Ministering with the Family Experiencing Disability

Christian Churches Disability Ministry

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Ministering With the Family
Experiencing Disability

CCDM wants to meet the needs of persons with disabilities and their families. One of the ways we seek to accomplish this is by providing booklets such as this for congregations and individuals to use. However, we ask that you contact us for permission to reproduce any portion of this publication.

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Introduction

This booklet has been compiled to help your congregation minister with the family experiencing disability. The contents address:

- needs of the family (emotional and physical)
- special needs of the siblings
- how to get started
- practical ways to help
- definition of terms

Families experiencing disabilities need the ministry of the church. This ministry begins with understanding. First, understand that the family did not plan for this to happen and suddenly everything has forever changed. Understand that they question why this has happened to them. Understand that they often deal with a negative, staring society. Educational services are not always easy to get. Other family members may have difficulty with the disability. The information they get is not always clear. Disability is expensive. The medical community can be confusing. Their friends may not be supportive. If you understand and are empathetic with this much, you will be a source of invaluable help to the family. Understanding is the key.

You can help the family by:

- **Knowing their situation**
  Learn as much as you can about the disability. Be a good listener. Let the family and the individual talk to you about how they feel.

- **Empathizing with their needs and feelings**
  You may not be in a position to fully understand—this is not happening to you. But you can respond to their needs and be supportive of them.

- **Providing support and respite care**
  Your mere physical presence is a support. Rolling up your sleeves and getting busy is a support. Learning how to take care of the person with the disability so that the family can enjoy a respite now and then is an invaluable support.

- **Training to be a school system advocate**
  Dealing with the school system can be a frustrating, confusing, and sometimes frightening experience for parents who are new to the procedures. You can help families in your congregation by wading...
through the information and regulations and passing the information along to them. Two of the terms that parents will have to know are “IEP Team” and “ICEP.” These are explained on pages 19 and 20.

If you have a public school teacher in the congregation, he or she will be an excellent resource person. This teacher may volunteer to be the advocate, or can teach someone else to be the advocate. Sometimes, the school administrators themselves may not be well informed of the latest government regulations or assistance programs. When you can offer advice in these areas, your help will be invaluable.

**Ministering to the siblings**

Often the person with a disability requires so much of the caregiver’s time that the other children in the family are neglected. The best way to alleviate this problem is to provide respite care so that the parents can spend more time with their other children. The second best way is to do things with the siblings. When you do, assure them that their parents would like to be with them, if only they could.

Another way to minister to the siblings is to locate a “Sibshop” for them. These recreational programs provide opportunities for siblings of children with special needs to obtain peer support and education. To learn more about them: [www.thearc.org/siblingsupport](http://www.thearc.org/siblingsupport).

**Getting Started . . .**

- **Begin with a plan, not a program.** You must plan your ministry approach to meet the particular needs of each family. Do not attempt to fit individual families into pre-designed or existing programs.

- **Remember that each family who experiences disability is unique.** No two families will respond to crisis in the same fashion. The family’s religious beliefs, values, emotional stability, and socio-economic status will all affect their reactions.

- **Treat each member of the family as a person first.** Do not dehumanize a person with insensitive or indifferent comments and actions. Remember that families want to have friends, not be mission projects. While individual members need support, they also need support and acceptance of their family as a whole.
• Fathers and mothers react differently to their child’s disability, so think about programs for both.

• Spouses, siblings, and children of adults who have disabilities, have many questions. To be supportive of them, you need to help them find answers. First Peter 3:15 tells us, “Always be prepared to give an answer to everyone who asks you to give the reason for the hope that you have. But do this with gentleness and respect.” Was ever a Bible verse more applicable? Think about the following list of questions and prepare a thoughtful response to each, should you be asked. If you don’t know the answer to factual questions, try to find out. Someone who is less emotionally involved in the situation can often do a better job of researching (and remembering) facts. If you don’t know the answer to anguished questions, be prepared with open arms, a listening ear, and a shoulder to cry on. And remember Peter’s admonition: whatever you say, say with gentleness and respect.

Questions family members may ask:

• Is this my fault?
• Can I catch this disability? Is it permanent?
• If problem is genetic, will my children be disabled?
• Can I afford the care?
• Will I have to take care of this family member when I grow up?
• What will happen to my child after I am gone?
• What options do I have for my loved one’s care?
• Why did God allow this to happen?
• Can my child still be productive?
• How do you discipline a child who has a disability?
• Will I still have a normal family?
• What do I say to people who stare at my loved one and make thoughtless remarks?
• Where do I get more information?
• When people tell me, “If you had more faith, God would heal your child (spouse/parent),” what do I say?
• Will my child ever be able to accept Jesus?
• I thought parents naturally loved their children, but I do not feel that way about my son. What is wrong with me?
• How do I find a support group?
Life Span of Needs in Families Dealing With a Disability from Infancy

Pre-Natal
One of the most difficult situations in life is when a family learns that their expected baby is going to have a disability. The dreams that they had for this child must change. Instead of dreaming about the day their child will get married, they long for the day when he or she will walk. They do not know if their child will ever be able to go to school, let alone graduate from college. They do not even know if their child will live to be school age.

How can the body of Christ help in this devastating situation?

• Be there! Do not avoid the family now because you feel uncomfortable!
• Help the family prepare for the unexpected needs of this baby. Will they need a special bed? Monitoring equipment? Nursing supplies?
• Help them gather information. The more they know about what to expect, the better off they will be. Be ready to encourage them as they learn more about the limitations and risks of this particular disability.
• Ask them if they need or have thought of getting genetic or personal counseling. Research the sources for them.
• Be there to love and support them. Help them come to a place of acceptance. Pray with them, cry with them, hope with them.

Infancy and Childhood
As the family begins to cope with the lifelong care of this child, they will encounter discouragement, fear, doubt, hope, anger — a rollercoaster of emotions. From the church they will need

• Respite care
• Financial support
• Accessibility in the church building(s)
• Advocacy in medical and educational arenas
• Assistance with household chores such as laundry and grocery shopping
• Public education for their child in the least restrictive environment possible
• Inclusive Christian education in Sunday school and other church programs
• Parental support in areas such as child rearing, coping skills, community resources, and dealing with emotions
• Camp/retreat opportunities for the family as a whole and for individual family members
• Help in developing esteem as a family and as individuals
• Transportation to medical appointments and to church/school activities
• Appropriate and meaningful social activities
• On-going information gathering
• Love and acceptance
• Sibling support

**Youth**
• Sex education
• Socialization and fellowship
• Peer support in striving for independence
• Preparation to make moral choices
• Ministry opportunities
• Love and acceptance

**Adulthood**
• Independence — complete or supported
• Skills in self-advocacy
• Support for parents and siblings as they plan for the future and cope with “letting go”
• Employment opportunities with adequate and appropriate supervision
• Counseling in regard to marriage and family
• Preparation for the aging and death of relatives and friends
• Full integration into the life of the church
• Financial planning
• Love and acceptance

**Elderly**
• Acceptance of personal aging and death
• Preparation of funeral plans, living wills, and other legal documents
• Independence
• Feelings of self-worth
• Love and acceptance

As you read through this list, remember this important fact: a child without a disability generally grows from stage to stage, leaving the old needs
behind. This is not always the case with a child who has a disability. As he
grows and matures, new needs are constantly being identified; however
the old needs do not necessarily diminish. Instead, these needs generally
continue from one age period to the next.

If you minister to a family who is experiencing a disability that began in
childhood, realize that there are **four major times of stress** and concern in
their lives:

1. At the time of diagnosis;
2. When a child starts school;
3. During the transition period after education is completed; and
4. When it is time to decide who will provide care when the parent or
   family is no longer able.

Be especially available during these times. Be prepared with information
that can help the family. Alert others in the church that the family is going
through a difficult time. Don’t make the mistake of thinking that because
this family is “used to dealing with disability” that they ever get to a point
where they do not need the help and support of good friends. All of us
need help of one kind or another as we go through life.

If assisting this family seems overwhelming to you, think of how they must
feel. They cannot walk away from the situation, and they have no idea of
how independent or self-sufficient their loved one will ever become. This is
an opportunity to “lay down our lives for our brothers” (1 John 3:16). In the
case of the church body however, this responsibility does not have to be
met by one person, but by many.
Needs in Families Dealing with
Adult Onset Disability

Certainly not all disabilities are present at birth or even early childhood. Many are the result of accidents, diseases, or manifest themselves as a person ages. The family structures may be varied. The person with a disability may be completely independent. Their primary caregiver may be a spouse, daughter or son, brother or sister, father or mother, friend, etc. These families still have many of the same needs as those who have dealt with disability from infancy or childhood.

As you minister to a family experiencing an adult onset disability know that they too experience four major times of challenge and concern in their lives:

1. When the diagnosis is made;
2. When the person begins a rehabilitation program;
3. When the person comes home and/or returns to the work force; and
4. When the person must enter a residential facility.

During these times, let the family know you are there. Send a card. Make a telephone call. Keep in contact.

When you visit, be vigilant. If you see a particular unfilled need, such as grocery shopping, house cleaning or yard work, discreetly offer your assistance. Supply them with a meal from time to time or regularly if needed.

Be an advocate for the family. Accompany them on medical visits, write down instructions and questions. Help them navigate the maze of paperwork with insurance forms or legal matters.

Financial concerns usually are a cause of stress. Offer to help find sources of assistance, if needed. Ask their permission before soliciting funds or materials on their behalf.

After any life changing event, there is often the need to reaffirm or renew our relationship with Christ. This is certainly the case with adult onset disability. Make sure the family has everything they need to attend church. Offer transportation. Provide respite care. Keep them connected to the church.
How the Church Can Help

Provide Practical Support
Anything that you can do to lighten the family’s load will be appreciated. You cannot just walk into a person’s house and take over, but once you form a friendship, you can be persistent with your offers to help.

- Assist with house cleaning and laundry.
- Provide transportation to medical appointments and church/school activities.
- Take care of lawn maintenance and home repairs.
- Help with writing letters, balancing the checkbook, paying bills.
- Do the grocery shopping.
- Help with homework.
- Provide family meals.
- Provide childcare.

Provide Respite Care
“Respite care” is just a fancy name for another kind of practical support. Actual respite care means that you give the family a break by taking care of the person with the disability for a period of time. This is the number one need of families who are dealing with disability. Without it, the family unit may not survive.

- To care for the individual, you may need to get some training either from an outside source (Red Cross, community groups that deal with disability) or from the family.
- Organize a network of support people who can provide some stability to the family. (For example, they know that they will have a caregiver every third Saturday, or every other Wednesday.)
- Provide opportunities for the family to pursue sports and hobbies. You may have to persist in offering this support because families dealing with disability often feel that they have no time for recreation. Even though, it is in fact, the very thing that they need.

Be an Information Specialist
- Help families gather and organize information regarding the child’s specific disability.
- Help the family learn the new terms they will be dealing with. Pages 19-20 are a good place to start.
- Attend medical appointments to provide an unbiased and unemotional evaluation of the information presented (and help the family remember).
• Sort through the red tape of social services, government forms, insurance policies, and school requirements. The family may be too distraught to deal with bureaucracy. Once you figure out the paperwork, you can be an invaluable support to other families in the church. “There is no point in reinventing the wheel” each time. Keep a file of this kind of information in the church so that other families can be helped.
• Be a school system advocate (see page 1).

Help Locate or Begin an Appropriate Support Group
• Offer the use of your facilities for a community group.
• Check with existing groups about receiving training for leaders.
• Be aware of and utilize existing community support groups.
• Consider creating a support group for families, parents, siblings, and the individuals with disabilities.

Help the Family Maintain their Church Activities
• Provide transportation.
• Modify buildings and rooms to provide accessibility.
• Train peer advocates to assist the child with a disability.
• Be certain all family members are included in the life of the congregation.
• Teach your congregation to be accepting and loving toward the individual and the family.

Offer Financial Assistance
• Provide camp/retreat scholarships.
• Assist with the purchase of specialized equipment.
• Treat the family once in a while (dinner and a movie, day at an amusement park, tickets to a sports event, concert, etc.)

Give Support and Attention to Siblings
• Locate or begin appropriate support groups (see the information on “Sibshops” on page 14.)
• Offer encouragement and help educate the siblings on specific disabilities.

Train the Entire Congregation to Assist the Family
• Teach young children how to react positively to disability (CCDM has a good brochure on this subject).
• Utilize the energy of youth groups.
• Educate adults on disability issues.
## Dealing with Feelings

<table>
<thead>
<tr>
<th>The family is feeling . . .</th>
<th>You can help by . . .</th>
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</thead>
<tbody>
<tr>
<td><strong>Confusion</strong></td>
<td></td>
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<tr>
<td>- No firm information has been given.</td>
<td>- Going along to medical appointments.</td>
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<tr>
<td>- No definite diagnosis has been made.</td>
<td>- Gathering and organizing information.</td>
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<tr>
<td>- They face extended periods of testing, evaluation and study.</td>
<td>- Caring for children while parents attend appointments.</td>
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<tr>
<td>- Long-term expectations and prognoses are unclear.</td>
<td>- Praying.</td>
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<tr>
<td><strong>Denial, Shock, Unrealistic Hope, Fear</strong></td>
<td></td>
</tr>
<tr>
<td>- Numbness.</td>
<td>- Not encouraging denial.</td>
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<tr>
<td>- Cannot believe there is a problem.</td>
<td>- Accepting quantity and quality of grief without judgment.</td>
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<tr>
<td>- Always searching for another opinion.</td>
<td>- Being a good listener.</td>
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<tr>
<td>- Counting on a cure.</td>
<td>- Avoid making suggestions or recommendations.</td>
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<tr>
<td>- Seeing only a small part of the picture.</td>
<td>- Praying.</td>
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<tr>
<td>- Looking for someone or something to blame.</td>
<td>- Not encouraging denial.</td>
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<tr>
<td><strong>Anger</strong></td>
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<tr>
<td>- The shock is wearing off.</td>
<td>- Conveying that anger can be a positive emotion if well-directed.</td>
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<tr>
<td>- Feeling vulnerable.</td>
<td>- Encouraging family members.</td>
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<tr>
<td>- Pain is becoming intense.</td>
<td>- Being a good listener.</td>
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<tr>
<td>- Lashing out is common—being angry feels better than being afraid.</td>
<td>- Not offering judgments.</td>
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<tr>
<td>- Commending family members for efforts to use anger in a positive way.</td>
<td>- Praying.</td>
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<tr>
<td><strong>Bargaining with God</strong></td>
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<tr>
<td>- Praying for a temporary truce</td>
<td>- Being a good listener.</td>
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<tr>
<td>- Telling God, “If You will just . . . I will . . .”</td>
<td>- Not encouraging bargaining behavior.</td>
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<tr>
<td><strong>Guilt</strong></td>
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<tr>
<td>- Anger that is self-directed.</td>
<td>- Not offering judgments.</td>
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<tr>
<td>- Refusing to validate feelings of guilt.</td>
<td>- Praying.</td>
</tr>
<tr>
<td>- Remembering this is a crucial stage - do not judge.</td>
<td>- Encouraging self-forgiveness.</td>
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<tr>
<td>- Realizing that family members experience feelings of guilt because they perceive that they are inadequate even though they are doing their best.</td>
<td>- Praying.</td>
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<tr>
<td>The family is feeling . . .</td>
<td>You can help by . . .</td>
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<tr>
<td><strong>Sorrow and Depression</strong></td>
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<tr>
<td>• Acknowledging that a loss has truly been suffered.</td>
<td>• Allowing family members to cry and crying with them.</td>
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<tr>
<td>• Everyday life is becoming overwhelming.</td>
<td>• Sharing the loss.</td>
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<tr>
<td>• A heaviness of spirit is ever-present.</td>
<td>• Gently offering encouragement by pointing out all the things the family members are doing well in coping with the disability.</td>
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<tr>
<td>• Hopelessness begins to set in.</td>
<td>• Sharing the load by giving practical assistance.</td>
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<td></td>
<td>• Remembering that this stage in life is the most painful.</td>
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<td></td>
<td>• Providing pleasant diversions.</td>
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<td>• Praying.</td>
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<tr>
<td><strong>Acceptance</strong></td>
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<tr>
<td>• Beginning to see the family member with a disability as a person first.</td>
<td>• Taking a genuine interest in the accomplishments of the person with the disability.</td>
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<tr>
<td>• Developing a sincere appreciation of the family member with the disability.</td>
<td>• Being sensitive to the times when depression resurfaces.</td>
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<tr>
<td>• A more relaxed attitude is evident.</td>
<td>• Continuing to offer practical assistance.</td>
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<tr>
<td>• Experiencing growth and joy in the family relationships.</td>
<td>• Praying and praising God.</td>
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<tr>
<td><strong>Understanding</strong></td>
<td></td>
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<tr>
<td>• Viewing experience with disability as an asset.</td>
<td>• Being available for ongoing encouragement and problem-solving.</td>
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<tr>
<td>• Seeing experience with disability as enriching.</td>
<td>• Encouraging family members to share their experiences with others.</td>
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<tr>
<td>• Recognizing that family members have derived strength, insight and a greater ability to love and accept unconditionally from the experience.</td>
<td>• Praising God.</td>
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Dealing with the Feelings of Siblings

Researchers and counselors who work with the siblings of those who have disabilities report a wide range of emotions. Each emotion requires the support, understanding, and tender guidance of caring friends.

**Resentment and Isolation**
The priorities of the family are necessarily going to change. As the family schedule and events revolve around the needs of the one with the disability, siblings may feel anger and resentment. The child without the disability may feel that he has been forgotten, is left out, and possibly, unloved. Notes and words of encouragement may arrive for the parents, but who offers such support to children? Who talks to them about how they are feeling? One of the very best ways to help this child develop his own sense of self-worth is to provide them with service activities, or even longer mission trips. Because the family dealing with disability may be under financial duress, the church may need to pay the costs for this child.

**Jealousy**
Children see that the person with the disability is getting a lot of attention. They may fantasize about being sick or injured themselves (or pretend to be sick or actually feel that that are) so that they can receive this attention too. You must be patient with them. Remember they are children. It is hard for them to understand that their brother or sister must have this extra attention. Assure them of their parents’ love and try to help them work through their feelings.

**Guilt**
Siblings will quarrel. If the one with the disability has an episode or runs a fever soon after an altercation, the well sibling may feel that he or she caused the occurrence. They need reassurance that this is not the case. They may also suffer from “survivor’s guilt syndrome,” wondering why this awful thing happened to their sister or brother instead of to them. When appropriate, try to begin a conversation with a question like this: “I understand that sometimes brothers and sisters of children with disabilities think that the disability or illness is their fault, caused by something that they did or said or thought. Do you ever wonder about this?”

**Sadness**
Siblings may regret that they were not nicer or did not spend enough time with their sister or brother before he or she was injured or became ill. They may regret “taking their sibling for granted.” They will most certainly feel deep sadness on behalf of their brother or sister.
**Embarrassment**

We all know how vitally important peer acceptance is to children. When kids make fun of the disabled sibling, the one accompanying him is embarrassed—and angry. He wants to protect his sibling, but he doesn’t want to be associated with him—it is a terrible dilemma. He may not want to go out in public with his sibling again.

**Fear and Confusion**

Many times, children are not given enough—or appropriate—information about the disability or illness. Left to their own understanding, they will make up meanings to long, complicated medical words. The words may then take on a much more severe meaning in the child’s mind than they actually mean. Children may assume that their brother or sister is dying, or that “bad people” did this to him or her. They may also believe that they can catch the disability or illness. Of course, if the disability is an inherited trait that may show up in their bodies, caregivers should know this. It is not your place to tell the child this news, but neither do you want to promise the child that “this will never happen to you.” Talk with the parents. Honesty is the best policy, but it has to be tempered by the child’s age. Parents and teachers should have an understanding on this matter.

**Pressure to Achieve and Excess Responsibility**

Siblings who stay at home while the other is taken to the hospital or to therapy or to special classes are sometimes left to fend for themselves. Or they are expected to baby sit younger siblings, clean the house, and start dinner. Some children respond well to the additional responsibility, thinking it is cool that “mom trusts me to make dinner and take care of my sister.” Others resent being expected to be a super kid—the one that parents say they “can always count on.” This is a difficult situation, and it is one with which the church family can help.

First, talk to the children about the admittedly difficult situation they are in. Agree with them that it is rough and unfair. Help them to vent. Assure them that it is OK to hate the cancer or the brain abnormality or the accident. Then talk to them about the opportunities that this situation presents for them to become mature and responsible and to be real helpers to their parents.

Also talk to the parents about the fact that their other children still need their time and attention. Counsel the parents on how much responsibility is too much. Older children can and should be expected to help with this family situation, but remember that they are still children. This is when the offer of respite care becomes so valuable. Take the child with the disability out of the household if just for a few hours, so that the parents can
spend time with their other kids. Also, offer activities to distract siblings from the daily stress of living with a person with disabilities. Provide transportation and financial assistance for outings, if necessary.

**Concerns About the Future**
Many times siblings are extremely concerned about what will happen in the future. They may assume that caring for their brother or sister will become their responsibility when they get older. The non-disabled sibling may be concerned that he or she will not know what to do, how to make the right decisions, or they may worry that they will never be able to get married because of their responsibilities to their brother or sister.

**Not All Bad**
Not all emotions expressed by siblings of children with disabilities are negative. As mentioned earlier, the additional responsibilities can awaken a sense of independence and responsibility in some kids. Having to deal with a disability in the family can also encourage some kids to mature much faster than their peers. As it is God’s way to bring good out of a bad situation (when we let Him), dealing with a disabled sibling may bring out the very best in some kids. It is the church’s responsibility to help kids recognize and welcome this possibility. One of the most beautiful character traits that can be born from dealing with disability is loyalty. Brothers and sisters are often fiercely protective of one another anyway; when one of them is disabled, his sibling may become his champion. Children who grow up in this setting very often choose careers in the service sector or become great humanitarians. It is God’s way.

To make sure that siblings are included in the body of Christ, ask yourself these questions:

1. Does our church make a special effort to reach the siblings of those with disabilities or illness?
2. Does our church educate staff and volunteers about the issues facing siblings?
3. Does our church offer or support a program specifically designed for siblings?
4. In our efforts to reach siblings are we listening to them? Do we include siblings in the planning stages to make sure that we know the needs and issues faced by siblings of those with disabilities?
Helping Parents Deal with Siblings

When you feel you need to speak with parents, be sensitive to the timing. When parents are dealing with life-threatening issues surrounding their child with a disability or illness, it is not the best time to bring up issues relating to siblings. Look for a more appropriate time to encourage families to define their roles as family members and stick to them.

Lead the parents into seeing that they should not allow siblings to be treated as caretakers for their brother or sister—at least not all the time.

Remember that siblings are often neglected at times of stress in families—when brothers and sisters have serious medical problems. That is the time for you to step in and offer your help. Be persistent about it.

Provide activities designed just for parents and siblings of children with disabilities or illness. Offer respite care during this time.

Encourage parents to share correct information with their children. In the absence of accurate information, medical terms can take on false meaning in the minds of children. Become familiar with the disability or disease so you can help the parents present the information to their family. Help them sort out fact from fiction. Help them to focus on the good possibilities, not the bad.

Make a list of available resources within your community. Offer this list to families on a regular basis. Find your local “Sibshops” (workshops for siblings of children with disabilities) and promote them within your congregation. If there is not one nearby, consider allowing one to meet in your building. Encourage singles and seniors to volunteer at the local “Sibshops” (http://www.thearc.org/page.aspx?pid=2661).
Why Don’t All Families Receive Respite Care?

Sometimes, in spite of the church’s best intentions, families will not receive the care they need. The operative phrase in that sentence is “will not receive” — the family will not accept the help that is offered to them. There are many complex reasons for this refusal of help.

If you can appreciate what the family may be feeling, you will be in a better position to minister to them. Families (or a certain strong member of the family) may be feeling one or more of the following emotions:

- The Martyr Complex; “This is my problem. I’ll deal with it myself.” It may be unfair to call this a martyr complex as some people simply feel unworthy of receiving help.

- They confuse “Respite” with “Hospice,” thinking, “My child is not sick enough to need that kind of care.”

- Pride: “I do not need anyone’s help.”

- Lack of knowledge of how to obtain services, or they think that services are not provided in their town or city.

- They fear that quality care will not be provided.

In all cases, be patient and try to help the family sort through their feelings. Be ready with the answers to each of these objections. Remind the family that it is God’s will for us to serve one another. By refusing help, they may be denying someone else their opportunity to serve.
Putting Your Plans into Action

Pray for God’s guidance during every step of this process.

Contact your insurance company and find out the liabilities of the church. Find out if there are any legal restrictions to a respite care program or church daycare program in your state. Take the necessary legal precautions.

Discover the need in your church and your community. Do this by conducting a church-wide and/or community-wide survey. (See the sample survey form on page 25.)

Find volunteers. (See sample survey on page 25) Look for responsible people among singles, retired folk, professional people, and teenagers. Do not ask the families dealing with disability to participate in this program. Also avoid asking people who are already overly committed, young married couples, and couples with small children.

It may be helpful to call a local facility and ask for help from people who are trained in respite care. The church can hire them to care for families, and/or can hire them to train church members in this type of care.

Offer a training program in which you explain to volunteers what will be required of them. (CCDM has a booklet on training volunteers.) It is always best to set a time of commitment so people do not feel like they will have to volunteer indefinitely. A nurse or someone trained in CPR will be very beneficial during this training.

Once you have a list of volunteers, decide the types of programs you will offer (see page 23) and the number of people who will attend each program. If you have a long list of people needing services, you may want to rotate volunteers so that each family receives a fair share — and so that no volunteer is overworked. If you are going to offer an in-church activity, make sure that your building is fully accessible and equipped. This is a good thing to check on for any outside activity as well.

You may decide that a small fee to support an on-going program is not out of the question. If so, make sure that the families who need this pro-
gram can afford it. Any funds collected beyond the expenses can go into an account to help these families or help with future programs.

Plan and advertise your program and/or activity.

Carry out the activity. Remember to have enough volunteers on hand so that every guest is well cared for.

Meet with volunteers and recipients of the outreach and get feedback on the event. How did it go? What should you/can you do differently?

**When Training Volunteers**

You will want to provide basic information about the types of disabilities your volunteers will be dealing with. The book, *Exceptional Teaching*, (available from CCDM) is an excellent source of this information. You can also search the Internet.

Collect information from parents or caregivers about children or adults the volunteers will be serving. Share this information with the volunteers. Remember to respect the person’s privacy and dignity.

Teach basic first aid skills, and, if possible, CPR.

Stress that the people receiving care have feelings just like everyone else. They can hear all comments and see all facial expressions you make. (Even if they can’t see and hear, they will sense negative attitudes.) You are there to love, not judge, and certainly not to ridicule.

Give the volunteers general information about the types of programs your church will have. Allow them to choose the things they feel most comfortable with. Give times, places, number of people involved, etc.

Teach your volunteers how to communicate with people with disabilities and the proper etiquette. CCDM has material on both topics.

Give adequate instructions about specific duties they will be required to perform and specific restrictions on things they are not to do.
Ideas for Respite Care Programs

Mother’s Day Out
Offer child care one day a month so that mothers can participate in a group activity such as shopping, lunch out, or just to enjoy some time alone.

Father/Child Events
Plan an activity in which fathers and their children participate in group activities with other fathers and children (forming a network with others in similar circumstances). This also provides mothers with time to catch up on the housework, relax, or spend time with their other children.

Weekend Relief
This type of care should probably be done in the child’s home if at all possible. This allows the other family members time to get away for a quick vacation or just to spend time together; a treat for families in which disability is present.

Family Retreats
Provide a weekend away for the whole family. Offer fun activities as well as support group activities for the whole family. Group people together (parents, siblings, spouses with disabilities, etc.) and allow time for them to share common joys and heartaches. Also provide time for the family to sit down together as a whole to discuss what they have learned.

Trade Off Program
Pair families who are dealing with disabilities and have them trade one day a week or one day a month to care for the other’s child for the entire day.

Emergency Care List
Provide a list of names and phone numbers of people who are willing to help at a moment’s notice. (For example, in case of an emergency.) This can provide families with a sense of comfort knowing that there are several people they can call on.

NOTE: When organizing an event or outing where several children or adults with disabilities will be gathered, it is a very good idea to have a nurse or someone trained in CPR come along. During church services, know the members of your congregations who are trained in CPR, and keep track of where they are each hour.
Definitions

**Advocate**—Someone who pleads the cause of a person with disabilities or a group of people with disabilities, especially in legal or administrative proceedings or public forums.

**IEP Team**—(formerly known as M-Team; multidisciplinary team) Individualized Education Program teams are composed of professionals from different disciplines who work independently of one another. Each team member conducts assessments, plans interventions, and delivers services.

**Individualized Education Program** (IEP)—Written document required by the Individual With Disabilities Act (P.L. 94-142) for every child with a disability: includes statements of present performance, annual goals, short-term instructional objectives, specific educational services needed, relevant dates, regular education program participation, and evaluation procedures; must be signed by parents as well as educational personnel.

**Individuals with Disabilities Educational Act** (IDEA)—a law formerly known as PL 94-142—stating that all children with disabilities will receive free and appropriate educations. It calls for a mandatory IEP for all children receiving special education, giving educational rights to both parents and students.

**Least Restrictive Environment** (LRE)—The educational setting that most clearly resembles a regular school program and also meets the child’s special educational needs. For many students with disabilities, the regular classroom is the LRE; however, the LRE is a relative concept and must be determined for each individual student with disabilities.

**Mainstreaming**—The process of integrating children with disabilities into regular schools and classes. Inclusion is a similar term.

**Occupational therapist**—A professional who programs and/or delivers instructional activities and materials to help children and adults with disabilities learn to participate in useful activities.

**Physical Therapist**—A professional trained to help people with disabilities develop and maintain muscular and orthopedic capability and make correct and useful movement.

**Special Education**—Individually planned, specialized, intensive, outcome-directed instruction. When practiced most effectively and ethically, special education is also characterized by the systematic use of research-
based instructional methods, the application of which is guided by frequent measures of student performance.

More About the IEP

What does the IEP Team do?
The IEP Team is responsible for determining the child’s eligibility for special education, creating an Individualized Education Program (IEP), and seeing that the IEP is carried out.

Who participates in the IEP Team?
- The parent (or legal guardian)
- The person with the disability (if appropriate)
- A special education teacher who knows about the instructional needs of the child
- A regular education teacher
- Any specialist who understands and can explain the results of the person’s assessment (This specialist is required to attend initial meeting and may return periodically as deemed necessary.)
- Any other specialists whom the school administrator or parents request
- For a meeting to discuss transition services, any organization or agency that is likely to be responsible for providing or paying for transition services must be invited.

What is an Individualized Education Program?
An IEP is a written document required by the Individuals with Disabilities Act (P. L. 94-142) for every child with a disability. It includes statements of present performance, annual goals, short-term educational objectives, specific educational services needed, relevant dates, plans for regular educational program participation, and an evaluation procedure. It must be signed by parents as well as educational personnel.

The people who construct a child’s IEP are the same people who attend the IEP Team meetings. During those meetings, all the specialists who work with the child discuss the child’s present educational level and set goals for the future.

All individualized education programs must consist of seven components. These include:
1. A statement of the child’s present levels of educational performance, including both how the child’s disability affects the child’s involvement
and progress in the general curriculum, and how the child’s disability affects the child’s participation in appropriate activities.

2. A statement of measurable goals, including benchmarks or short-term objectives.

3. A statement of all services to be provided to the child and a list of all support that will be provided to the child.

4. An explanation of the extent to which the child will not participate with non-disabled children within the regular class.

5. A statement of differences within the statewide assessments of student achievement, why the child will not be assessed in the typical manner, and how the child will be assessed.

6. The date the services will begin and the frequency each one will occur.

7. A statement of how the child’s progress towards the annual goals will be measured and how the child’s parents will be regularly informed of child’s progress toward the annual goals and whether, by their current progress, the child will be able to complete the goals by the end of the year.

From the time the child turns fourteen he/she must have transition goals built into the IEP.

**Services Provided**

The following services must be provided by the school system as far as they pertain to the child’s education.

- Transportation
- Hearing/vision services
- Counseling
- Physical, occupational and speech therapy
- Assistive technology
- Education in the least restrictive environment (LRE)
- Testing
- Supplementary services
- Resource program
- Full time special program
- Home/hospital instruction

In reading through this list you can see that these services are very helpful for the family dealing with disability. Just knowing that all these services must be provided to them should alleviate a lot of unnecessary worry.
Parental Rights

- Parents are given a booklet at the initial IEP Team meeting that outlines all procedures taken by the school system and defines terms relating to special education.
- At each subsequent IEP Team meeting, parents should be given a list of parental rights.
- The school system must contact parents before evaluating their child to be placed in special education.
- The child must be tested in his or her native language.
- Parents have the right to have all test results explained to them.
- If parents disagree with the test results, they may have their child re-tested by someone outside the school system. The child must be placed in the least restrictive environment (LRE) possible for him or her to achieve maximum learning potential.
- The school system must contact parents before changing the child’s educational program, destroying the child’s records, transferring the child’s records to another school, or releasing the child’s records to other agencies.
- Parents have the right to review/copy all school records pertaining to their child’s special education.
- When the child turns eighteen he/she may review his/her own records and sign his/her own IEP providing he/she has not been declared unable to represent himself or herself.
- Parents have the right to a surrogate parent if by some chance they are unable to represent the child.
Sample Survey of Disability Needs
(for congregation and for community)

1. Do you have a disability or do you frequently interact with any person who has a disability?  Yes □ No □

2. Who is that person?
   □ friend □ relative □ neighbor
   □ co-worker □ my child’s friend □ my friend’s child

3. What is the age of the individual who has a disability?
   □ under 18 □ 18-25 □ 26-30
   □ 30s □ 40s □ 50s □ 60 & over

4. Does that person regularly attend church?  Yes □ No □

5. What is the nature of the disability?
   □ deaf or hard of hearing □ Down syndrome □ stroke
   □ physical disability □ traumatic head injury □ autism
   □ mental illness □ visual impairment □ cerebral palsy
   □ mental retardation □ learning disability □ ADHD
   □ behavior disorder □ other ____________________________
   (Please explain)
6. Do you, your friend, or relative need:

□ assistance with weekly shopping          □ counseling
□ transportation for appointments         □ respite care
□ sign language interpretation            □ support group
□ Braille Bible study materials           □ large print Bible
□ Amplification equipment
□ medical equipment (specify) ______________
□ other needs (explain) ____________________

7. If you were to receive respite care, how often would you need help - weekly, monthly overnight, or weekend help?

_______________________________________

8. What can we do to help include you, your friend, or relative participate in the fellowship of our church?

□ provide transportation
□ provide a specialized Sunday school class
□ provide better accessibility
□ other (explain)________________________

9. What else can we do to provide support and encouragement for you, your friend, or relative?

Name_____________________________________
Address___________________________________
City/State/Zip_____________________________
Phone___________________ Email____________

Sample Survey of Congregational Participation

How Will You Reach Out?

☐ I am interested in learning more about this ministry.

☐ I will attend an informational meeting on ___________________.

☐ I am unable to attend the meeting, but would like a member of the team to contact me.

☐ I would like the Disability Ministry team to contact me.

☐ I would like to be trained as a volunteer in the following areas:

(Please check all that apply.)

☐ Education
☐ Respite care programs
☐ Sunday school teacher
☐ Mother’s Day Out
☐ Sunday school assistant
☐ Friday Night Live
☐ Bi-weekly Bible studies leader
☐ Saturday morning
☐ Transportation
☐ Prayer Partners
☐ Driver (Sunday mornings or mid-week activities)
☐ Pray for ministry
☐ Pray with people who have disabilities
☐ Carpool
☐ Invite the family to my home
☐ Adopt-A-Friend
☐ Buddy with a person who has disabilities in Sunday school and worship
☐ Take person out, invite to my home, send cards and notes

Name ____________________________________________________
Address__________________________________________________
Phone ______________________ Email ________________________