

Outreach and In-Reach to Families Affected by Disabilities: Ministering through Family Groups

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On that bright Southern California day that my wife delivered one of the sweetest little stork bundles anyone could ever imagine, it was obvious something was wrong. Our daughter moved very little. Later that night her heart stopped. Thankfully, doctors were able to resuscitate her. After the long wait for the diagnosis—a full two weeks later—the phone rang and our doctor said, “I am sorry, but your daughter has Down syndrome.” Stunned, I went to the hospital where my daughter was still in an intensive care incubator. As I gazed broken-hearted at my little Joanna struggling for life, I noticed out of the corner of my eye that a nurse who helped deliver her was watching in the next room through an observation window. When she saw how distraught I was, the nurse burst into tears and ran out of the room. I felt sick. I had not eaten for days. I finally found our doctor who was busy attending to patients. As we ran down the hospital hallway together, I blurted out, “What do I do?” Stopping abruptly in the middle of the hall, he looked me straight in the eye and said gently, “Just take her home and treat her like your other kids, but give her a little extra care.” Although not completely accurate, his advice was what I needed to hear. Maybe with God’s help I could do this. He then added, “Oh, by the way, another couple in Valencia just delivered a child with Down syndrome. You should contact them and you can encourage each other. In one short but life-changing conversation, a wise and caring doctor had moved me from personal tragedy to personal mission.

We couldn’t wait to call the other couple, Jeff and Shirley. As we talked on the phone with them, we soon discovered that they were also Christians and seemed as excited as we were to get together. Amazingly, they not only had a daughter with Down syndrome born within a week or so of our daughter, they even had a sibling who was her older sister’s age! Shirley and my wife became close friends almost instantly. Jeff and I were stamped from the same mold—had no siblings, grew up in small towns, and came from solid Christian homes. The compatibility seemed like a breath of fresh air. We were not alone. As we walked into their home for the first time, we were warmly welcomed. We started off by doting over our two little round-faced sweethearts side-by-side in their carriers. The afternoon passed quickly with chicken on the grill, lots of laughing with a little crying, and plenty of advice exchanged. Toward the end of our time together, someone said, “Hey, we need to form a group for families with children with Down syndrome.” Encouraged and blessed, I thought to myself, *We already are a family group.*

This section offers some of the lessons we learned about family groups and disabilities during our times together. Our journey began with many questions. This section is framed by some of the crucial ones.

What is a Family Group?

We soon discovered that a family group is two or more families who assist one another. Our particular commitment was toward the process of coping with problems then moving to finding solutions. Coping is

not wrong. It is a phase that almost everyone must pass through, but some seem to get stuck. Of course there is a period of shock. Our goal was to move beyond passive coping to active problem-solving as soon as we comfortably could, but without ignoring our emotions. In our group, we especially valued single parents and those with adopted disabled children, because their needs increase with singleness and adoption issues. Studies vary on marriages with children who have disabilities, but the divorce rate is significantly higher than the national average. These marriages break up over stress related to the disability. This alone is a strong argument for caring family groups.

The primary purpose of a family group is to assist a struggling individual or couple by encouraging, comforting, and assisting in the context of close personal relationships, and to help them find good information and service people, and develop problem-solving skills.

What are some crucial questions to ask before starting a Family Group?

We started by identifying specific needs. Because relationships are critical, we focused first on those. Do the immediate and broader family circles support the family? Can our couples talk to those same people in their family circle about their child with a disability? These and other family-related matters are important to everyone, but especially to a couple with a child with a disability. Basically, they are looking for acceptance and assistance, usually in that order.

We then tried to identify needs for personal development in matters of knowledge, skills and confidence. Pointing out resources became a major objective. Where could families find reliable information? How could they identify the right professional people in the schools or local service systems? Just developing skills for survival can be a critical issue. When parents find information and develop effective skills they also gain confidence. That confidence is a huge benchmark.

Another question asked is, “What are the available resources?” Locating them is the first challenge. What agencies, organizations, foundations, and other types of organizations are out there to offer assistance? However, locating them is only half the battle. Accessing the resources can be a bewildering and discouraging experience.

Finally, “How will the resources reach the needs?” It does no good if you live in a community of abundant resources but can’t locate them or don’t know how to access them. When you have a child with a disability, not many people come offering to provide you with resources. This leads to questions of how to best structure your group so that you can assist in the ways we described.

How should Family Groups be structured?

There are many ways to organize and structure your group. Each has its own strengths and weaknesses. First, there are relationship structures. Should you partner one parent with another, or a couple with another couple, or put both single parents and couples in a mixed group? The best solution seems to be a mixture of these structures, focused on supporting the specific needs of your group. Let’s look at these options, briefly:

- **Each parent with another.** Although you may choose to do a lot of social activities that help people to get to know one another as couples, there will be times when wives and husbands, even siblings, need to talk one on one. Although husbands seem less inclined to this personal level of interaction, the need is as great as it is for the wives. Some argue that husbands need it more because they will not pursue interaction without some facilitation.
- **Each couple with another.** Couples helping each other one on one is a very effective relationship structure. But try to be careful that cliques or circles do not develop. These will destroy the closeness of your group. It is understandable that some couples are more compatible than others. But for the good of the group, it seems best if this can be avoided. Talking about this problem openly may help.

- **Each parent/couple as part of a group.** Special speaker instruction is perhaps most effective in this context. Setting up a calendar will be necessary just to coordinate all the different family schedules. Group frameworks also make it easier to network with other groups and organizations. For example, our group chose a national Down syndrome organization primarily for the resources, network connectivity, and general organizational support it offered.

What are some crucial organizational factors?

- The same geographical area. If you live in a metropolitan area, you will likely find many families for your group within a short driving distance. This is a significant factor because you do not want a group that is so large that you lose the intimacy. After all, a major motivation for such a group is intimate personal support for families. That said, it is great every now and then to be part of a group of 1,000 or more families that share your struggles.
- The same disability. Probably no other structural factor is as important as sharing the same disability challenges as others in your group. Because disabilities vary considerably in their nature, scope, and treatment, being able to connect with those experienced and knowledgeable about your child's specific disability is crucial. This also helps parents find the right information, services, medications, and hospitals.
- The same needs (e.g., to learn sign language). In our group, about 80 percent of the families needed to go through open-heart surgery in the first year of their child's life. The need for good information, recommendations, and ongoing support is hard to overstate. We came alongside each other during the surgeries for prayer and encouragement. Even the doctors commented on how impressed they were with the comforting support. They felt it was beneficial to all of the families involved.
- The same organization. Here again, a mixture of options will probably serve you best. We lived in a booming suburb of Los Angeles where there were many young families with children with Down syndrome and many of our children were about the same age. For this reason, we chose to blend a mixture of group structures. Regarding the selection of an organization with which to identify, again, we chose a national Down syndrome organization because it was well-networked and mature as an organization. Examples of other organizations include churches, schools, or hospitals.

How do you start a Family Group?

Although it may seem like a big challenge to start a group, be assured that it is also great fun. You just need to take it one step at a time. If you keep your focus on the needs of the group, you will meet needs and people will seek you out for help. Let's discuss how to start a group from the standpoint of incremental steps.

Before meeting for the first time, it is good to gather a small group of committed people who will start and maintain the group. The greater the diversity in this group, the broader reach you'll have into the community. This first step requires vision. Feed your vision with good reading, interaction with committed and creative people, and prayer—these will sustain you and your core group when the going gets tough.

Select an effective form of leadership for the group. Veteran parents make good leaders. The selection process must be done carefully. Equal consideration might be given to structure and to personal character and experience. Passion for the role should also be an important factor. Finally, consider the ability to counsel others since people in the group will look to their leaders for models of how to parent and how to serve others.

Include several professionals such as doctors, teachers, and therapists. I had the privilege of being involved with starting a group in Romania. The first two members, Luchia and Dora, were single-parent mothers whose husbands had abandoned them when they gave birth to children with Down syndrome. These courageous working moms were the ideal start. One was a teacher and the other a surgeon. Consequently,

they not only understood parenting but were also a part of the educational and medical communities, which are so critical for families with a child with a disability.

Choose a group model but keep it flexible to the needs. I believe structure is commonly overrated yet essential. If you meet together and enjoy it, a natural structure will emerge very quickly. The Internet offers a generous and even overwhelming source of information about support groups. It would be good for you to work through a reliable, disability-specific organization and its guidelines for the simple reason that a seemingly infinite number of configurations are available.

For the first meeting invite potentially enthusiastic parents and those needing support to a lowkey introductory session. It is good to have a mixture of ages and years of experience in your core group so there is a blend of wisdom from age with the enthusiasm of youth. In that meeting, discuss how soon you should schedule another meeting and consider future special speakers such as qualified local service providers. Finally, you should seek the names of those needing support from agencies, physicians, and other sources, being careful to observe privacy laws.

Be sure to keep a portion of the meetings informal, relaxed and enjoyable. While it is good to be efficient and avoid the perception of disorganization, people must enjoy themselves and not feel threatened when attending group functions. Nothing will drive families off quicker than if they feel uncomfortable, left out, pressured or embarrassed. Be sensitive and make sure everyone is included. People who have children with disabilities experience a lot of discouragement! When they visit your group they need to feel uplifted, recharged and part of the group.

Establish a referral system for physicians, specialists and other service providers and organizations. Although potentially risky due to criticism of physicians, teachers, and providers, your group will be the best source of information and an ideal context for discussion. Remember to cultivate an atmosphere of objectivity and show zero tolerance for attacking individuals. It is too easy to fall into a mentality of professionals versus parents.

Why should my church start a Family Group?

One of the greatest appeals for family groups is that they are mutually beneficial for both families and their churches. First, let's consider ways that churches can strengthen families who have children with disabilities. The emotional and practical needs of these families are obvious and pressing. It is our privilege to love and serve others, but we love people best by pointing them to the Gospel. This should never be far from our thinking and our conversations.

Second, family groups can also serve families of children with disabilities by helping parents better understand their child's disability. For Christians, it is essential that they consider their child's disability within the context of a Christ-centered life.

Finally, family groups will help these families by offering ongoing encouragement to parents. Churches can make a significant difference in times of challenge. Families want to know how to respond to their difficulties and crises from a biblical perspective. Churches can offer this like no other organization. Churches can also help parents by keeping them informed of available resources, including those based on a biblical worldview.

Now, let's look at ways that family groups can strengthen the Church. The potential impact of family groups upon a church is often not realized. Family groups provide another path for outreach to families who have children with disabilities. Churches should always be looking for effective ways to strengthen their families and conduct outreach into their communities. These family groups offer the opportunity to meet real needs.

Second, family groups can mobilize members of the congregation who might not otherwise be serving. Many people in your church may have a family member or close friend with a disability. Moved by compassion toward that person and their family, church members might want to help, but are unsure of how to get started. This impulse is far more common than most of us can imagine. Family groups provide an

opportunity to serve through conversation and friendship. Because they do not require teaching or other high profile ministry skills or gifts, they serve as good entry-level ministries.

Finally, family groups offer married couples an opportunity to serve together, even in the context of their own or others' homes. This is critical. I know a couple who have served together in this manner for years. They are identified as "the disability ministry couple" in their church and the broader community. They have had countless opportunities to help people with disabilities and their families. Having watched them, I am at a loss to think of a better way that a couple could invest their lives for God's Kingdom. They look like one of the happiest couples in the church!

How can your church start a Family Group?

The following details may help make a parent group a truly effective local church ministry:

- Pray for God's will and commit the ministry to God. This will be a great opportunity to serve families who are in need. Although you can do a lot to help them prepare for life with a child with a disability, please remember that their greatest need is for a saving relationship with Jesus Christ and for growth in the Christian life. If you prioritize evangelism and discipleship, you are sure to have an effective ministry in your church.
- You will want to be sure to work with the leadership of your church. Too often ministries of this nature meet in the church but work outside of the church administratively and relationally. This is your opportunity to fully engage the church in the world of disability. Although it will take more time and patience to work with church leadership, there is no substitute for involving leadership in meeting the needs of disabled persons and their families. If you will be patient and persuade leaders through conversation and effective materials, your church can be a family's best resource in times of personal crisis.
- Approach a leadership-capable married couple, perhaps one with a disabled family member. Usually, greater long-term commitment and benefit comes from a family experienced in disability. On the other hand, we should not hesitate to involve people who have no direct connection to disability. The couple I mentioned before who lead a disability ministry in my community do not have a family member with a disability.
- Read up on disabilities and attend events about ministering to the disabled. You will need to find a good source, which offers reliable and updated information about specific disabilities, particularly if the ministry will involve many types of disability. It is crucial that you be informed, but do not panic. Plenty of good material is available free of charge especially on the Internet.
- Reach out to parents, siblings and extended families. Although it's easier to focus on the child or the parents, we can't ignore the siblings or the extended family. At first it may seem like spinning plates to keep everyone involved, but with time you will improve in your ability to reach entire families. My observation is that it is both a gift and an acquired skill.
- Support the ministry as it develops. Ministry is sacrifice, and yet it can be a lot of fun. However, fun is not the primary objective. Be prepared to invest your time, energy, and money. Churches cannot operate like businesses trying to turn a profit in every ministry effort. This does not mean that you can't charge for some materials, food and other needed items. It does mean that you cannot depend on that source alone.
- Model positive attitudes about disability from the pulpit to the pew. You will get tired and frustrated—that is true in all ministries. Ministry is about people, and people bring their needs and

their challenges with them. But you can also look forward to great joy and satisfaction in serving the Lord by ministering to others. It is, as you may already know, some of the best of blessings.

- Give God the glory for what he accomplishes through your family group ministry. If you commit the ministry to Christ, pray for his strength, and do all things in the service of others, you will see God work through your parent group. Be sure to give him all praise and honor. It can be easy to take the credit or promote yourself, but that is not God's way in ministry.

Conclusion

It has been 21 years since the day that Joanna Ruth Deuel came home from the hospital that first time. There have been multiple surgeries, adjusted expectations, outright frustrations, and challenges of all sorts when we least expected them. But the joy of life with Joanna is something no one in our family can do without. Soon, she will walk down the aisle as the maid-of-honor in her older sister's wedding. I get to perform the ceremony. There will not be a dry eye in the church. After all, to the people in our community who love Joanna and enjoy being with her, many of whom will be at the wedding, Joanna's participation is an affirmation of our love, not just for her as a person with a disability, but to the community gathered around her. We share her with them. Instead of being an outcast, she is the center. She is known, accepted, even appreciated in our community. And we will never forget that our first community was our parent group.

About the Author

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