

Voices Unheard: Exploring the Spiritual Needs of Families of Children with Disabilities



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Abstract: Many church members believe that churches are places of support and acceptance to all families. Most would be surprised to find that families of children with disabilities have difficulty establishing and maintaining church relationships. As a general rule, faith communities struggle in their response to this growing population. This article addresses the spiritual implications for families of children with disabilities and how faith communities can provide support to them.

Introduction

Until recently the discussion concerning disabilities and spirituality was virtually non-existent and even now, the literature is quite limited. In the last decade, however, a number of articles have emerged regarding the value of religion and spiritual development for children with disabilities and their families (Bennett, Deluca, & Allen, 1995; Poston & Turnbull, 2004; Webster, 2004). This more recent literature addresses quality of life for families of children with disabilities and offers coping strategies for parents and siblings (Tarakeshwar & Pargament, 2001). The literature, however, offers few models for *how* a ministry can go about meeting the needs of the entire family once a child with a disability is born.

According *Christianity Today* ("Fear Not," 2005), there are an estimated 50 million people with disabilities of all kinds in the United States, and 600 million worldwide. Each one, to borrow a phrase from the late Mother Teresa, is "Jesus in distressing disguise." Families of children with disabilities live in all communities, yet many are not a part of a church. Churches have not been especially welcoming to these families.

Collins, Epstein, Reiss, and Lowe (2001) state that families who have religious ties tend to have better coping skills in dealing with the added stress often present when children have disabilities. These religious ties provide 1) a framework to make meaning, 2) practical resources, and 3) hope that can lead to positive acceptance (Poston & Turnbull, 2004). Unfortunately, parents of disabled children are not likely to visit a church without an invitation or

knowledge that a program exists for their children (Fuller & Jones, 1997), and currently, few of these programs exist. Many families have endured great disappointments and embarrassments when they have assumed that anyone, even the church, will accept their children.

Though most active Christians believe that churches are places of support and acceptance to all families, they would be surprised to find that religion may not necessarily be supportive and may even be a source of stress for some families (Bennett et al., 1995). In fact, Tarakeshwar and Pargement (2001) reported that 30 percent of families of children with autism indicated that they were abandoned by their church. This abandonment can take many forms from apathy to direct rejection of their child.

As indicated, churches and faith communities struggle in their response to persons with disabilities and the ministry needs of their families. This chapter addresses the following inter-related questions: How does the presence of a child with a disability impact the faith journey of their families? And how, from their perspective, can faith communities provide support? The findings and ideas promoted in this chapter are based primarily upon a qualitative study conducted in 2006 with members of King David's Kids, a support group for families of children with disabilities. Our attempt was not to generalize findings from this study, but to raise questions for churches through hearing the voices of those walking this often difficult and little understood journey.

King David's Kids (KDK): A Ministry Model as Context

Ministry and support to families of children with disabilities often begins with a core of individuals who have family members with disabilities. King David's Kids is such a ministry and provides the context for this study. KDK was founded in February of 2000 by a group of parents of children with developmental disabilities along with interested professionals. The group is comprised of interdenominational Christians and the goals of the organization include 1) providing support and encouragement through bi-monthly meetings, 2) teaching the message of Jesus to children with disabilities in ways that they can "hear" while families attend support meetings and have respite time, 3) providing education and training to parents and caregivers, 4) supporting siblings by providing special events, education, and group activities uniquely geared toward them, and 5) providing a Vacation Bible School for developmentally delayed children and their siblings.

The vision for the group was set by the mother of one child with autism while traveling from a conference. She shared that this vision came out of an overwhelming burden:

God made it heavy on my heart. I got out a piece of paper and started writing out a brochure and a mission statement and kind of a general outline for it and it kind of just all flowed out of my heart onto a piece of paper . . .

The regular meetings of KDK occur twice a month on Tuesday nights. The evenings are comprised of three separate sessions. While special needs children participate in modified Bible classes and play time, the siblings meet with counselors for support. The parents conduct their own faith- and biblically-based support group which begins each evening with prayer and a bountiful potluck dinner.

Volunteers are essential to the success of KDK. Without volunteers to work with the special needs children, the parent group cannot meet. Two very important criteria are required of volunteers: 1) they must have a working knowledge of the needs of children with disabilities and the needs of their families, and 2) they must have a strong willingness to work consistently with children who are difficult to teach and often difficult to manage.

Methodology

KDK consists of approximately 16–20 families. Study participants included seven parents and two siblings who participate in the program on a regular basis. Procedures consisted primarily of semi-structured interviews using a phenomenological lens. The interviews were conducted during the regularly scheduled support group meeting times, and the interviews were tape-recorded and transcribed. The data were analyzed utilizing the constant comparative method for coding emerging themes. All investigators examined the data, and study participants were debriefed and allowed to review data and give input.

Results and Discussion

The following section describes the responses of the research participants. First, the voices of two fourteen-year old siblings representing two families disclose the challenges inherent in family life. Their responses are followed by seven parents representing five families. For some of these families, the diagnosis was new while others had lived with it for several years. The parents include those new to KDK, those who had been coming for many years, and the founding parents of the program. Not only do the voices of the parents echo those of the two teenage participants, they provide insight into their own faith journey and what they need from faith communities.

Responses of Siblings

Kassie and Mindy are fourteen-year-old middle school students who have been attending KDK for several years, Kassie since she was ten and Mindy since she was eleven. Kassie is the daughter of parents who live together. Mindy is the daughter of parents who are divorced. Both of the girls attend church together where Kassie's father serves as the minister. Kassie's mother began a Bible class at their church several years ago for children with disabilities. While the purpose of this portion of the paper is to describe the spiritual development of these girls, it is helpful to examine the circumstances of their lives and the lens through which they view their personal experiences.

Family Life

When asked about family life, the participants compared their lives to the lives of their friends who do not have siblings with disabilities. "I can't even imagine not having [Tiffany] as my sister because I wouldn't know how to. . . I wouldn't know how to. . ." Mindy turns to Kassie and asks, "Could you imagine having a regular sister?" Kassie smiles and responds, "No, I go to my friend's house and it's so different, like they're always fighting and everything. And that's so different at our house. . . I mean [Jana] gets on my nerves sometimes but we don't fight."

Both participants expressed concern for their parents raising their younger sibling with a disability. Mindy reported concerns for her mother's ability to sleep:

Tiffany has to sleep with my mom now because one time she went to sleep by herself and we found her in the morning and she was just lying on the ground [due to a seizure]. I've seen her go into [a seizure] because I was waking her up from a nap and she just went into one and it was just scary. Now we're just afraid. Well, I'm afraid for my mom because whenever I saw it I thought, "Oh my gosh, that's really bad!"

Mindy's sister suffers from approximately two seizures a week, usually during the sleeping hours.

Kassie also expressed concern for her parents when her sister becomes ill:

It's just so hard for [my parents] when she gets sick. She doesn't have any words at all so she can't tell us. You can tell that my parents feel bad because they don't know how to help their kid. They just get this look on their face like 'we don't know what to do,' and they don't know how to help her. And then sometimes they kind of get in a bad mood and kind of

snappy at each other and me and everybody. Then everybody just gets all mad and then my sister is running around and she's screaming because she doesn't feel good, but we don't know how to help her.

Coping strategies for the girls vary. Each makes an attempt to cope using different strategies; the need to cope with such difficulty is apparent in their voices. I asked the girls to explain what happens in these difficult situations.

Well, I mean, at first I try to get my sister to go to a different room and just try to keep her occupied so that [my parents] can calm down. But that doesn't usually work because she really wants my mom. . . . After I try, I just usually go to my room and turn on the music or turn on my TV or something so that I can't hear.

Both also report that their attempts to help their parents are often unsuccessful. Consequently, they either isolate themselves in their rooms or attempt to drown out the noise with music or the television. Mindy also escapes to her room where she paces in silence. "I'm a worrier. I know I worry too much."

Because both girls are in a youth group at church, they have many opportunities to be away from the home and with friends who share common interests. They report feelings of concern for their parents when they are away from home saying, "My parents can't really get away from the house like I can." While the girls use the opportunity to be with friends as a coping mechanism, the concern for family remains. "I can get my mind off the problem for a while if I go out with my friends [from church] but I still feel bad that I left my mom back there." Kassie adds, "I just feel bad for my parents for having to go through this. I mean I can leave but they just can't leave their kid."

Clearly these teenagers feel a sense of responsibility for their siblings and to their families. They articulated that responsibility in our conversations.

I guess I'm a little bit responsible. I get her ready in the mornings. I feed her and I like to take her on walks. I don't think about it being a responsibility though. It's just what you do. So if my mom isn't doing it and it needs to be done, then I just go and do it.

The sense of personal responsibility extends into the future. Thoughts of their own future are presented with an overwhelming sense of responsibility. Very early on, these girls grapple with the moral and ethical issues unique to families of children with disabilities (Gottlieb, 2002).

I'm really dreading to . . . after my parents are gone. I have to decide where she goes. Because I can't just keep her I don't think. I want to . . .

but I'm going to have a life. And I'd rather not put her somewhere where she's not going to like it. I'd just rather not put her anywhere else whether she likes it or not. I have this feeling that people just don't understand her like I do. . . . And so I just think about it all the time what I'm going to have to do whenever I get older, you know? I try not to think about it because I really don't want it to come, but I know it's going to come.

Few fully grasp the biblical concept of sacrificial love in the way these young women do. They struggle with what it means to lay their lives down for another.

Social Life

The girls' social life is not unlike the social life of many teenagers. They are concerned with what others think. Of course, their concerns go beyond those of teenagers who do not have siblings with disabilities. Mindy and Kassie had much to say about the perceptions of others as seen in this description of a simple trip to the store:

Tiffany has a big wheelchair. And I mean it's really big because she's bigger now and so we have to. . . . It's this huge purple chair. It's really big and just trying to get through the store; there's like a thousand people all over and people don't think, "Oh, you have a wheelchair and you need to get through." You have to say, "Excuse me. Sorry."

Concern for what others think was a major theme.

I guess other kids don't have to worry about being embarrassed if their siblings come to their games or go to their school or if you're in public and your friends see you there. They don't really have to worry about that.

A lot of people at my school thought I was an only child because my sister was never around. Then when they find out I have a sister they ask me where she goes to school and when I tell them they say, "Really?" and I say "Yeah," and you just have to explain the whole story.

I get embarrassed when we go places; [Tiffany] will start throwing a fit and just start screaming and we can't make her stop. There's nothing we can do. I just get embarrassed for her. Well, it's not so much that I'm embarrassed for her—it's just watching other people look at her. It's really annoying. And my parents get upset by it and that makes me really sad too. Surely their parents taught them not to stare at people, I mean

come on! And adults stare too. I think it's even worse for adults because they just stare; they ought to know better.

When asked about having friends in their home, they both confessed that this is not something they do often.

I think [my friends] are just kind of confused. They don't really know how to act or they don't really know what to say or what to do. Sometimes my friends will ask me "What's wrong with her?" And when you say autism, no one really understands it. So it's really hard to explain to them why she's being like this. Like, if she does something weird while we're in the house. Okay, my sister loves shoes. There's this one pair of boots—my dad's old boots—that we always have to wear. And [my sister] will just go up to someone and make them wear those shoes. And they ask, "What's she doing?" And you can't really explain why she's doing it. It's just what she does. So I think to myself, "Shut up and wear the shoes. It really doesn't matter; just do it."

When people come over to our house to spend the night, it's just kind of hard because sometimes I have to get Tiffany dressed or something like that and that's kind of weird for them because they don't do that and she's 13 [years old]. That makes it a little awkward.

Social and spiritual development are intertwined. For these girls, spiritual immaturity is not an option because of the unique aspects of their family and social context. At younger ages than most, they are already dealing with the Christian virtues of humility, forgiveness, and unconditional acceptance of others at a depth that many of us never confront.

Spiritual Development

Evidence of spiritual development is reflected in a deep and abiding faith in God and a commitment to remain connected to Him for peace and strength. Mindy began by talking about prayer. "Prayer helps me to be more calm. I know God has a plan and that all this will be okay." Kassie added, "Yeah, He's in control. He knows what He's doing and this is happening for a reason. The hard things we are going through are going to make us stronger." As the conversation continued the girls reflected further on their relationships with God.

God gives us good days like a day when my sister is really happy or something like that. When that happens I know that God is showing me that it's not always going to be bad. There are going to be fun times.

Yeah, and sometimes when I'm doing my devotional or reading my Bible, God will lead me to a verse that goes with what I'm going through. Then every time things start getting hard with [my sister] I can just remember it.

Having a sibling with a disability is not always bad. It's good. It teaches you a lot of lessons. I just wish people would take the time to actually get to know [someone with a disability] before they just automatically think, "Oh I don't want to have anything to do with them." I just want others to know the good things about my sister. I don't want people to feel sorry for us or for her. I think God picks special people to have siblings or kids like that.

I think that more churches should have a special needs ministry because that would really reach out to a lot of families and I'm sure a lot of families can't go to church because there's no place for their kid.

Experiences with Churches

Both girls currently attend church where they are surrounded by people who love and accept their siblings and their disabilities. This unique church is comprised largely of families who have a child with a disability. Church communities, however have not always been accepting. Both recall events where their families felt rejection from someone at church:

If I hadn't met [Kassie's family] at KDK, we wouldn't be going to church. I probably wouldn't even have a relationship with God. We've been turned away by churches because they didn't have a place for Tiffany.

You can't just put [our sisters] in the nursery. There'll be a nursery and usually the nursery has just got toddlers then you start taking little five- and six-year-olds in and you can't put them in the nursery. Pretty soon, they come to you and say, "We can't keep them in the nursery." Then they tell you that you can't take them into church because they're screaming and they just say "Sorry, you're going to have to go somewhere else."

And you think that a church . . . would make a place for them. But they don't. It's not their responsibility to have to find a place for them. It's just one kid. Maybe if there were more, they would find a place for them, but not just one.

These girls clearly recognize what most forget—that we serve a Savior that left the ninety-nine for the one. Christians are called to care for "the one."

Responses of Parents

Like the teenage girls, these parents indicate experiencing isolation and describe life as being unpredictable and often fragmented. A common frustration that the parents voiced is misinformed judgment from those who do not understand the implications of disability.

One mother of a son with autism said:

They just think it is a discipline problem or he meant that rudely. Not, oh he has autism or he has whatever, and I think that's the hardest thing. You know it's easier for people to have to deal with people in wheelchairs, but when you get into the more developmental problems with them, they don't know what to do; they don't understand.

Another parent said:

We heard things like, "If you would spank her she wouldn't be this way. My child used to do that but I spanked [him] and now [he doesn't] act that way."

Even when others were aware of the diagnosis, sometimes there was little support:

When we got the diagnosis of autism . . . there was the initial, "Oh, I'm sorry," and then that was about it. I think . . . people didn't understand the long-term implications of autism or what that meant to us, but we felt extremely isolated.

In the midst of their own feelings of helplessness and frustration they were hearing the message that they were just not doing things right.

Spiritual Support

KDK provides a faith context where these parents feel welcome and understood. While their voices are often excluded from conversations where parents of typically developing children share stories about T-ball and ballet lessons, at KDK their voices are heard and validated.

I come because they can understand. Even if her behavior is extreme, the other parents can relate. We celebrate little stuff, the small things our kids do. . . . They are big for us. Other parents wouldn't understand that, but here we all do.

One couple shared that the first night they attended KDK they were overcome by the opportunity to just talk about their child. “We talked more that night about Trey than [we] ever [had]. It was unreal.” When asked why they come to KDK, the opportunity to talk about their child to others who understand is often the first thing mentioned.

Their stories of personal and spiritual growth affirm the power of religious experience to provide families with a “framework to make meaning” of the disability and to give them “hope that can lead to positive acceptance” (Poston & Turnbull, 2004). One father described how their participation provided for his family the path to salvation. Prior to their involvement with this ministry, faith was not a significant aspect of life for this family.

Before we came to KDK we were just trying to figure out what to do. We had a special needs child that was four years old. We were struggling with just not knowing anything. And then we went to KDK. We met on a Thursday night and it was just a bunch of families. It didn’t seem like church. It didn’t seem like anything to do with church. We would say a prayer, but it was just people sharing things and they all had kind of similar things that we could all kind of relate to. . . . Basically they were giving testimonies and I didn’t know what they were doing. I didn’t know what a testimony was.

As time went on this father not only learned what a testimony is, God has given a voice to his own personal testimony.

I give credit to God; Tiffany’s favorite verse is in John 9 where the apostles are asking Jesus why this guy was blind and he says it is nobody’s fault. It was basically that it just proved that God can be glorified. Jonathan’s special because God can be glorified through him. Because Jonathan is the way he is, our family has been saved. You know we have been brought to Christ through the struggles. It is all part of God’s plan.

The parent support meetings of KDK include Bible study. Parents often indicate that these studies have helped them to make sense of their experiences.

It started off as a place where we could at least come and be with other parents. It has become in recent years a place . . . well, it has really shown me that the Bible has applications for parents with special needs kids that I didn’t see.

Insights about Churches

The parents also described rejection by churches. One parent had been told that it would be best to find another church where they would “probably feel better.” Her response in the interview was: “I don’t think Jesus would have ever said that.” Several parents recounted the frustration of trying to go to church.

We went through at least three years of not really being able to attend church because there wasn’t a place for her (the child with autism) and it was always very difficult to get her into the building. Then she would get in there and have a hard time and they would immediately call us to come get her and take her home because they couldn’t deal with her behavior. I understand that, but it just got to the point of, “Why am I wrestling her into the building if I am just going to turn around and take her home?”

These parents know that their children exhibit behaviors that can be very difficult to manage in the church setting.

It is not easy to teach these children. They sometimes act out and they are aggressive and parents know that. I think they are terrified to bring their child to a new place and have him act out and kick and scream the whole time.

You know, just be open and honest with them (the parents) and say, “You know, we’re not sure how to handle this but we would like to try.” They will give you some suggestions. Parents would be happy to do that and we know that our child is different.

In the spirit of 1 Corinthians 13, one parent provides the reminder that while strategies and programs are important, the place to begin when working with these children is with the heart.

Someone can teach you how to do modifications. Someone can teach you how to structure the class. Someone can teach you all of those things. [But] if you don’t have the attitude of Jesus and the heart of Jesus toward those kids then it doesn’t matter. If you do, then the rest can come.

When asked what message they would give churches seeking to minister to families of children with disabilities, they state that churches must move beyond merely “finding a place” for them. What these children need is to be

truly welcomed, and the parents' deepest desire is that their children be wanted, not just tolerated:

Welcome them, number one. The parents need to know above all else that you love their children and not just that you love their children but that you *want* their children.

Convey to those parents every time you see them that you are happy when their child is there and you are sad when their child is not there. And unless there is blood, don't go get those parents during worship service. Let them know you are perfectly comfortable dealing with the child. If there is a behavior problem or a meltdown, that you love them anyway. It is not a burden for you to deal with if they have a meltdown. Reassure them of that over and over and over.

One parent described the overwhelming feeling when one church welcomed her child in this way.

It was different with the church that John pastors. He (her son with autism) was never overlooked. He was looked for, you know? It was like, "We want this kid. We want him." They wanted him. It wasn't, "We can find a spot for him." It was, "We want him. If ya'll want to come too that's great, but we want him." That was different. That was really everything to us.

For these parents, welcoming their children includes recognizing their spiritual capacity. "We want people to believe she can learn about Jesus." When the focus is on the child's cognitive capacity, the risk is that we will ignore the intuitive aspects of relationship with God (Webster, 2004).

Show those kids the love of Jesus and . . . that God has promised that we will know his voice and that in some way, some how, in a way that we don't understand, God has promised that these kids can know him and will know him.

In addition to recognizing that these children can experience authentic relationship with God, they can also serve as a witness to God's love and acceptance of all people.

You want to meet everybody's needs, but in a way God might use some of the special needs children to show others that people might love them too. If the people at this church can love somebody who doesn't fit into society, maybe they can love me too. Seeing that God loves them (chil-

dren with special needs) and has a place for them might help reach others. God works that way.

Families of children with disabilities have been described by *Christianity Today* (2005) as one of the greatest unreached groups of our time. The families in this study have found a place to belong, to be encouraged, and to grow spiritually. However, they recognize that this is not the experience of all families.

Conclusion

Families of children with disabilities face many struggles—financial, health, emotional, social—as well as the simple activities of day-to-day life. As such, many turn to their faith and spirituality in an effort to find meaning and purpose in their lives. Many of these families are in search of religious communities for the support they need. Without that support, however, parents are either reluctant to attend or are unable to benefit from attending because they spend their time providing direct support to their children with disabilities. In other cases, families of these children are actually rejected by church members.

The comments from families in this study indicate that they are looking for at least three things: 1) acceptance of their child with disabilities 2) spiritual and emotional support and 3) a program for their special needs child so that the other members of the family can have a meaningful experience in religious practice.

Serving families of children with special needs doesn't just begin in the Sunday school teacher's classroom although that is important. Serving these families is ultimately dependent upon the entire church; it means making a commitment to the special needs child through his adulthood. What vision do we have for including people with disabilities in our churches? Should we discuss with the leaders of our churches a mission statement regarding individuals with disabilities?

A well-grounded philosophy among the leaders of any organization is fundamental to the success of such a program. Are all members in the church treated fairly? Does everyone have an opportunity to contribute? Are individuals with disabilities really included in the worship service or are they relegated to a small section in the auditorium? Are they greeted when they enter the sanctuary or must they keep to themselves? Do we have enough accessible parking? Are the aisles wide enough to accommodate wheelchairs?

Faith provides a framework through which families—all families—can bring meaning to their lives. Given this premise, are there opportunities to explore how the biblical text brings relevance and meaning to these families' unique journeys? How can we, the church, connect those families farther

along in the journey with those who have heard “the bad news” for the first time? How can we provide them with a safe space to grieve the loss and lament freely and ultimately empower them to move forward to claim joy despite the struggle.

Should we send teachers to seminars and workshops so that they can receive the proper training? Because divorce rates among parents of children with disabilities are higher than average, what are we doing to minister to these families? If our churches provide a place of community, then we must be careful not to draw the proverbial lines around those who are included in the community and those who are not. All of us—not just some of us—comprise the body of Christ.

A church that is “inclusive” is grounded in an attitude of acceptance. Once this attitude is adopted it will drive the decisions and actions made by the church (Breeding, Hood & Whitworth, 2006). The lives of these children and their families have not been lived in vain and we have learned a great deal about hope from them. As one parent put it, “I think as time goes on most churches will find the way to reach our kids, especially if they understand it’s critical.”

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