

BECOMING A PLACE CALLED ACCEPTANCE: MINISTRY WITH FAMILIES OF CHILDREN WITH DISABILITIES

PURPOSE

This workshop will facilitate participants in understanding and strategizing ways to help their churches become more welcoming, more accepting, and more supportive of children with disabilities and their families.

DESCRIPTION

This workshop, used in conjunction with the handbook *A Place Called Acceptance: Ministry with Families of Children with Disabilities* by Kathleen Bolduc, available for \$7.95 plus s&h from the author's website at kathleenbolduc.com or by calling (513) 484-1756, is designed to raise participants' awareness of the impact of disability on the family system, and to provide practical suggestions for welcoming children with disabilities—and their families—into the life of the church. Workshop leaders will need to have a copy of *A Place Called Acceptance* on hand and *may* want to order copies for participants to purchase (this is optional).

A variety of groups will benefit from this workshop—Sunday school teachers, deacons, Stephen Ministers, disability task forces, adult Sunday school classes, church committees, church clusters, and regions—anyone with a commitment to finding ways to become more inclusive of those who live with disability.

It is not necessary for this workshop to be led by an expert in the field of disability ministry. It will, however, be enhanced if a parent of a child with a disability is part of the leadership team. The parent's insight and experience will be invaluable.

TIME FRAME: 2½ hours with a 10-minute break

RATIONALE

When children are born with a disability, or are disabled later in life by illness or accident, parents grieve. Not only do they grieve, they face enormous pressures—getting a diagnosis; obtaining and carrying out treatment; handling medical, financial, and transportation needs; coping with reactions and attitudes of significant others; altering lifestyles to accommodate the child's needs; and accessing medical and community resources. These families face tremendous obstacles as they seek what is best for their children. And yet, these families are often ignored within the ministries of our churches. Too often, parents of children with disabilities are expected to spearhead any ministry efforts that would allow their children to participate in the body-life of the church.

Families that live with disability have a deep need to be welcomed and accepted, as well as a need for practical assistance from their church families. In a world that judges a person's worth on physical attributes and performance, these families long for a community that will love and

embrace their children, *just as they are*, no matter their physical, intellectual, emotional, mental, or behavioral abilities.

Ancient church tradition tells of second-century Saint Lawrence, who was asked by Roman persecutors to hand over the wealth of the Church. The persecutors wanted gold and silver and jewel-encrusted chalices. Imagine their surprise when Lawrence brought forth the very sick, those who were blind and deaf as well as those who couldn't walk, and said, "Here, here, is the wealth of the Church."

Those who know and experience disability—be it physical, intellectual, emotional, mental, or behavioral—are the wealth of the human family. They tell the rest of us something about what it means to be human. They are living signs of fragility, of mortality. They are also a sign of interdependence. Many of us cannot do everything by ourselves and need others to help us—a profound challenge to values of Western society, with its exaggerated emphasis on independence. People with disabilities remind the church that we need one another to be fully human. This truth is powerfully illustrated in 1 Corinthians 12: "God has set each member of the body in the place where God wanted it to be. If all the members were alike, where would the body be? There are, indeed, many different members, but one body. The eye cannot say to the hand, 'I do not need you,' any more than the head can say to the feet, 'I do not need you.' Even those members of the body which seem less important are in fact indispensable" (1 Corinthians 12:18-22, paraphrased).

In ministering with children with disabilities and their families, the church becomes "a place called acceptance." In doing so, we answer the call of the prophet Isaiah: "Enlarge the place of your tent, and let the curtains of your habitations be stretched out; hold not back, lengthen your cords and strengthen your stakes" (Isaiah 54:2, RSV).

BASIC WORKSHOP OUTLINE

- I. Welcome and Introduction (*15 minutes*)
- II. Asking for Help: Large Group Discussion (*10 minutes*)
- III. The Grief Process Experienced by Parents of Children with Disabilities (*15 minutes*)
- IV. Ways in Which Disability Impacts the Entire Family System (*20 minutes*)
- V. Family Rules Exercise (*20 minutes*)
- Break (*10 minutes*)
- VI. Ministry with Families of Children with Disabilities (*25 minutes*)
- VII. Action Steps Toward Becoming A Place Called Acceptance (*30 minutes*)
- VIII. Closing (*5 minutes*)

PREPARATION AND MATERIALS

- Carefully review the workshop to become familiar with the content you will need to present.
- Make sure that the meeting place is wheelchair-accessible.
- Order for leaders and read through *A Place Called Acceptance: Ministry with Families of Children with Disabilities* (Louisville: Bridge Resources, 1-800-524-2612; <http://www.pcusa.org/bridgeresources/availabletitles.htm>; item 095656; \$7.95); order additional copies for participants (optional).
- Name tags
- Pens and paper
- Flip chart and easel
- Prepare PowerPoint with basic content, if you opt to do a PP presentation
- Prepare for presentation on newsprint, overhead, or PowerPoint slide:
 - discussion questions (Section II)
 - Stages of Grief (Section III)
 - Robert Perske quote (Section IV)
 - Bold items from lists in Section IV
 - questions for family rules exercise (Section V)
- Tables and chairs, allowing for small groups of 3–4
- Photocopy handouts for each participant
- A copy of *The Message* by Eugene Petersen
- Mobile to hang as an illustration of the family system
- For break, snacks and beverages—coffee and tea (including non-caffeinated) and water

CONDUCTING THE WORKSHOP

I. Welcome and Introduction (15 minutes)

Extend a welcome to the workshop participants. Thank those hosting this event. Introduce yourself and anyone working with you. Make sure everyone knows where the facilities and drinks are and encourage permission to take care of needs, while noting that there will be a break half-way through the workshop.

Review the rationale of the workshop, and share why the topic is important to you.

Read aloud 1 Corinthians 12:18-25 from *The Message* by Eugene Petersen, and give participants a moment to think about what body part they might represent in their church community (offer a few suggestions: someone who likes to serve behind the scenes might be the hands; someone in leadership might be the brain; someone who shops for office supplies might be the feet, etc.). Then ask the participants to share their name, the church they attend, and the body part they represent in the body of Christ, and list the mentioned body parts on newsprint. Invite discussion of how diminished the body would be without each listed body part.

II. Asking for Help: Large Group Discussion (10 minutes)

Read the following quote:

When I really acknowledge that I am in need of help, I become more civilized because I need to relate to you. And when you become aware, and your children become aware, and our society becomes aware, and our parish becomes aware, truly on a gut level, as well as on a head level and a spiritual level, that we need each other, what have we formed? We've formed a powerful sense of community. It binds us together. Your needs, your strengths; my needs, my strengths. Together, those intertwining threads weave the strongest fabric of society, of church, of community.

—Mary Jane Owen, Founder and National Director of Disabled Catholics in Action: video cassette, “Disability Ministry: Perspectives on *Disability*” (University of Dayton: Center for Ministry with Disabled People), <http://www.dcia.us/board/mjbio.htm>

Explain that parents of children with disabilities are often overwhelmed by all of the tasks required of them as they care for their children. Often it’s difficult for them to ask for the help they need, and there are many cultural barriers to asking for help. Invite participants to discuss the following questions:

- Would you rather be the giver of help, or the recipient of help? Why?
- Are there some things for which it’s okay to ask for help? If so, please give examples.
- Are there some things for which you would feel uncomfortable asking for help? If so, please give examples.
- If someone needs your help, in which areas are you comfortable in giving help? (Cooking meals? Babysitting?)
- Why do you think it’s so hard, in our culture, to ask for help?

III. The Grief Process Experienced by Parents of Children with Disabilities (15 minutes)

Explain or paraphrase the following points:

- Parents of children with disabilities ride a roller-coaster of emotions as they try to gain their bearings in a world turned upside down and inside out by disability. Disability is a word shrouded in mystery. Many people have no experience with disability—it’s something that only happens to other people, other families, other children.
- When disability strikes, at birth or later, parents grieve. They’re plunged into a time of mourning similar to the death of a loved one. They’re grieving the death of a dream. The dreams we have for our unborn children are as numerous and unique as the parents who dream them.
- Professionals have found that the most crucial time in the lives of these families is from the time of diagnosis to the time they learn the options for moving ahead. This time interval is one of intense emotional upheaval as they reorganize their lives in order to live with long-term disability. [***Present the following list of stages of grief on a PowerPoint slide or flip chart.***]

The Stages of Grief

Denial – fear – anxiety
Anger – blame – fear – guilt – shame
Bargaining – with God, with self
Depression – sense of loss
Acceptance – not a static state

Distribute Handout 1, “Descriptions of Stages of Grief,” and review the stages of grief using one of the following options:

- 1) Read aloud or ask for volunteers to read the descriptions.
- 2) Allow time for individuals to read over the descriptions by themselves.
- 3) Invite the participants to form groups of 5 and take turns reading the descriptions.

Continue explanation with the following points:

- Parents of children with disabilities may experience what is called “chronic grief,” cycling in and out of the above stages as their child moves throughout each life phase.
- These stages are not necessarily experienced in sequence, nor the same by everyone.
- Acknowledgment of and embracing feelings is a gateway to renewed hope and reworked dreams; holding back or denying feelings can lengthen the time it takes to process the loss.
- Support groups have been proven to be an effective way to work through grief issues, providing a framework for understanding the roller coaster of emotions, for helping to overcome isolation, and by serving as a vehicle for learning how others cope.
- Parents need help in working through the grief process after they’ve received a diagnosis. Information about the disability itself is not enough. Parents need to know that: feelings of fear, guilt, anxiety, and pain are appropriate to their situation; that disbelief and shock are normal responses; that self-pity and mourning are appropriate responses to shattered dreams; and that they are likely to feel self-blame and guilt.
- Parents also need to know that feelings of shame surrounding disability are natural and normal, even unavoidable, when we consider our society’s obsession with perfection.
- Parents need to know that denial is an automatic defense mechanism and acts as a buffer against shocking loss; that there will be extraordinary claims made on their time and resources by this very special child; and that feelings of resentment will naturally arise.
- Until parents realize that these emotional responses are natural and to be expected, the healing process will not be able to begin. For this reason, counseling (individual, marital, and family) is highly recommended, especially right after receiving a diagnosis. This is a very vulnerable time in the lives of these families, as parents with no prior experience of disability find a way to build a framework that will enable them to understand their feelings, find answers to the disability’s cause, what can be done about it, and what the future holds.

IV. Ways in Which Disability Impacts the Entire Family System (20 minutes)

Present the following quote on newsprint or PowerPoint slide:

Every child comes into a family somewhat like a rock thrown into a pond. The ripples caused by the new arrival affect everyone. Nobody in the family remains exactly the same. Everyone changes. When a youngster has a handicap, the family often expends energy beyond the ordinary. An increased sharpening of wits and

widening of hearts become necessary so that the one with the handicap can be understood, loved, and accepted as a member of the close-knit family circle.

—Robert Perske, *Circle of Friends* (Nashville: Abingdon, 1982, 12)

Using a mobile as an illustration, explain that a family system is like a mobile. Each person in the family plays a role in the life of the family, and family rules are implicitly understood, as are family values. Each family finds its own equilibrium over time, its own way of coping with changes. The mobile shifts and dances with each change—new jobs, loss of jobs, moves, divorce, new family members. The mobile always tries to find its former equilibrium, even if that equilibrium was dysfunctional, and over time, it generally does. When a child is born with a disability, or is disabled by accident or illness, the mobile is put under tremendous stress. It is no longer able to find its former equilibrium. A reorganization of all parts of the system is necessary to find balance once again.

Review the following “Four Situational Tasks Facing the Family” [*Present bold items on newsprint, overhead, or PowerPoint slide*]:

- 1. Obtaining treatment:** getting a diagnosis, finding therapists
- 2. Dealing with financial and transportation needs**
- 3. Coping with reactions:** grandparents, aunts and uncles, cousins, friends, neighbors, church community
- 4. Altering lifestyle:** may require relocation to be near services; husband or wife may have to give up a job to be full-time caregiver; unstructured, go-with-the-flow families may find their freedom compromised, while very structured families may have difficulty with the disruptions to routines.

Review the following “Four Changes in Family Member Roles” [*Present bold items on newsprint, overhead, or PowerPoint slide*]:

1. Spousal roles often become traditional.

- Some studies have shown that the mother’s attitude toward the child impacts the rest of the family’s reaction, which puts an additional (enormous) burden on women, who most often become primary day-to-day caregivers. Since the child’s needs are often so great or the child is medically fragile, finding care outside of the home can be impossible. Caregivers can feel overwhelmed with care at home, trips to specialists and therapists, and handling behaviors.
- Fathers often fit the traditional role of provider and may feel panic at the thought of chronic disability for the entire lifespan of the child. There is an almost universal fear and anxiety over an uncontrollable future, and these fathers often speak of feeling a second-class status with doctors and educators. Anger and frustration are common among fathers. The culturally defined image of men as powerful and in control is crushed as the father realizes he has absolutely no control over the child’s impairment. The dreams he brought to the child’s life (e.g. lineage, vocational success, athletic achievement) are threatened by the disability.

2. Marriages experience strain.

- Numbers vary according to different studies, but up to 70% of couples who have a child with a disability report to a strain on their marriages. Marriages that are fragile or unstable to begin with very often fall apart under the stress.
- At the same time, studies also show that 85% of marriages that did not break up under the stress of a child’s disability reported that their families drew closer because of their shared experience.

- The crux of the problem of families of children with disabilities is that many of the problems with which they deal can never be resolved.
- Husbands often exhibit jealousy and resentment over the inordinate amount of time and energy the wife has to spend with the child, while the wife may feel resentment over carrying the bulk of responsibility of caring for the child. Communication problems may surface as the husband tries to “fix” the problems the wife has faced in her long day as caregiver.
- Husbands and wives must deal individually with their own vulnerabilities. We are all disabled in one way or another, and the disability of one’s child often magnifies one’s own limitations. A child’s disability can bring our own feelings of unworthiness, hurt, and shame to the surface.
- Unresolved family-of-origin issues may surface when disability enters the family. For the parent not yet ready to deal with such issues, the “blame game” may start as a defensive strategy to keep uncomfortable feelings at bay.

3. Siblings need honest, straight-forward communication.

- Siblings feel isolated, neglected, and helpless when not given information about the disability. Giving them facts in an age-appropriate manner is of paramount importance.
- A study of college-age siblings found that talking to their parents about their sibling’s disability was as difficult as talking to them about sex. It also showed that their feelings and attitudes toward their siblings mirrored the way the parents had handled the disability.
- Siblings need and want a fair distribution of parents’ attention. They may feel resentment and jealousy over time the parents spend with the child with the disability, over the new demands placed on them, or over the lifestyle changes of the family.
- Siblings may feel guilty that they were “spared” or feel guilty over feelings of anger and resentment. They may think they somehow “caused” the disability. They need permission to express their feelings and ways to work through negative feelings, including through family or individual counseling.
- Siblings may feel the pressure to excel in compensation for the disabled child’s inability to do so and/or in an attempt to gain the parents’ attention.
- Siblings often worry about their sibling’s future: what will they do as adults, where will they live, who will take care of them? Many worry about having children of their own who have disabilities.
- Many siblings speak of enormous pride in their disabled brother or sister, knowing the struggles and challenges and hurdles overcome.
- Many siblings demonstrate intense loyalty and will fight to defend their brother or sister from teasing, unfair treatment, and prejudice.
- Siblings of children with disabilities need to know they belong, that they have their own special place in the family, and that they bring their own unique gifts to the family.
- Siblings also need time alone, and with their friends, without constant responsibility revolving around the child with a disability.

4. The child with a disability brings tremendous gifts to the family.

Explain that while having a child with a disability brings many stresses and strains to a family system, families report many gifts and blessings brought to their homes and lives through these very special children. Distribute and review together Handout 2, “Some of the Many Gifts a Child with a Disability Brings to the Family.”

V. Family Rules Exercise (20 minutes)

Introduce the “family rules exercise” by reviewing the following points:

- The church functions very much like a family system, with each person playing a role, and when disability enters that system, the mobile shifts and dances.
- Many of these shifts have to do with unspoken “family rules” that the church has and that are implicitly (often unconsciously) understood, such as: “People should be quiet and reverent in church”; “Everyone should be on their best behavior in church”; and “Church is for those who ‘have it all together.’”
- Often, as disability becomes part of the family system, these unconscious beliefs and values become baggage that no longer works, for example:
 - People should be quiet and reverent in church doesn’t work with children with ADHD.
 - Everyone should be on their best behavior in church doesn’t consider that some disabilities, such as autism, bipolar disorder, or Tourette’s syndrome, make controlling behavior very difficult.
 - If this were true that church is for those who “have it all together,” our churches would be empty. The church is not a country club—it’s a MASH unit!

Lead the participants in the exercise as follows:

- List 5 spoken or unspoken rules in your church.
- Break into groups of 3–4 and share your church family rules.
- Discuss these questions [*Post on newsprint, overhead, or PowerPoint*]:
 - 1) Which rules would make it difficult for families that live with disability to be members of your church?
 - 2) Which rules no longer work?
 - 3) Which would you like to change?

Allow about 10 minutes for discussion.

Break

Remind the participants where the facilities, drinks, and snacks are and invite them to take a 10-minute break.

VI. Ministry with Families of Children with Disabilities (25 minutes)

Distribute and review together the scriptural imperatives on Handout 3, “A Place Called Acceptance: Scriptural Imperatives.” Invite comments.

Ask the participants what attracted them to the church they now attend and record responses on newsprint. Explain that parents of children with disabilities desire the same things from their churches as the rest of us, such as [*Point to or add to the items on the newsprint*]:

1. Acceptance
2. Worship
3. Fellowship and Support
4. Christian Education
5. Spiritual Growth and Discovery of Giftedness

Briefly review the graph on page 22 of *A Place Called Acceptance: Ministry with Families of Children with Disabilities*, then distribute and review together Handout 4, “A Place Called Acceptance: What Parents Desire.”

VII. Action Steps Toward Becoming a Place Called Acceptance (30 minutes)

Distribute Handout 5, “A Place Called Acceptance: Action Steps,” and invite the participants to consider ways their churches can become more supportive of families that live with a child’s disability, using the handout to stimulate their thinking. Also distribute Handout 6, “A Place Called Acceptance: Student Information Form,” as a sample form for use in their churches, as well as Handout 7, “Resources,” for further information.

Give the participants two options: either working in a small group (3–4 people) or spending quiet time reflecting. Encourage them to be as concrete as possible in their suggestions. Allow about 15 minutes for small group discussion and personal reflection.

Reconvene and ask for individuals to share their ideas. Ask if anyone is willing to set a goal to complete one action step in a specific amount of time.

VIII. Closing (5 minutes)

Read aloud the Epilogue from *A Place Called Acceptance*, pages 31–32. Allow a few moments of silent reflection then close with a prayer of dedication for the plans that have been made for ministry with families and children with disabilities.

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DESCRIPTIONS OF STAGES OF GRIEF

Denial is a defense mechanism that buys parents time to discover the inner strength they'll need to handle the situation—time to assimilate the impact the child's disability will have on them individually, on their marriage, and on the entire family. It may be a time of going from doctor to doctor, looking for someone to say it isn't so, or a time of resisting doctor recommendations, or a time of delaying enrolling the child in special programs. This stage can last longer when the diagnosis is a long time in coming or when misdiagnosis is made. Fear and anxiety are part of this stage: fear of the unknown, of ambivalent feelings toward the child, of not being able to meet the child's needs. A moderate amount of anxiety is needed for day-to-day functioning—it helps us to anticipate problems and helps us to concentrate on what to do to keep our children safe. So, fear can be a healthy response that mobilizes energy. Denial is unhealthy only when it becomes chronic.

Anger is often the result when denial ends. Anger can be a scary and socially unacceptable emotion. The parent may direct his/her anger toward God, their spouse, other children in the family, toward the disabled child, or toward the self. It can take the form of blame (it's the doctor's fault, the hospital's fault, my spouse's fault). It may be turned inward, obsessing on "if only's"—if only I'd eaten better; if only I'd exercised less; if only I hadn't taken that antibiotic or had that glass of wine; if only I'd seen the doctor sooner. Anger may be manifested as seething resentment or rage, of shaking a fist at God and asking, "Why me? Why my child? Why my family?" It may be spewed out in words that poison relationships. Such intense feelings may cause parents to isolate themselves. Holding anger in only prolongs the pain. Parents must find a safe place to share their feelings of anger. It helps to learn to use anger to activate and energize the self to get the best services and education for the child.

Guilt and shame—it's not unusual for parents to blame themselves for the child's disability. This is particularly true of mothers, because they are the ones who carried and gave birth to the child. Some parents ask, "Is this punishment for some sin in my life?" Guilt comes about when we blame ourselves for our actions. Shame is a failure to live up to inner ideals and makes us feel small, inadequate, and powerless. Dealing with a child's disability often brings up buried feelings of unworthiness, incompetence, and powerlessness. The antidote to shame is finding pride in oneself and in one's child by redefining oneself and what is possible for the child.

Bargaining is the "let's make a deal" stage. This is where parents make pacts with God. "If you heal my child, I will..." Parents also bargain with themselves, believing if they just work extra hard, find the right doctors, do the right therapies, their child will get better. Again, bargaining is a way to buy time while reorganizing one's life around the advent of disability into the life of the family.

Depression occurs when parents begin to realize that the disability is a reality that is not going to disappear or "get better." Parents may find themselves unable to do routine chores, and find little interest in activities that once brought great pleasure. They may be prone to aches, pains, fatigue, poor digestion, and too little or too much sleep. In this stage, anger and hope are replaced by a great sense of loss at what might have been. When this stage is severe or prolonged, parents may need professional counseling, and possibly medication.

Acceptance is not a static state. It is part of the journey, not a destination. Acceptance, surprisingly, is not necessarily a happy stage. In this stage, the pain has lessened. There may even be a void of feelings. There is the realization that the hard work is just beginning. It's a time of getting on with life; a time of re-working dreams; a time of beginning to trust oneself and others again. It's a time of reaching out for help. The original hope of misdiagnosis has come full circle to the hope of establishing as normal a family life as possible. Parents who have reached this stage are able to accept their children as they are—to appreciate their strengths, tolerate their weaknesses, and genuinely take pleasure in them.

SOME OF THE MANY GIFTS A CHILD WITH A DISABILITY BRINGS TO THE FAMILY

♥ A Source of joy

“Watching the source of gusto with which Mark greets the day gives me a new form of courage to meet life’s little challenges” [from *Uncommon Fathers*, Donald J. Meyer, ed. (Bethesda: Woodbine House, 1995), 2].

♥ Life lessons

- * blesses us with knowledge of life as a precious gift
- * helps us learn the true worth of being a person
- * helps us reprioritize our lives
- * causes us to ponder what’s really important

♥ Giving and receiving love that reveals the essence of unconditional love

♥ Supplying blessing and fulfillment

♥ A Source of pride

- * new appreciation for even the smallest steps forward
- * new realization of the courage needed to meet life’s demands

♥ Strengthening the family

- * forces the family to grow layers of unconditional love
- * teaches selfless consideration and quiet strength
- * can knock down communication barriers, leading the family to new levels of understanding, compassion, and empathy

♥ A deeper relationship with the God who became vulnerable among us

A PLACE CALLED ACCEPTANCE: SCRIPTURAL IMPERATIVES
(RSV translation unless indicated)

“And what does the LORD require of you but to do justice, and to love kindness, and to walk humbly with your God?”—Micah 6:8b

“Enlarge the place of your tent, and let the curtains of your habitations be stretched out; hold not back, lengthen your cords and strengthen your stakes.”—Isaiah 54:2

“The Spirit of the Lord GOD is upon me, because the LORD has anointed me to bring good tidings to the afflicted; he has sent me to bind up the brokenhearted, to proclaim liberty to the captives, and the opening of the prison to those who are bound; to proclaim the year of the LORD’s favor, and the day of vengeance of our God; to comfort all who mourn; to grant to those who mourn in Zion—to give them a garland instead of ashes, the oil of gladness instead of mourning, the mantle of praise instead of a faint spirit; that they may be called oaks of righteousness, the planting of the LORD, that he may be glorified.”—Isaiah 61:1-3

“From now on, therefore, we regard no one from a human point of view....Therefore, if any one is in Christ, he is a new creation; the old has passed away, behold, the new has come. All this is from God, who through Christ reconciled us to himself and gave us the ministry of reconciliation.”—2 Corinthians 5:16-18

“Bear one another’s burdens, and so fulfill the law of Christ.”—Galatians 6:2

“Now there are varieties of gifts, but the same Spirit; and there are varieties of service, but the same Lord; and there are varieties of working, but it is the same God who inspires them all in every one. To each is given the manifestation of the Spirit for the common good.”
—1 Corinthians 12:4-7

“This is my commandment, that you love one another as I have loved you.”—John 15:12

“Whoever welcomes you welcomes me, and whoever welcomes me welcomes the one who sent me.”—Matthew 10:40, NRSV

“As many of you as were baptized into Christ have clothed yourselves with Christ. There is no longer Jew or Greek, there is no longer slave or free, there is no longer male or female; for all of you are one in Christ Jesus.”—Galatians 3:27-28, NRSV

“So if I, your Lord and Teacher, have washed your feet, you also ought to wash one another’s feet. For I have set you an example, that you also should do as I have done to you.”
—John 13:14-15, NRSV

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A PLACE CALLED ACCEPTANCE: WHAT PARENTS DESIRE*

- Ask what you can do to help.
- Don't act or speak as if everything's OK. It's not.
- Don't tell me God chose me to parent this child because I'm strong enough.
- My child can't walk and she's heavy. Help carry her into church.
- Act as if you're happy to see my child.
- Interact with my child, even though she doesn't talk.
- Invite my child to do things.
- Be my child's friend.
- Ask how my child is doing.
- Help our family feel connected in the church.
- Pray for our family.
- Make meals, baby-sit, or help clean the house when we're in a medical crisis.
- Don't judge our family by our child's behavior.
- Don't judge our child for his/her behavior when the behavior is part of the disability.
- Don't say "it could be worse."
- Educate the children in the church about different disabilities.
- Please include my child in church activities.
- Train staff and volunteers in disability issues.
- Develop a relationship with my child and with us as a family.
- Find volunteers so my child can take part in summer activities.
- Find a person willing to act as mediator—someone who can link people together.
- Come to our home occasionally to anoint my child and pray for her.
- Find one-on-one volunteers so that my child can be successful in Sunday school.
- Pair new members up with older members.
- Pair families of children with disabilities with families with typical children of the same age.
- Give siblings of children with disabilities "extra" attention.
- Support our marriage by offering respite care so we can spend time together as husband and wife.
- Equip Sunday school classes with special needs toys for my child.
- Provide very small classes as needed for my child who is medically fragile.
- Hold IEP-type meetings at church so that everyone working with my child is on the same page.
- Help me put together a brochure that describes my child's strengths/needs/disability. This will make transitioning to new classrooms and teachers easier.
- Offer Sunday school in Braille for my child who is blind.

*Results of an Internet survey conducted in 1996 by Kathleen Deyer Bolduc.

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A PLACE CALLED ACCEPTANCE: ACTION STEPS

1. Commitment is the first step. Find like-minded people in your congregation to join in a prayerful commitment to minister with persons with disabilities. Consider forming a task-force on disability issues. Invite persons with disabilities, as well as parents of children with special needs, to serve with others who have a heart for disability concerns. Meet regularly to brainstorm and set priorities and goals to help you move out of the theoretical and into the practice of real hospitality. Attitude filters from the top-down, so it would be great if a staff member got on board. It's extremely important that pastors be familiar with and support participation of the children with disabilities in the congregation.
2. For children's ministries, utilize parents'/guardians' knowledge of the child. Ask them to identify the child's strengths, interests, best methods to keep the child's attention, as well as the child's physical limitations, behaviors, and effective interventions (See Handout 6). Arrange a meeting with the parents and the Sunday school teacher to go over the list before the child joins a class. Find out if the child needs one-on-one support and arrange for a buddy (see Action Step #6 below). If the child has significant behaviors that go along with the disability, make sure to have a plan in place for redirecting the child, and if that does not work, for removing the child until he or she settles down.
3. Once a year plan an "Access or Disability Awareness Service" with an entire worship service focused on the theme of disability. Invite members of the congregation who have disabilities, as well as those whose children have disabilities, to help plan and lead the service. This is an excellent way to highlight the gifts those with disabilities bring to the church and to learn to be more welcoming.
4. Nothing compares with the power of personal story when it comes to changing attitudes. Ask parents of children with disabilities to give personal testimony during worship or adult education classes. The lessons they have learned in Kingdom living will inspire the entire congregation.
5. Train Sunday school teachers in inclusion. See Handout 7 for resources. Consider bringing in a professional (e.g. a special education teacher) to lead the training.
6. Recruit and train volunteers to be "special buddies" to children who need extra support. All that is truly necessary is flexibility, a nonjudgmental and prayerful attitude, patience, a love for children, and a conviction that Jesus calls us to share the gospel with all children. Buddies can accompany the child in church school and sit with the child during the worship service. Often, children with behavioral disabilities will behave better for another person than for Mom & Dad.
7. Find ways children with disabilities can contribute in educational activities and worship.
8. Get kids with disabilities involved in Youth Group. If a junior high or high school youth is interested in buddying up with a child with special needs in Sunday school, they would be the perfect person to introduce that child to their peers in youth group. Here again, it's important for the attitude to filter from the top down, so the youth leader really needs to "get it!"
9. Offer large-print bulletins and hearing devices in worship and train greeters and ushers in disability etiquette (see Handout 7 for a list of resources).
10. Make it known, through the church bulletin, that someone on staff or in the congregation is available for counseling with families living with disability.
11. Furnish your church library with books, videos, and audiotapes on disability and inclusion.
12. Hold workshops on disability issues on an occasional basis, including people with disabilities, parents of children with special needs, and secular agencies that deal with disability on a daily basis.

A Place Called Acceptance: Student Information Form

(Please keep confidential.)

Name _____ Age _____ Birthday ___/___/___

Hobbies _____

Favorite Pastimes _____

Favorite Friend _____ Favorite Foods _____

What does he/she do best? What are his/her strengths?

What tasks can he/she handle alone?

With what tasks does he/she need help?

What are his/her weaknesses?

How does his/her disability limit functioning?

What does he/she have the hardest time with?

Are there any things he/she is afraid of?

Are there any acting-out behaviors? How do you handle these behaviors at home?

Are there any circumstances under which you want to be called?

Any other information you would like to share about your child:

RESOURCES

For Access or Disability Sunday Services

Joni and Friends Ministries, P.O. Box 3333, Agoura Hills, CA 91301-3333, 818-707-5664,
<http://www.joniandfriends.org/>.

For Disability Etiquette and Inclusion

“Epilogue” in *A Place Called Acceptance: Ministry with Families of Children with Disabilities*, Kathleen Deyer Bolduc (Louisville: Bridge Resources, 2001), 1-800-524-2612.

Different Members, One Body: Welcoming the Diversity of Abilities in God's Family, Sharon Kutz-Mellem, editor (Louisville: Witherspoon Press, 1998), 1-800-524-2612.

Equal Access Guide for Meetings, Conferences, Large Assemblies and Worship, A free, downloadable resource from the National Council of Churches' Committee on Disabilities, <http://www.nccusa.org/elmc/disabilitiesmanual.html>.

For More Stories about the Bolduc Family and Joel

His Name Is Joel: Searching for God in a Son's Disability (Louisville: Bridge Resources, 1991), 1-800-524-2612, or visit Kathleen Bolduc's website: <http://kathleenbolduc.com/>.

General

Christian Council on Person's with Disabilities, 301 E. Pine St. Suite 150 Orlando, FL 32801, 407-210-3917, <http://www.ccpd.org/>.

DisABILITIESBOOKS, Inc., www.disabilitiesbooks.com.

National Council of Churches, Committee on Disabilities, NCC Committee on Disabilities, c/o Ministries in Christian Education, National Council of Churches of Christ, 475 Riverside Drive, Room 848, New York, NY 10115, <http://www.nccusa.org/nmu/mce/dis/>.