with a family and their children, as with others, is to work with them so that a therapeutic/pastoral partnership is established in which a counselor empowers persons to advocate for themselves and develop their own leadership skills, while also being willing to advocate with and for them when called for. Joining in the advocacy may need to be within the faith community or outside of it. Many families will say that one of the reasons they may not participate in their faith community is that they are tired of having to advocate all week long with the school system or in other arenas and do not want to have to do that when they “come to church.” If your role is not connected to the family’s congregation, then there may be ways you work in alliance with the family, to talk with their pastor or others in the congregation or help the family find resources to help them do so.

Second, do not underestimate the power of your role as an advocate. Many educational, health, and service systems are committed, in theory, to assisting a person with a disability and their families to use "natural," "generic," or "community" supports. Pastoral counselors, and the faith community they represent, are prime examples of natural, community supports, in fact the oldest and most prevalent version of them and ones often more preferred than private or public human service systems. In practice, many people with disabilities and their families feel less than

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powerful in the face of interdisciplinary planning processes, categorical services, and complex systems. Your contact or presence, on behalf of, or with, a person with a disability is a real and symbolic expression of the fact that this person has allies and supports in the community.

The parent who taught me that was a mother of a daughter with Down Syndrome at a Down Syndrome conference in South Carolina. I spoke and then opened the floor for “church stories.” She stood up and said, “We took our minister with us to her IEP (The Individual Education Plan) meeting with the child study group at school.” (This is far too often an adversarial relationship or one in which the parents feel that they are at the mercy of a group of professionals.) “It was wonderful,” she went on, “we got everything we wanted....They thought he was our lawyer.” It is a guaranteed laugh line in any presentation involving families and professionals, for family relationships are often adversarial and in number of families have led to the use of lawyers and lawsuits to get what they need for their children. Families have the right to invite others to the IEP, and the simple presence of a pastoral or congregational representative may be supportive to the family, and also indicate to the interdisciplinary team that there is a whole community behind this family that wants to learn how best to support the child and his/her parents.

Third, a pastor or pastoral counselor as advocate working with one or more families and/or children with disabilities may feel called to help address issues in communities and service systems. If a child and family seek pastoral counseling because they do not know what to do about bullying at school and the impact on their child, could your role extend to working with the school and the young people in the school? If you are a pastor in a congregation, can your church building be a resource to parent support groups, programs for kids, or advocacy groups? And don't overlook the siblings in a family. There are excellent national networks and resources

to support brothers and sisters of a child or adult with a disability (See Resources at the end of the article).

Fourth, when you are called upon to advocate with the religious community, on behalf of, or with, a person with a disability and their family, remember the irony that the faith community, which might have led the way in acceptance and hospitality, is usually exempt from public laws which support inclusion and accommodations. Therefore, your advocacy role may move into a role of the guide or coach who can help a minister or congregation realize the significance of what they can offer a child with a disability and family, and conversely, the gifts which that family may offer to them.

Community builder

While many counselors may see themselves as working on one-to-one relationships in pastoral counseling, the roles of guide and advocate lead into pastoral roles of facilitating participation and inclusion in a community of support. Many of the problems or issues a child with a disability and a family may present to you may be related to issues of isolation or exclusion rather than issues inherent in the disability itself. This means, as with other counselees, helping individuals address issues in their own communities or networks, finding new ones as necessary, dealing with the boundaries you establish in counseling relationships, and working with someone, in your own style, on ways to empower or facilitate their connection to supportive communities and networks.

The temptation may be for counselors to see the issues presented by a person with a disability or family member as personal rather than as systems- or community issues. I remember clearly a mother of a child with a significant disability who went to a pastoral counselor, and, after a short time, quit. She told me the counselor wanted to talk about her relationships with her

mother and parents, and, what she needed, she realized, was some time for respite care away from the day to day (24 x 7) demands of caring for her child. Respite care is being seen by many congregations as a form of ministry, both with families with children with disabilities and with families caring for an aged parent. Sometimes families are doing both. Where and when is their Sabbath time? If a congregation is willing to do what it takes to enable a child to participate in the typical children's and youth activities in their congregations, that is also a form of respite care for parents, just as it is for any parents who are able to participate in their own religious activities when their child is somewhere else, or celebrate a weekend together when their teenager is away on a youth retreat.

Community building is also counter-intuitive for many professionals because it begins not with needs and issues, but rather with recognition of gifts and capacity. A key role you may have as counselor is helping children and families to recognize their own gifts and strengths. That does not mean disregarding the issues that may have brought them to you, but as discussed earlier, the individual and divine worth you convey to them and affirm in them can be transforming. Children and adults with disabilities, and their families, are so often put in the position of seeking and receiving help for deficits, limitations, and struggles that they may not have people helping them see gifts, capacity, and ways that their child and family might make contributions to others (Gaventa, 2012).

There are three at least three bodies of knowledge and strategies of supporting children with disabilities and their families with origins in the worlds of disability supports and community building that may be of particular assistance to a pastor or pastoral counselor working with a family:

1. Person-centered planning processes. These are known by different names, such as MAPS (McGill Action Planning System (O'Brien, Pearpoint, & Kahn, 2010), PATH (Planning Alternative Tomorrows with Hope, (O'Brien, Pearpoint, & Kahn, 2010), ELP (Essential Lifestyle Planning) (Smull & Sanderson, 2005) and Group Action Planning (The Beach Center on Families and Disability, 1996). Each of them involves a facilitator working with an individual and family and their friends to collaboratively create a vision and plans that start with strengths, gifts, and interests of a child/adult and their close circle. Essential Lifestyle Planning captures the essence of all of these by asking the core question, "What is important **to** this child and family as well as what is important **for** them?"
2. Circles of support and other community building strategies. A person centered planning process can begin in or lead to a circle of support, a group of friends of a child and family who commit to working together to help meet some of the hopes and needs of the child and parents. The circle uses the gifts of its individual members to assist a child and family in collaboratively planned ways. Congregations are perfect places to help organize a circle. The Mennonites have a model for a circle of support in a congregation in a little booklet called *Supportive Care in the Congregation* which also links to a number of other resources and their facilitation (Preheim-Bartel & Neufeldt, 2011).
3. Positive behavior supports. There is growing set of resources and skills to help parents, teachers, and friends address "behavioral issues" in ways much different than traditions of punishing bad behavior or behavior modification through rewards and punishment. Positive behavior supports is based on the assumption that all behavior is communication, and that by processes such as applied behavioral analysis (very common in services with

children with autism), a team can determine what a particular behavior is attempting to communicate or acquire. Then the focus moves to teaching alternative behaviors to reach those same ends. This has been so successful in working with individuals that schools are working on development of school wide positive behavioral supports (Lovett, 1996; Lohrmann, & Brown, 2006).

As a final note in this exploration of pastoral roles of presence, guidance, advocacy, and community building with people with disabilities, a counselor might indeed say that these roles and skills are not that different from what they already do with others. The language and particular strategies may be different, but both pastors and pastoral counselors may already see themselves as helping a child and family to discover a welcoming and safe place where the counseling relationship can assist them to find internal and community supports for their lives. That is just the point. The other is that these roles and skills, developed in response to the particular needs and gifts of children with disabilities and their families, and drawing from other field, may be useful and helpful for many others in your ministry and practice.

Conclusion: Resources for pastoral caregivers

As pastoral caregivers begin to reach out to, welcome, and include families with children with disabilities into their offices, ministries, and congregations, it may be helpful to know that in the past decade, there has been a blossoming of new resources focused on the nexus of theology, faith and disability. Those include parents writing their stories of their faith journeys, Biblical scholars re-examining understandings of disability in the scriptures (Schipper, 2011), pastoral theologians speaking and writing about autism (Gaventa, Walsh, & Walsh, 2007; Swinton, 2011) and other disabilities, including Alzheimer's (Swinton, 2012), and theologians exploring Sacred Spaces: The e-Journal of the American Association of Pastoral Counselors (2014), vol.6

multiple dimensions of disability and care (Reynolds, 2008; Yong, 2007; Reinders, 2008; Creamer, 2009). Key pastoral practice resources include Erik Carter's book *Including People with Disabilities in Faith Communities: A Guide for Families, Congregations and Service Providers* (Carter, 2007); and Episcopal priest Susan Richardson's *Child by Child: Supporting Children with Learning Differences and their Families* (Richardson, 2011). Ben Conner's new book entitled *Amplifying our Witness: Giving Voice to Adolescents with Developmental Disabilities* (Conner, 2012) is an excellent resource that illustrates one of the premises in this chapter, i.e., that good ministry with teenagers and young people with intellectual and developmental disabilities is good youth ministry, period. Audio and videotapes from the Summer Institutes on Theology and Disability are available free with presentations by many of these leaders and may be useful for both individual and group reflection and learning (www.bethesda-institute.org/theology) as well as two classic video presentations of two well known authors and writers: Parker Palmer (1986) and Henri Nouwen (1994).

To summarize, my thesis is simply to reiterate that pastors and pastoral counselors have very important gifts to offer children with disabilities and their families on their journeys. The worlds of disability may be unfamiliar, but the resources are now there (and growing) to support any clergy who recognize that their role can be just as valuable, if not more so, with children with disabilities and their families as with anyone else. The "more so" simply comes from the fact that those children and families are so often on the margins or outside the typical circles of ministry and care. Thus, the welcome and embrace of a pastoral caregivers' role and that of the faith community can change spiritual and psychological location from outside to inside, and in doing so, be a transforming role in the lives of everyone involved.

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Resources

1. The Elizabeth M. Boggs Center, UMDNJ-Robert Wood Johnson Medical School offers a number of one-page resource listings, such as “Beginning and Strengthening Inclusive Ministries in Your Congregation” and “New Resources from the Past Three Years,” and much longer ones, such as *Dimensions of Faith* (2009) and downloadable booklets on pastoral care and autism and brain injury, respectively. http://rwjms.rutgers.edu/boggscenter/projects/faith_based.html
2. The Congregational Accessibility Network maintains a listing of faith group ministry resource offices and resources: www.accessibilitynetwork.net.
3. *The Journal of Religion, Disability, and Health* (www.tandf.co.uk/journals/WRDH) is moving into its sixteenth volume, with back issues offering a wide, interfaith variety of perspectives and viewpoints.
4. Multimedia resources, such as the award-winning documentary *Praying with Lior*, Sacred Spaces: The e-Journal of the American Association of Pastoral Counselors (2014), vol.6

about Lior Liebling's bar mitzvah (www.prayingwithlior.com) and *A Place for All*, an interfaith documentary exploring inclusive faith supports. *The Ten Commandments for Communicating with People with Disabilities* (www.disabilitytraining.com) which you may be able to borrow from a local agency; and/or put "disability etiquette" into your search engine and locate many others.

5. The Quality Mall, an online resource directory in many areas of life pertaining to disability, including spiritual and faith supports: www.qualitymall.org.

6. Sibling Supports: For children and teenagers:

http://www.siblingsupport.org/about/copy_of_index_html, For adult siblings:

<http://siblingleadership.org/>

7. The Summer Institutes on Theology and Disability. Audio and video presentations by many leaders in theology and disability. Begun in 2010 as part of a grant from the Pennsylvania Developmental Disabilities Council, the Summer Institute is now an ongoing event. www.bethesdaoinstitute.org/theology