

Welcoming Children with Special Needs

A Guidebook for Faith Communities

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UNITARIAN UNIVERSALIST ASSOCIATION
BOSTON

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Cover design by Kathryn Sky-Peck
Text design by Communicáto, Ltd.

ISBN 1-55896-479-7
978-1-55896-479-2

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We are grateful for permission to reprint the following:

Page xiii: “We Are,” Words and music by Dr. Ysaye M. Barnwell, Barnwell’s Notes
Publishing, Washington DC.

*For the gift of unconditional love
and a vision of what is and can be,
I dedicate this book to my children,
Sarah and Tyler*

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Preface

Never, ever forget that you have been chosen for this very special journey. It matters not what the challenges may be; what matters is that you open your heart to this child. For as difficult as things may get, you will discover that this soul, wrapped in this precious little package, has much to give and volumes to teach you about yourself—if you are willing to learn.

—Trena Tremblay, *You Will Dream New Dreams*

ALTHOUGH I DID NOT REALIZE IT at the time, the diagnosis of my five-year-old son, Tyler, as severely dyslexic would launch me on a spiritual journey of discovery and healing that continues today. Back then I was, I suppose, an agnostic. Today, I believe we are all manifestations of God.

My journey to this vision of the wonder of life and the spiritual connectedness of all living things was not an easy one. For too long, I felt I was living permanently in the dry desert of no possibilities and few beginnings. But somehow, I made it to the green forest, where I was nourished but still terribly confused. At times, I could climb a tree and gaze briefly on what might be and receive moments of clarity. I had no idea, however, that the process of understanding and helping my son would heal me. I was able to leave the forest of confusion with deep gratitude for the divine in every

person and return to my original passion and profession of working with children with special needs—only this time, in a spiritual way.

Writing this book has become part of my journey of spiritual awakening. At times, this work has been intensely emotional and extremely confusing, but it has always been deeply satisfying. Although I had a background in special needs, researching current practices in this field led me to discover a totally different way of looking at children with special needs. I came to the conclusion that while labeling may help children obtain the services they need, it ultimately hinders and even harms them. I was primed for this discovery by the insights I had gained educating myself about learning disabilities and struggling to obtain needed services for my son. I immersed myself in the literature and resources for each disability group and came away with not only a much greater understanding of the human condition but also a new vision for spiritual healing of the world. To put it succinctly, I now look at children with special needs through different eyes. I am much better able to see the wonder and incredible beauty in each and every child. I can now embrace the opportunity that children with special challenges provide for my own spiritual healing and growth.

I hope that religious professionals, lay leaders, and parents will use this resource to begin the process of welcoming all children into our congregations. I also hope that parents will find it useful in their search for help for their special-needs children. Although I have a master's degree in education in developmental psychology and have worked in the disabilities field for over thirty years, I am not a professionally trained expert on any of the disabilities described in this book. Rather, I reviewed the literature and tried to condense a staggering amount of information into a helpful, easy-to-understand format. Regardless, much more information is available on each disability group than is presented here. I only scratched the surface.

In reviewing the literature, I came to my own conclusions about the debates and disagreements among professionals. My biases are clear and some, I know, are controversial. One such bias concerns how our culture has defined what is acceptable behavior, what is intelligence, and what we should believe about related issues. For the most part, these definitions are quite narrow, not allowing for much diversity of thought or behavior. Any person who deviates from these normative definitions may be labeled *disabled* or *disordered*.

Another area of debate in this field concerns the use of medication. I believe we have come to rely too heavily on drugs as the solution for all our problems. To borrow Wayne Dyer's phrase, I believe instead that we can find a spiritual solution to every problem. When the children are safe and loved, we are all safe and loved. For if each one of us can love all the children who are labeled *different*, *wounded*, *disabled*, *ugly*, *defiant*, and *angry* and make them safe, then our love has no bounds. We can change the world, and we can heal the hate.

We have a long way to go to form this spiritual, inclusive world, but our Unitarian Universalist faith communities can lead the way. In some respects, it may seem like a small step, but in other ways, it can be huge. Bears Kaufman, of the Option Institute in Sheffield, Massachusetts, said to those of us attending a workshop, "You have enough love in you to float the world." I believe that. Our love and acceptance can change the world for children who are perceived as different. We can be models, we can lead the way, and we can float the world with our love. Opening the doors of our churches to all children, no matter their disability or struggle, will move us one step closer to healing the world. I truly believe this.

Introduction

For each child that's born
The morning star rises
And sings to the universe
Who We Are

We are our grandmothers' prayers
We are our grandfathers' dreamings
We are the breath of our ancestors
We are the spirit of God.

—“We Are,” Ysaye M. Barnwell

IF WE BELIEVE THAT EVERY PERSON is born with a mission and a purpose, what does this mean for our ministry to children with special challenges? Often, we get so wrapped up in the difficulty or the problem itself that our reactions to the disabling condition prevent us from seeing who the child really is. In actuality, it is the perceptions and prejudices of other people that often prevent children with disabilities from participating fully in society.

Children with disabilities are, first and foremost, children with dreams, strengths, and weaknesses, and they have the right to be loved and nurtured. Somewhere in the morass of labels, diagnoses, opinions, facts, myths, and misinformation is a unique and individual child who has gifts to offer the world. Unfortunately, he or

she is often lost in the hunt for help, the search for a cure, and the desire for relief and healing. As Unitarian Universalists, we may not be able to provide therapeutic resources, but we can nourish the spirit and help heal the soul.

As faith communities, we can reach out, accept, and be supportive of people who are suffering, struggling, or perceived as being different, not only by accepting special-needs children into religious education programs but also by involving them in the lives of our faith communities. Unitarian Universalist congregations can be welcoming and inclusive places for all children as we affirm and promote all our Principles, especially the inherent worth and dignity of every person; justice, equity, and compassion in human relations; and respect for the interdependent web of all existence. In our churches, children with special needs can gather strength and support for overcoming the obstacles that society imposes.

The majority of books written about children with special needs are intended to help parents and professionals understand the nature of specific disabilities. They generally address treatment, advocacy, education, and parenting strategies. This book is written for ministers, lay leaders, religious educators, and parents within faith communities and provides descriptive information and resources for further reading. However, the emphasis is on a spiritual exploration of each disability and how to fully include children with special needs in our congregations.

It is appropriate for faith communities to discuss spiritual growth, not only to understand what it means to be an inclusive community ministering to marginalized people but also to prepare religious professionals and lay leaders to provide meaningful and effective pastoral care for families. When we view children who struggle from a spiritual perspective, we usually see them in alternative and affirming ways that differ substantially from how mainstream professionals see them. The professional community focuses almost exclusively on these children's deficits and problems and ways to fix them.

Parents are exposed to this perspective on an ongoing basis. When they approach a minister, lay leader, or religious educator for advice or pastoral care, most are not looking for more of the same information. Instead, they want help exploring the complex moral, ethical, and spiritual meaning of having a child with disabilities. Therefore, it makes sense that this book, written for a spiritual setting, provides an alternative, life-affirming perspective in contrast to many conventional views.

Labeling children by their disorder or disability is a double-edged sword. When used properly, labels can help us understand children's behaviors and problems. They can also help parents obtain needed services for their children. At the same time, labels can cause pain, isolation, and confusion. They can be misleading and emphasize differences for the purpose of exclusion. In an ideal world, we would not have to label. All children would be accepted for who they are and receive the appropriate services and education for their needs. We would accept that everyone is different and that our uniqueness is an opportunity for connectedness.

This book uses traditional labels to describe various disabilities because they are necessary to provide a framework for understanding the children in our congregations. When the meaning of the sentence allows, a term such as *special needs*, *difference*, *challenge*, and *difficulty* is used instead of *disability* to humanize the diagnostic process. The person is presented first and then the disability, so that the text reads *a child with a disability*, not *a disabled child*. Language does affect perception. By putting the person before the disabling condition, we convey that a person is a human being first and foremost. No one *is* his or her disability.

Section One of this book focuses on why and how to implement an inclusive ministry for children with special challenges, including awareness training, teaching strategies, and congregational and pastoral care for families. Section Two provides information on how to apply the lessons from Section One to children with specific disabilities, considering disabilities from an alternative, spiritual perspective. It is not possible to include all the

different types of diseases, disorders, and impairments in the world that can cause disabling conditions. This book includes the major disability groups as well as the disabilities that are most prevalent among the children in our congregations.

As you read and use this book, try to drop whatever assumptions you may have about people with disabilities and go beyond the labels to find ways to minister to the children and families that seek your spiritual understanding. What will come shining through on this journey of discovery is a spiritual connection as well as a sense of wonder and appreciation for all life. The endurance and sacredness of the human spirit is demonstrated by the thoughts, perceptions, and actions of children who struggle courageously with sometimes enormous and often painful challenges to attain a sense of self-worth and beauty.

Accepting All Children into Our Faith Communities

Welcoming children with special needs into the congregation is a blessing for everyone concerned. The children feel the welcoming acceptance of their peers; the parents can relax into their own spiritual journey, knowing that their children are in a safe and loving environment; and teachers and other children have a unique opportunity to live out some of the UU Principles, including respect for all humanity, fair and equal treatment and sharing, and support of those who are differently abled.

—Cynthia Wade, Director of Lifespan Religious Education,
Unitarian Universalist Society of Geneva, Illinois

A UNITARIAN UNIVERSALIST WOMAN who was a leader in her congregation once told me that her church welcomed children with special needs. Then she went on to describe what happened when a boy with autism tried coming to her church. “He made noises in the service and noises in his religious education class. He just did not work out,” she said.

This woman probably thought the members of her congregation had done all they could to welcome the boy, yet when children are considered valued members of the congregation, the noises they make in the service are expected and accepted. The baby

crying and the child fidgeting or occasionally wandering down the aisle are part of what happens in a community.

Children are accepted as vital members of our faith communities when we embrace the idea that they are connected to our souls. When we forget this, we cut out an essential part of who we are and why we are here. In her book *The Gift of Faith: Tending the Spiritual Lives of Children*, Unitarian Universalist minister Jeanne Harrison Nieuwejaar emphasizes that children are spiritual beings born with an innate connection to the sacred and the holy. It is the parent's responsibility to nurture the child's spiritual nature. Nieuwejaar feels that the parent can do this best in a religious community that provides the sacred space for deepening the faith of both parent and child. The essential role of a congregation is to be a place of hope, to help us remember the sacredness of all life, and to nurture what educator Thomas Armstrong calls the "radiant child":

This is the essence of the radiant child. Belonging to both heaven and earth, the radiant child dances into our lives as a bridge between dark and light, body and spirit, ego and Self, the individual and God. The radiant child spans and sings this wholeness in every fiber. We would all be wise to listen. Even better to sing and dance along!¹

A religious community that cherishes its children invariably learns to cherish all life. When we make the world safe for children, we make the world safe for everyone. Imagine the astounding changes that would occur if government leaders decided to pass only laws that made children safe. This would have revolutionary consequences, as war, pollution, pesticides, and poverty are clearly not safe for children. The world would be made safe for absolutely everyone. As Gabriela Arrieta, a thirteen-year-old from Bolivia, told the United Nations at its first children's summit, "We want a world fit for children, because a world fit for us is a world fit for everyone."²

Before a congregation can minister to children with special needs, it must first weave children into the overall fabric of the

church community. Only after a congregation has assessed and embraced its ministry to all children will it be ready to create a ministry for special-needs children and offer a religious education program that is inclusive.

Creating congregations that are safe for children and thus everyone means confronting feelings of discomfort and awkwardness around adults and children with disabilities. Even *talking* about disabilities can make people uncomfortable. What we often fail to recognize is that people and children with disabilities are *us*. Any one of us can have a car accident that leaves us disabled. Any pregnant woman can have a child with special needs. The emotions surrounding disabilities are complex; they may include an unspoken relief that the disability happened to someone else and not us. This is an honest feeling, neither bad nor good, and acknowledging it can free us to see people with disabilities as human beings with their own needs, wants, desires, dreams, weaknesses, and strengths.

In our congregations, the subject of including children with disabilities can be divisive. Too often, the needs of children with disabilities are pitted against those of other children, especially when resources are scarce. Some people may feel that too much time, attention, and resources are needed to accommodate one or two children with serious disabilities. The question is often asked, How can we, as responsible and caring Unitarian Universalists, respond to the needs of children with disabilities without jeopardizing the needs of all our children? Perhaps a better question is, How can our congregation benefit from the participation of children with differing needs and abilities?

The notion that “God does not make mistakes” is held by many people of faith and often used in reference to adults and children who have a disabling condition. Even for those who question the existence of God, this notion has profound implications for children with special challenges. Believing that children with disabilities are *not* mistakes is essential to our ability to minister to or parent them. We must be able to see the wholeness of spirit

instead of only brokenness or deficits. Otherwise, we lose sight of the whole child and his or her unique gift to the world.

Judith Snow, a woman who can move only her thumb (which she uses to drive her wheelchair), travels the world speaking about the giftedness of people with disabilities. In her book *What's Really Worth Doing and How to Do It: A Book for People Who Love Someone Labeled Disabled (Possibly Yourself)*, she offers inspiring insight into what it means to be different and also have gifts. Snow says that the common use of the word *gifted* connotes extraordinary abilities but that *gifted* has a broader and more ancient meaning. She writes,

Everyone has gifts—countless ordinary and extraordinary gifts. A gift is anything that one is or has or does that creates an opportunity for a meaningful interaction with at least one other person. Gifts are the fundamental characteristics of our human life and community.

There are two gifts that all people have and that every other gift depends on. The first is presence. Since you are here, you are embodying the possibility of a meaningful interaction with someone else. . . . Secondly, you are different from everyone else—in countless ways. Difference is required to make meaning possible. . . . This means that human interaction arises from presence and difference. . . .

Walking is a gift. It offers the possibility of meaningful interaction. Not walking is also a gift—also creating the possibility of meaningful interaction. Speaking is a gift. Not speaking is also a gift. It is a different gift. Seeing and not seeing, hearing and being deaf, behaving in ways people expect and disturbing others . . . all gifts. They are different with different potentials but all gifts arising from difference. All gifts add to the mosaic of the potential available community.³

My son, Tyler, is hesitant to try new activities and terrified of speaking in front of groups of people. This fear is exacerbated by a word-retrieval problem. One Sunday when he was ten years old, I

brought Tyler to church early to listen while I practiced with the choir. While he was waiting, our senior minister asked him to help set up the candles of concern. The minister chatted with Tyler about the purpose of lighting the candles and suggested that if he wanted to light a candle, he would have time to prepare a concern to share with the congregation.

The service began. I was sitting in the choir loft, and Tyler and his sister were sitting in the pews. When it was time for the candles of concern, Tyler immediately got up, gave his name, and said that he was lighting a candle for his teacher, who had just had a baby. I was overwhelmed with tears of gratitude and joy. Because of Tyler's comfort with and trust in the adult church community and the thoughtfulness of a minister who knew he needed time to prepare for such a courageous act, my son was able to overcome his fear of appearing inadequate in front of people. This was a moment of transcendence for Tyler, made possible by an adult worshiping community that weaves its children into the fabric of its life. It was also a moment of transcendence for me, a moment of healing and feeling touched by grace.

In their book *Engaging in Transcendence*, Barbara Kimes Myers and William R. Myers write,

Often we want to “give the ocean” to young children when splashing in the “puddle” is enough. We fall into this trap by the ways we choose to share our adult faith with our youngest children. In our hurry to communicate our faith, we often assume that words are the most effective vehicle. Yet by using only words, we may fail to engage children in those common mud-puddle experiences where God is most visible, such as sitting on a loved person's lap and hearing a story, helping to bake bread, sharing a doughnut, or going with someone for a walk. These are the simple ways by which adults nurture and tend to the religious experiences of children.⁴

These authors believe that the actual experience of the divine is achieved in an atmosphere of support and affirmation created in a

caring adult community. Young people experience the sacred when they are part of an intergenerational worshiping community that encourages trust and relationships of intimacy.

Ministry to all our children flourishes as a result of creative inclusivity. In ministering to children with special challenges, we remind ourselves that all of us and all of our children have different ways of learning and responding to the world. We often find that the old ways of teaching are not the best ways to educate and inspire our children. Working with children with special needs can help to prevent us from becoming complacent and can challenge us to grow, learn, and expand our own spirituality.

Creating a ministry for children with special challenges usually does not occur in any systematic way. In most cases, a family with a special-needs child starts coming to church and the religious education director and teachers scramble to find a way to include him or her in the existing program. Some churches handle the challenge well, while others constantly struggle to find ways to involve these children and youth. The experience of Betty Skwire, a former director of religious education and now a special education teacher, is typical of what is happening in our churches. In her view,

Special needs children in our RE programs are a big issue. So far, I have had one severely autistic child, one deaf child, a number of children with minor behavior disorders, and two children with severe birth defects. Sometimes it worked out, sometimes it didn't.

It is important to put together a systematic process of looking at the church's ministry for children with disabilities and their families. This process may go hand in hand with assessing the church's ministry to adults with disabilities. Often a church's efforts to accommodate a family with a special-needs child, especially one with a mobility impairment, will force the congregation to look at how they welcome adults with disabilities as well.

Raise Awareness and Offer Sensitivity Training

All congregations can benefit from some training about people with disabilities. Identify where there is resistance. There may be a need for churchwide training, or you may only need training for parents and teachers in how to work with children who have certain disabilities. Also identify the area of most concern in your church. Is it making the building accessible, or is it training teachers to address learning differences? If the issue is accessibility, then the whole congregation needs to be part of the education process. Many congregations become so stuck on funding major building renovations that they overlook what can be done with interim accommodations and an inclusive religious education ministry. While it is important to make the building accessible so that everyone can use it, the ongoing needs of children with emotional and learning differences must also be considered.

Once you start the process of examining accessibility in your church, you will probably discover people with special talents and expertise who can help develop training. Do not forget the parents of children with special needs; they know where to go to find information and get help. Emily Green, a former director of religious education, felt fortunate to be able to minister to children with special challenges because of support from people within the church who were special-needs teachers, psychologists, and pediatricians as well as from other concerned adults and parents of special-needs children. She emphasizes, “It’s never easy, but it’s always well worth the effort! Don’t overlook the talents in your own community.”

Activities to raise awareness are easily incorporated within Sunday services, discussion groups, coffee hour talks, miniforums, and adult religious education programs. Ministers can offer sermons on disability awareness. Testimonials from people within the congregation are also very effective ways to raise awareness. One activity that works extremely well in many different settings involves asking questions of the group. Ask people to raise their

hands if any of the following questions apply to them and to leave their hands up until all of the questions have been asked: “Who has a disability?” (A few people will raise their hands.) Then ask, “Who knows someone with a disability?” (A few more people will raise their hands, but most will not.) “How many know someone who has had a heart attack? How many know someone who suffers from arthritis? How many know someone who struggles with learning to read? How many know someone who is depressed? How many know someone who is addicted to drugs or alcohol? How many know someone who is in chronic pain? How many know someone who has asthma? How many know someone who is constantly anxious? How many know someone who is hyperactive and totally disorganized? How many know someone who uses a cane or a walker? How many know someone who uses a hearing aid?” Continue asking questions until everyone has raised his or her hand.

This activity clearly demonstrates that people with disabilities are not *other* people but rather our friends, our families, and ourselves. All of us will probably have to cope with disability in our lifetimes—our own or that of someone we love. Creating an accessible church is about creating a welcoming church for ourselves.

Another effective way to raise awareness of disability and accessibility is to invite people to share their struggles in school. Having people remember their own school experiences can help generate empathy with children’s struggles. Discussion can center on the different ways children learn and the different gifts they bring to the faith community. Teacher training about individual learning styles and special needs is critical for the successful integration of special-needs children into the religious education ministry.

Develop a Task Force

A task force is usually necessary to make lasting changes to a congregation’s ministry to adults and children with disabilities. The church’s governing body can undertake this responsibility, but it

may address only one issue, such as physical accessibility, rather than assess the overall ministry to people with disabilities. A special task force is more appropriate.

Make sure that representatives of all pertinent church groups serve on the task force, including but not limited to the governing body, the building and grounds committee, the music committee, the religious education committee, the adult programs committee, the worship committee, and the membership committee. The minister should also be a member of the task force or come to as many meetings as possible. His or her leadership on this issue is critical for the group's long-term success.

Have the task force develop a statement of philosophy or mission concerning ministry to adults and children with disabilities and share that statement with the rest of the congregation and ask them to endorse it. To secure the congregation's endorsement, offer disability awareness training that includes discussion groups, guest speakers, and parent and other adult testimonies about living with disability.

Once its mission statement has been approved, the task force can develop a five-year plan detailing specific goals and objectives for inclusion of adults, youth, and children with disabilities. This plan should also be endorsed by the entire congregation and approved by the governing body. The task force can then serve as the oversight committee for monitoring the five-year plan.

The task force can consider any of a number of topics in its meetings. A booklet by the National Organization on Disability (NOD), *That All May Worship: An Interfaith Welcome to People with Disabilities*, suggests these topics and activities:

- Divide into small subgroups so that individuals have ample opportunities to exchange ideas.
- Discuss experiences within the congregation that may be creating barriers for people with disabilities and their families.
- Take time to examine the moral dilemma created when a congregation excludes or does not reach out to people with disabilities.

- Reflect on what it means to be human. What binds people together in community?
- Make a list of access problems someone with physical or sensory disabilities who is trying to enter or use the building would encounter.
- Consider policies and practices that could be discouraging to someone with a disability.
- Divide the list of barriers and problems by type.
- Strategize about fund-raising. Ideas might include urging the high school youth group to sponsor a needed program or inviting families to contribute money for a ramp or an enhanced sound system in honor or in memory of a family member.⁵

Provide Accessibility

Resistance to renovating a building to make it accessible usually comes from a misunderstanding about the use of space. For instance, people may see only one member of the congregation who is in a wheelchair and secretly wonder about the expense to help just one individual. Present accessibility as a benefit to everyone. Done with care, the process of making a building accessible can create a space that is livable, functional, and beautiful for all. Ramps, accessible bathrooms, elevators, hand grips, and larger, more airy spaces help not only people in wheelchairs but also those in casts and on crutches, parents with strollers, people with arthritis and heart problems, pregnant women, small children, and the elderly. Talk about what image the church building conveys to the public. Does it feel open and welcoming or closed and inhospitable?

Making renovations all at once can be overwhelming, especially with old buildings. Take a look at what can be done in the short term and with minimal expense. If a child with a physical disability cannot get to the upstairs religious education room, consider having that group meet downstairs. If there is no place to put a wheelchair in the sanctuary, take out a pew. If someone is having

difficulty getting from the car to the building, designate a handicapped parking space close to the entrance. If someone who is visually impaired needs a braille version of the order of service, contact a local agency for the blind and visually impaired and ask for assistance. Some of these suggestions may seem obvious, but you would be surprised how often people overlook simple solutions.

Create a task force subcommittee to look at accessibility issues and draw up a specific five-year plan to incorporate into the overall five-year plan. You may find that your congregation has already addressed physical accessibility issues without considering the overall ministry to people with disabilities. There is a lot more involved in welcoming adults, youth, and children with disabilities than building a ramp or installing an elevator. Nevertheless, those churches that have already made these efforts are in a much better position to launch a congregationwide effort to be inclusive and inviting to all people.

Reach Out to People with Disabilities

Once you have developed an awareness in your congregation concerning special needs, you can begin to reach out to adults, youth, and children with disabilities in your community. The task force can help and encourage this by identifying relevant agencies and letting them know that your church welcomes people with special needs. The word will spread.

Transportation to the church may be a barrier for some people with mobility issues or sight impairments. In order to serve these people, the congregation will need to address how these people can attend. Be aware that some parents may need help getting their children with disabilities to and from the church.

Since ushers are usually the first to greet people on Sunday morning, it is important to train them on how to greet people with disabilities graciously. According to the NOD, a motivating part of this training is to ask adults and children with disabilities to share their stories about what causes them to feel welcome or

unwelcome in church. NOD offers these suggestions for ushers on Sunday morning:

- Ask about a preferred location for seating.
- Seat a new person, especially one with a disability who arrives without a companion, with members who have agreed ahead of time. (Also suggest this for families with a special-needs child.)
- Offer audio loops, large-print or braille bulletins, and large-print prayer books and hymnals.
- Request feedback on the effectiveness of mechanical devices, and report any that are not in good repair.
- Station someone near heavy swinging doors to assist those with mobility impairments.⁶

Make sure that any family that has a child with a disability connects with the congregation's religious educator or religious education representative. If children are not involved in the service that morning, have someone bring the family to where the new child will be participating. If children are part of the service and the new child is having difficulty sitting still, offer some quiet materials to use in the pew, such as pipe cleaners, modeling clay, or drawing materials.

Issues of Social Justice and Advocacy

Because our society often defines children with disabilities by their disability, parents must fight a constant battle to educate and advocate for their children. When they convey the uniqueness and wholeness of their children, they can transform the culture's view and help heal that which separates us. Similarly, a congregation that commits to ministering to children with disabilities cannot help but be changed. The energy of this welcoming, transforming process will have a positive affect on all aspects of congregational life, so that no one group or individual will be separated out because of being different.

Children with special needs were granted the basic right to public education with the Education for All Handicapped Children Act of 1975. While this revolutionary legislation drastically improved opportunities, the struggle continues to provide all children with needed services. In an era of shrinking school budgets, special education is sometimes blamed for consuming much-needed resources. Parents may still have to fight hard for needed services from the school, but they should not have to struggle to find a spiritual home for their child and family. As one mother said, "Where can I bring my son if I cannot bring him to church?"

Ministering to children with special needs is both a personal and social challenge. While our Unitarian Universalist congregations are not social service agencies, it is critically important to our ministry, religious education, pastoral care, and social advocacy that we understand the enormous difficulties and stresses experienced by families with special-needs children and youth. In order to provide an effective and compassionate ministry, we need to understand the complex spiritual, ethical, and moral concerns that affect how we as a society treat people with disabilities.

Many parents of special-needs children say that no one who does not have a child with a disability can ever truly understand what the experience is like. In many ways, this is true. However, it is not necessary for everyone to totally understand. Nor is it realistic. What we can hope for is that people will let go of their fear of disability and learn to see each child with special needs as a human being with the same right to be loved and respected as any other.

Parents bear the primary responsibility for educating people and advocating for their children. Yet by the time parents have exhausted themselves fighting for professional, medical, and educational services, they have little energy left to continue the fight in their religious communities. If the church is not initially welcoming, many of these families will leave. Even when a congregation makes a sincere but misinformed and halfway attempt at inclusion, the family may turn away in frustration. When this happens, some congregations will shrug and say they tried.

Jennie's story of her experience of trying to attend UU churches illustrates the experience of many parents:

My son, Isaac, has autism. We tried attending a UU church in Illinois, but nobody knew how to watch or include my son, so it did not work out. Then we moved back to New England and attended another UU church. One volunteer tried to help figure out a way to include my son but could not arrange it on a regular basis and did not know how to approach the congregation. I did not have the energy to figure out how to make it work. We moved again, and since then, I have not tried going to any other churches. I want community and I want my son to be part of it. In some ways, he needs it more than anyone else—a sense of acceptance and belonging and welcome. Many people, particularly in the autism community, have shared how lonely they are for connection and for tolerance, and it is often least found in a religious setting.

A congregation can educate its members and develop a ministry that is welcoming to children with disabilities, but the efforts needed to include them in church life cannot be totally dependent on their parents. The entire congregation needs to embrace the complex challenges with significant commitment because this is an issue of social justice.

Ministering to children with differences helps us be more creative in our ministry to all children and reaffirm our beliefs. Lessons of compassion, caring, and acceptance benefit us all, young and old alike. Moreover, fighting for the rights of children with disabilities is an issue of social justice that Unitarian Universalist congregations can embrace. It is important that we not only welcome people with disabilities into our churches but that we also join them in their fight for equal access, education, pay, and opportunities. We deepen our faith when we embrace and fight for the vision of an inclusive community.

We should not miss opportunities to fight for social justice for children with disabilities who are already in our congregations. The following story of Hannah, a girl with multiple disabilities, illustrates a missed opportunity. Hannah's religious education director and teachers planned a bonding experience for the Coming of Age youth at a nearby camp with a ropes course. Hannah's mother was willing to accompany her daughter to the camp but told the religious education director that Hannah would probably not be able to do most of the activities. The director said that the camp would not allow someone who could not do all the activities to participate and that it was too late to plan something else. The mother was familiar with the course and felt that Hannah would like to walk along and watch or participate as much as she was able. The mother thought that this was not a safety issue but only a stated policy. And while the religious education director did not agree with the camp's position, she did not want to disappoint the other children. Hannah was politely but definitely told to stay home.

The mother understandably saw this as a missed opportunity to teach social justice. She pointed out that instead of excluding a child with a disability from a key activity, the UU community could have banded together, involved the children in lodging a protest to the camp for discrimination against persons with disabilities, and engaged the class in researching and planning an activity that would include the entire group. Congregations can and should model for all their children that discrimination against people with disabilities is something we cannot tolerate.

In *God Plays Piano Too*, Brett Webb-Mitchell talks about how the voices of children and youth with disabilities are often silent because we do not take the time to listen to their stories and because they are generally absent from our churches. Yet we have much to learn from these people about compassion and forgiveness, persistence and courage, and most importantly, the wholeness of their spirit and the gifts they offer if we allow them to flourish. Listening to children's stories encourages us to see each

child's uniqueness rather than their limitations. As Webb-Mitchell suggests,

If we listen to these voices, then we may learn more about the life around us. We may become advocates, urging others to listen to each unique voice of a child or a person with a disabling condition. These are voices wanting to be heard. We should make way in our congregations for these voices, learning to live in community with these storytellers rather than waiting for them to make community with us.⁷

Parenting, loving, befriending, and ministering to children with special needs changes people. How we handle the change will either mire us in the prevalent belief system about disability and limitations, or it will set us free and alter our ideas about who we are and why we are here. Whether you are part of the church's professional staff or a member of the congregation, you have a distinct but interdependent role to play in enhancing your faith community's capacity to minister to families and children with special needs.

Ministering to Families

We all need people who see us as good and competent parents, and who do not blame us for what is “wrong” and difficult about our child. We all need places to go where people can look past the fact that our child doesn’t talk or doesn’t respond to our directions. We need people who admire his physical beauty and his curiosity, or who recognize how clever he is in his mischief. We all need to go where our family is accepted as it is, and delight is taken in us and each of our children. And we all need people who show us the way, leading us by their example, to the confidence or pride we have been struggling for. An ounce of this kind of love can offset a pound of criticism and hostility. In its presence we open like a day lily to the sun.

—Barbara Gill, *Changed by a Child*

THE ARRIVAL OF A BABY INTO A FAMILY changes the family dynamics. The arrival of a child with a disability places exceptional demands on the family. The initial trauma of finding out about their child, whether at birth or later, can be overwhelming. The relationship between the parents and with their other children can become strained. A faith community can provide hope and support through this time, giving the parents some time to heal so that they can focus on their child with special needs and on any other children they might have.

Parents with a special-needs child will automatically seek answers and help from medical, mental health, and education professionals. Some parents will receive too much information about their child, while others won't be able to get enough. A lot of the information will be negative. When parents approach a minister or religious educator for pastoral care, they are looking for a different kind of information than what they have already received. They may be looking for spiritual guidance, emotional support, or a different perspective. Often they are searching for a spiritual meaning to their child's disability. The "Discussion" sections in the chapters on specific disabilities or disorders provide information about different perspectives and alternative views. They can help us think "outside the box" to be more creative with ministry to parents and all children.

Most of us in the helping professions are familiar with Elizabeth Kübler-Ross's five stages of grief, as described in her book *On Death and Dying*: denial and isolation, anger, bargaining, depression, and acceptance.¹ What most parents with a special-needs child experience is akin to the stages of grief because they are mourning the loss of their dream of a normal child. While the stages of grief are similar for those experiencing the death of a loved one, parents of a special-needs child must cope while parenting the child. This relationship becomes a constant reminder of their loss. Parents who can eventually accept the fact of their child's disability can heal and learn to love the child for who she is, rather than who she is not.

Yet even with this acceptance, parents must still contend with a culture that does not see their child as a gift but perceives only brokenness and limitations. Often the struggle to raise their child the best way they can in the face of such uncomprehending and unyielding beliefs means that parents bounce back and forth between the stages of grief. This process of grieving and parenting has been likened to a roller-coaster ride. However, once they have started down the road toward healing, most parents continue to make steady progress. (For more information, see Kathleen Deyer Bolduc's book *A Place Called Acceptance: Ministry with Families of*

Children with Disabilities, which describes the stages of grief as they affect parents of children with disabilities.)

Effective ministry to parents will change and grow, depending on what stage they are experiencing with their child. Healing and acceptance come with time, after the initial crisis is over. While many parents come to believe that their child with disabilities is a gift and has provided them with the opportunity for exceptional growth and understanding, this is not a message most will be able to embrace at the time of diagnosis or for many years afterward. The best ways to support parents are to listen, provide a different perspective, and help them find creative solutions to whatever problems come along.

In working with parents to include their special-needs child in the church's religious education program, you must be aware of how comfortable they are with his or her disability. Their comfort level usually corresponds to the stage of grief they are experiencing. Some parents are in denial and do not want to talk about their child's impairment, some overprotect their child, some focus too much on the impairment, and some have learned to cope, relax, and enjoy their child. In any case, try to develop an open, ongoing relationship with the parents in order to fully understand how the child functions and how best to include him or her in congregational life.

The most appropriate ministry may be to help the parents find needed services and to work through their fears and sadness. If the parents' relationship with their child seems unhealthy, you can gently suggest ways they can get more information and perhaps counseling.

Another goal of pastoral care is to understand how the parents are coping. They may be too exhausted, overwhelmed, or confused to search for answers and get help appropriate to their needs. Helping the parents take care of themselves first may be the most important function of pastoral care. Parents who can find peace inside themselves are more likely to be able to summon the energy to help their children. It is important when ministering to parents of children with special needs to realize that the path out of

paralysis, anger, and desolation to a celebration of their child's life is different for each parent, and some may never get there. Turning inward, going deep, and struggling to understand can turn sorrow into joy. It is a constant challenge to take what life gives us and find meaning. A well-known story by Emily Pearl Kingsley describes what it is like for parents when they discover that their child has a disability. Imagine that you have planned a trip to Italy. You have learned the language and the culture, and you are excited about being in Italy. But when you finally arrive and get off the plane, you realize that you have landed in Holland instead. Now you have to plan differently, learn a whole new language, get to know a whole new set of people with different customs and ways of being, and you also have to give up on your dream of being in Italy. But, as Kingsley writes, "if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely, things about Holland."²

There are several messages that will help parents on this healing path:

- Your dreams for your child do not have to die; they just need to change.
- Your child will have his or her own dreams.
- Let go of any guilt or blame about having a special-needs child. Guilt saps energy and eats away at family relationships. The past cannot be changed, so live in the present.
- Worrying about the future only creates miserable feelings about something that may not actually happen. Take care of yourself or you will not have enough energy for your family.
- Get support; you are not alone.
- Trust your own intuition, because the professionals do not know your child the way you do. Be a goodwill ambassador for your child, constantly communicating with everyone about him or her.
- Encourage your child's independence and celebrate every accomplishment, even if it takes longer or is different from the achievements of other children. Visualize what you want for your child; then plan and make it happen.

While federal legislation does not apply to our congregations, it is vitally important for families with children with special needs to obtain needed services. To minister to these families, it is important to be aware of three federal laws that affect our society's treatment of children with special needs. As noted earlier, Public Law 94-142, or the Education for All Handicapped Children Act, was enacted by the U.S. Congress in 1975. This landmark legislation guaranteed children with disabilities the right to attend school and get a "free appropriate public education" (FAPE) for the first time. In 1990, the Education of All Handicapped Children Act was reauthorized and renamed the Individuals with Disabilities Education Act (IDEA). Under IDEA (PL 101-476), the term *handicap* was changed to *disabled*, and autism and traumatic brain injury were made eligible for special education and related services. A child qualifying for special education services must have an individual education plan (IEP) implemented.

Section 504 of the Rehabilitation Act of 1973 protects the civil rights of children with disabilities. There are some children who do not qualify for IDEA but have a condition that "substantially interferes with their ability to learn." Section 504 is generally used for specific and special accommodations. Both Section 504 and the American with Disabilities Act (ADA) protect the rights of students from discrimination because of their disabilities. ADA entitles children with disabilities to all the educational services for which they qualify and access to all the programs and activities offered by the school.³

What It's Like to Be the Family of a Child with a Disability

Having a child with a disability will affect all the family members—mother, father, siblings, and grandparents. Most of the tension arises because the needs of the child with a disability consume vast amounts of time and energy from the parents. Grandparents may want to help but do not know how and may have their own disability issues that limit their ability to provide support. They,

too, are also experiencing the loss of a dream. Parents may feel resentful of each other but be too tired to deal with the undercurrents of dissatisfaction. Siblings can feel left out, ignored, resentful, and embarrassed by their brother or sister with a disability. It is vitally important for religious professionals and lay leaders to realize that siblings may also need individual support and care. It often takes family therapy to create a forum in which each family member is heard and listened to.

Families with a special-needs child have to redefine what the culture views as a *family*. In the book *It Isn't Fair! Siblings of Children with Disabilities*, Stanley D. Klien and Maxwell J. Schleifer talk about a wall of silence that keeps families with a child with a disability from having meaningful discussions about their experience:

It has taken many years, fraught with disillusion, frustration and the pain of outright rejection for parents' and families to change the misconceptions and correct the myths which have dominated the beliefs and attitudes of many in this country about disabilities. Only now is the disabled child coming to be perceived as a human being with the same basic needs for love, acceptance and belonging as other children.⁴

The constant caretaking, teaching, and advocating for a child with a disability can deplete parents' internal resources, so they rely more and more on their other children to help out and fend for themselves. Also, we frequently forget about the siblings' role in creating attitude change outside the family. Like their parents, siblings are ambassadors for the special-needs child in their family. Parents who recognize the special role their other children have in the family dynamics can allay their children's fears, help them understand what is special about each member of the family, and listen to them when they feel resentful about explaining their sibling with a disability to their friends or having to help more at home.

Most siblings—when they feel listened to and cared for and come to understand their special loving place in the family—find that they are also blessed to have a brother or sister with a

disability. When my daughter, Sarah Grenzeback, was fifteen, she expressed her feelings in a poem about her brother Tyler who has a learning disability:

At first I did not know,
Could not understand
What was different,
Why our parents
Went through so much
Fighting and suffering
To find an answer,
A solution to the problem
That was you.
Now with a name
The fight is easier;
Bridges of understanding
Slowly cross the void,
Thin threads of spider's silk
Weaving across the light.
At first I could not see;
My love was trapped,
Your essence shadowed,
Grey with mist,
Misleading, insubstantial.
How could I know
That perhaps it wasn't
A problem, a disease,
But a unique gift,
With strengths hidden
Beneath the weakness,
Making you no other
Than your own self.

Siblings' unique experiences can foster a special sensitivity, compassion, and caring toward people who are perceived as different. Many siblings as well as parents are drawn to careers that involve helping or advocating for children with disabilities. In

Changed by a Child, Barbara Gill writes, “Let me remember that first and last we are mother and son, father and daughter, a family. I will not let the cloud of disability block the sun of that truth. Birds sing in this experience too, and my child and I deserve to sing with them.”⁵

Ministers and Religious Educators as Listeners

Giving children with disabilities, along with their parents, siblings, and even grandparents, the opportunity to be heard is the best support we can provide. Children with disabilities and their families rarely get this opportunity. Professionals are constantly telling them what to do, what to expect, and where to go for services. It is a rare professional who will actually listen without dismissing concerns and feelings.

Being a good listener is an art that requires a nonjudgmental attitude. In *Power Dialogues, The Ultimate System for Personal Change*, Barry Neil Kaufman identifies the three components of a good listener:

- To be present is to be fully and completely attentive, curious, and energetic. A good listener is free of thoughts about oneself and other concerns.
- To be nonjudgmental is to make no judgments about what the person is talking about: no right, wrong, good, or bad. Being nonjudgmental also means being free of assumptions and totally accepting of what the person is saying, trusting that they know best for themselves.
- To be nondirective is to have no agenda and no expectations as to outcomes, to trust that the person is their own best expert.⁶

Listening and creating an atmosphere of trust may be all people need to find the inner resources to care for themselves creatively and compassionately. Ministers and religious educators can also ask families how they can best help. Rather than assume you know what would be helpful, let the family members tell you.

Support Circles

Many Unitarian Universalist congregations are using the model of *small group ministry* or *covenant groups* to meet the ministerial and spiritual needs of their members. Reverend Calvin O. Dame suggests that small group ministry fosters shared understanding in which everyone is called to participate in the ministry of the congregation, which deepens “spiritual resources, strengthens connections to the congregation, opens up the vision of service and beckons participants onto a path of mature spiritual growth.”⁷ The small group ministry model is the structure for creating *support circles* for adults and children with disabilities, which can be instrumental in building a truly inclusive faith community. Support circles would include people who want to examine and deepen their own contribution to the faith community as well as explore the spiritual side of inclusion as a healing process. The focus of a support circle is on the adult, family, or child who is vulnerable to exclusion, and the purpose is to listen and help bring dreams to fruition.

A good example of a support circle in action is Judith Snow’s Joshua Circle, which is comprised of the people who provide daily care for her. The benefits for Judith, who has multiple disabilities, are obvious. She receives the constant care she needs to function independently of a hospital. This independence allows her to be meaningfully employed and to be a guiding light for inclusive communities. The people in her Joshua Circle also enjoy several benefits. They find the experience immensely gratifying as well as challenging, and they have grown emotionally and spiritually from knowing Judith. In her book *From Behind the Piano*, Mike Green, Judith’s friend and colleague, explains it this way:

Inclusion is a spiritual practice. It is a practice of the heart. You have to do it to get it. I am realizing more and more that inclusion is not primarily something learned through the mind but something discovered through intentionally putting oneself in structures that foster the experience of valuing differences.⁸

In order to function effectively, a support circle or covenant group requires a *facilitator*. The minister or religious educator can work with parents of the special-needs child to identify someone within the congregation who is willing to send out invitations to other members of the congregation and to oversee the group once it is has been formed. The invitations to participate in the support circle will require personal contact and explanation. Once the group is organized, the facilitator needs to convene each meeting and keep the discussion focused on the family's needs, their dreams for their child, and their participation in the life of the congregation.

The task of the support circle is to help these dreams become a reality. Dreams may include having meals or transportation provided, errands done, extra help offered if they are feeling overwhelmed or the child is in the hospital. Dreams may also include more involvement of the child in religious education programming. In that case, the support circle could find a way to provide aides and mentors, if needed.

Helping dreams come true may also require advocacy and sensitivity training within the larger congregation. Church members may need help and encouragement to adopt a new perspective on people with disabilities. Developing support circles is one small but important step toward the creation of an inclusive faith community.

Parents can dream new dreams for their special-needs child when the dreams of the child are recognized and honored. An inclusive community honors everyone's dreams. Successful support circles practice active listening, establish relationships, and provide meaningful participation.⁹ The stories and needs of all family members are listened to, and the family's presence in the congregation is valued. The child and the family are no longer isolated from the life of the community.

Religious Education That Welcomes All Children

When will the church accept Joel (and others like him) for who they are, rather than focus on what they can or cannot do? When will the church love Joel (and others like him) with a no-strings-attached kind of love? When will the church wake up and realize that a child with mental retardation (or cerebral palsy, or autism, or blindness, or deafness) may minister to the most wise among us?

—Kathleen Deyer Bolduc, *His Name Is Joel*

IDEALLY, THE RELIGIOUS EDUCATION MINISTRY for children and youth flows from the love and support of the adults in the church. A new family with a special-needs child will therefore experience the church as a place where their child will be welcomed.

In a church that cherishes its children, there will most likely be a religious education committee and, if the congregation is large enough, a director of religious education or minister of religious education. A church that is truly committed to raising spiritual children will put its resources behind the religious education committee and religious education program. A congregation that supports its religious education ministry financially will have less difficulty deciding to pay for an aide for a special-needs child or an interpreter for a child who is deaf.

Here are a few ideas for engaging the support and involvement of your congregation:

- Invite the parents of a child with a disability to be members of your religious education committee. Recognize that many of these parents constantly have to advocate for their children and fight for needed services. Many will not have the time or energy to take on one more task. Find ways to get their input about the religious education program without expecting them to carry the full burden of advocacy and education. Also solicit other members of the congregation who may have professional expertise regarding disabilities.
- Offer disability awareness and sensitivity training about disability issues every time new members join the religious education committee. Also be aware of how long it has been since the whole congregation has had sensitivity training. If there is a task force dealing with disability issues, make sure that children and youth are always considered in its work. A religious education committee member should always serve on the task force.
- Make sure that parents and other interested adults regularly communicate with other committees and members of the congregation concerning the religious education philosophy of ministering to children, including children with special challenges. People new to the congregation need to be made aware of the church's commitment. After several years of a successful welcoming program, it is tempting to relax and believe that everyone is still behind the congregation's philosophy of ministry to children. However, with time or changes in leadership, you may discover that some people have forgotten the philosophy and that new members have never learned it. If a minister or a religious educator leaves, be sure that the staff search committee embraces the congregation's inclusive philosophy.
- Make sure the religious education committee is part of the budget process to advocate for what is necessary to minister to the congregation's children and youth. Even a congregation with a

strong commitment of ministry to children will need to be made aware of the costs of maintaining a successful program. Have religious education committee members and families who have children with disabilities be part of the canvassing process. Be as visible as possible in all aspects of congregational life.

Religious Education Mission Statement

A concise, well-written religious education mission statement that describes the congregation's ministry to children and youth in a positive and affirming way demonstrates to new and current families the value of children in the life of the church community. Periodically updating the mission statement as the church grows renews the church's commitment to its children and reassesses the religious education program in light of that growth. Use language that conveys the church's commitment to children with disabilities and congregational diversity while recognizing that we are all one.

Enlist the entire congregation in supporting the religious education mission statement in conjunction with the church's larger philosophy of ministry. The philosophy of ministry can be more controversial than a mission statement because it causes people to examine their faith beliefs, but it is valuable because it provides the underlying belief structure that makes the mission statement meaningful, livable, and effective. Include the mission statement in a religious education brochure that conveys to new and current families the church's philosophy of ministry to children and the programming that is offered.

Religious Education Registration and Gathering Information

The registration process should actively solicit information concerning disabilities. Some parents of special-needs children may not want to identify their child's disability, hoping to avoid labeling and perhaps creating a negative experience for the child.

However, the majority of parents are relieved to be part of a community that directly asks for such information. This immediately creates an atmosphere that says, “Yes, we welcome your child, and we will actively plan for the inclusion of your child in our ministry.” Those parents who are reluctant to share information will eventually feel comfortable doing so if they experience support for and affirmation of their child.

In talking and working with the parents of a special-needs child, our most important task is to gather information. The child’s age and level of independence will determine the type of accommodations needed. His or her parents can provide this information and help identify what changes need to be made in the religious education environment. Some children may need to be in a separate, structured program; some may need an aide; and some may be able to participate in the regular program.

It is also important to ask the parents for a contingency plan in case the agreed-upon approach is not working. This is to ensure the safety of their child as well as that of the other children. This strategy is crucial for such events as field trips and performances in front of the whole congregation.

Another way that ministers and religious educators can support parents is to partner with health and human service professionals in providing intervention services for the child with disabilities. For instance, the religious professionals can offer to meet with the child’s social worker or psychologist, and the parents can ask health and human service professionals to include church participation in the child’s overall treatment plan. This strategy will help tremendously in determining the most appropriate way to involve the child in the religious education program.

To be effective, religious education teachers need pertinent information about the behaviors and learning styles of the children who will be in their groups. Religious educators should discuss with the religious education committee how this information can be obtained. Familiarity with the special needs of each child in a group helps teachers plan successful sessions and successful

transitions between teachers. It also allows you to provide appropriate training and resources. Some training on how to handle discipline is a good idea.

Make Religious Education Less Like School

The emotional issues that surround the label *disabled* concern us as religious professionals and lay leaders. In our ministry to children, we do not want to perpetuate the difficulties with self-esteem and emotional problems that some children experience as a result of struggles in school. Many children with learning disabilities and other difficulties are ridiculed and verbally abused by teachers and peers. Although research demonstrates that most of these children are intelligent, we live in a culture in which intelligence is usually measured by how well a person reads and writes. Our attitudes and expectations can profoundly affect the feelings and behavior of our children.

Parents and children are often interested in a religious education program that has a structure different from that of school. Because certain language creates negative images for children, it might be wise to use different words—for example, *sessions* or *groups* instead of *classes*; *participants* instead of *students*; *ministry* or *program* instead of *school*. Freeing the church experience from images of school helps to create a safe space for children where they can discuss problems they may be having at school and convey that church is a place of understanding and healing.

Making the religious education program less like school does not mean providing no structure, however. Start the session with a gathering in which each child is welcomed by name. It is nice to open with the lighting of the chalice or another spiritual ritual that signals that this is the time for experiencing the sacred. Next, have the group review expectations of behavior that the children have helped develop and then begin the learning activities, which should engage a variety of learning styles. End the session with a closing ceremony that acknowledges the importance of saying

goodbye and helps the children make a transition out of the faith community. Blow out the chalice flame with a brief prayer or meditation, or quietly go around and speak personally with each child to share what he or she did during the session. The children should leave feeling that they are done for this Sunday and can take what they have learned and nurture it.

Some think that every curriculum should include an addendum that describes ideas and methods for the successful integration of special-needs children. What we really need, however, are ideas for training teachers so that they have the skills to use and adapt any curriculum according to particular needs. Sometimes, having a prepared lesson plan can save teachers who are too busy and overwhelmed to prepare properly for the Sunday session. Other times, a prepared curriculum can keep teachers thinking “inside the box” about how to lead activities. And still other times, a prepared curriculum can provide valuable ideas that will inspire teachers to be creative with the children. Less reliance on the school model of teaching, more experiential activities, and fewer cerebral, sedentary activities can create opportunities for everyday wonder or moments of transcendence that will help our children learn about what is sacred and meaningful in their lives.

The following strategies can make religious education less like school:

- *Mix age groups.* There is immense value in having different age groups interact and learn from each other. Offer several activities or learning centers around a theme, and allow children to choose which activity or center to engage in. Each learning center can include several appropriate activities for children of different ages or developmental stages. Mixing age groups also provides a wonderful way to integrate children with developmental disabilities without having to provide a separate program for them. Having older children mentor younger children can foster their self-esteem and make the younger children feel special.

- *Provide more experiential activities.* The maxim “Actions speak louder than words” certainly applies to teaching children.

We all know that children learn more about the problem of hunger when they help stock a food pantry or serve food at a homeless shelter than they do through discussion alone. If you are learning about other religions, such as Hinduism, engage the children in yoga, guided meditation, or appropriate celebration activities in honor of that religion. Interesting and spontaneous conversations usually occur when children are actively involved in a hands-on activity that is related to a theme. Experiential learning keeps them engaged, lessens their boredom, and helps those who have difficulty sitting still.

- *Engage children in storytelling instead of having them read out loud.* You can always assume that at least one child in your group struggles with reading. Asking for volunteers to read aloud causes anxiety for these children, who fear that everyone in the room knows their difficulty and thinks they are dumb because they never volunteer. Teachers should read or tell the story aloud and perhaps ask for volunteers to help act it out. Doing so encourages spontaneity and engages all the children in the activity, whether or not they are acting.

Another successful approach is to have the children tell a familiar story in their own words. Storytelling is a wonderful way to help them be co-creators in events that are meaningful to them. Some children who struggle in school find their own voice through storytelling. For children with special challenges, telling a story can be a nonthreatening, symbolic way for them to share their concerns and feelings. *Doorways to the Soul*, edited by Elisa Davy Pearmain, is a thoughtful collection of stories from spiritual and cultural traditions around the world and includes suggestions for activities, discussion, and moments of contemplation.¹

- *Provide visual cues.* Children who struggle with the written word or with processing verbal information benefit from having the session theme represented visually around the room with displays of words, pictures, and objects. These images remind them of the focus of the discussion or activity. Especially during a discussion, write key words on a flipchart as you are talking.

- *Be consistent and always explain what is coming next.* Some children with learning difficulties struggle with processing instructions and sequencing events. As a result, they can become easily confused if they expect one activity to occur and another happens instead. Try to be very clear about what is going to happen during the program. Always explain when one activity is ending and what will happen next, and allow for transitions between activities. Try to provide only one set of instructions at a time and keep them simple. If the instructions are too detailed, the children will be unable to remember everything they are supposed to do.

Know Your Class

For any educational setting, it is essential that teachers learn who the children are. This may sound basic, but overly busy volunteers who have agreed to teach (and especially new teachers) are often not briefed about the children before they begin. The religious educator can convey this information during teacher training sessions or at individual teacher meetings.

Physical limitations and cognitive delays, such as Down syndrome and autism, are often observable, but other disabilities may or may not be recognized, depending on whether the parents have disclosed this information and it has been shared with teachers. If the child has been in the religious education program for a while, special-needs conditions such as attention-deficit disorder, oppositional defiance behavior, anxiety and mood disorders, and epilepsy, may be apparent or the parents may inform the religious educator when they feel comfortable that their child is accepted. Always be prepared for children who are overly active or hyperactive, a normal occurrence in any group of children. Since learning disabilities often go undetected and all children, not only special-needs children, have different learning styles, it is always a good idea to teach to multiple learning styles. If you are having difficulty including a child, do not hesitate to approach his or her parents for help and ideas.

Create a Welcoming Environment

How we structure the environment can determine how well the program will go. Set up the room so that everyone is included. Make sure the space says, “You are welcome here.” If you are integrating children with physical disabilities, make sure the space looks like they belong there. For example, a child in a wheelchair should be able to get from one activity to the next without encountering obstacles. If all of the children are sitting on pillows on the floor for storytime, the child in the wheelchair may feel awkward sitting higher than everyone else. Discuss this with the child in the wheelchair and the other children so they can come up with solutions.

Sometimes, children with cognitive delays, multiple disabilities, or autism need an aide in order to function in the program. Ideally, an inclusive faith community arranges for volunteer aides from within the congregation, but hiring aides is another option. Teenage members of the congregation can serve as aides for younger children. The parents will need to explain to the aide what works best with their child.

Be sure to recruit enough people that coverage can always be provided and volunteers will not get burned out or feel guilty when they cannot be at church. If your congregation has committed to being an inclusive faith community for children with disabilities, finding aides will probably not be a problem. People will come forward in response to a request. A personal testimonial about how rewarding the job can be will help with recruitment.

Be sure all the children in the program understand the role of the aide, not only so they will feel comfortable with another person in the room but also so they will not try to divert the aide’s attention. The aide’s first responsibility is to the child with a disability. However, he or she should not be seen by the other children as a barrier to their getting to know that child. The aide can also act as a teacher’s assistant, as long as the teacher understands that the aide’s primary duty is to assist the child. Teachers should always give aides the plan for the day ahead of time. As the aides

get to know their assigned children, they may become valuable sources of information on how to maintain inclusive programs for them.

Separate Programs Are Usually Not a Good Idea

There are sometimes good reasons for involving special-needs children in parts of the church community other than the regular religious education program for their age group. For example, one congregation was struggling with how to include a girl with mental retardation in the Coming of Age group because she was having difficulty understanding and participating in the discussion activities. The director of religious education and the Coming of Age leader met with the girl and her parents and discovered that she loved being with very young children. So on Sunday mornings, she helped with the congregation's toddlers.

In this situation, it would also be important for the Coming of Age group to find other ways to include the girl so that she would feel connected with children her own age and have the opportunity to explore her own spirituality. Perhaps her work with the young children could be part of her Coming of Age program and she could participate in other Coming of Age activities that involve church trips or social justice work, such as serving meals to the homeless. She would also need to be included in the Coming of Age ceremony and offered a way to share her work and spiritual feelings with the congregation. If she is unable or unwilling to speak, she could use artwork or another visual display to communicate.

As Herbert Lovett, an expert on mental retardation, says,

We are slowly recognizing the need for people with disabilities to connect in socially ordinary ways. We have been less astute, I think, in recognizing that we also need to allow people to reconnect with themselves, with their own sense of accomplishment and dignity. At the moment, we are not doing this very well, especially for people with difficult behavior.²

The same could be said of people with *different* behavior.

Teaching the Anxious Child

All children, not just those with anxiety disorders, experience anxiety sometimes. Within a given group, the teacher will know who is excessively shy, who is afraid to try new activities or go on field trips, who has great difficulty separating from his or her parents, who has certain routines that seem very important, and who has difficulty attempting new ways of looking at problems. Many children gain strength and resilience from overcoming their fears, but others never do.

Children with all types of disabilities are especially susceptible to high levels of anxiety because of how people react to them and what they expect of them. Therefore, understanding techniques for coping with an anxious or fearful child will be helpful for teaching all children but especially those with special needs. Many of these techniques are adaptable for the religious education program and can benefit our ministry to all children:

- *Establish clear expectations, predictability, and security.* Children must know that they are absolutely safe in our programs. Feeling safe includes knowing that they will not be belittled for strange behaviors or have their fears dismissed or denied. Teachers need to be very clear about expectations and provide plenty of warning about changes in the program.

- *Develop opportunities and activities for creative problem solving.* All children benefit from activities that encourage flexible, creative, “outside the box” thinking to solve problems. Creative problem solving is an important skill to be able to access during times of stress.

- *Create ways for children to connect with others.* In *Your Anxious Child*, John Dacey and Lisa Fiore suggest that we help children develop a “bank of goodwill” through helping others.³ Developing a sense of connection and compassion is an essential part of the healing process.

- *Provide ways to foster self-esteem.* Children with high anxiety have low self-esteem because they worry so much that they cannot

trust themselves to handle new situations or the situations that they fear.

- *Include visualization and guided meditations.* Teach children how to use their vivid imaginations in healthy ways. Teaching guided meditation, in which they imagine being in a beautiful, calming place, will help them learn how to replace anxious thoughts with calming thoughts.

- *Include prayer and meditation.* Fostering children's sense of a higher power and ways to connect with that higher power provides them with a source of strength and healing.

- *Model positive self-talk.* Teachers can constantly provide positive self-talk and feedback to the children and suggest positive words that children can use to replace the negative, self-defeating words they use in moments of high anxiety.

- *Provide joyful music.* It is difficult to feel fear when singing a joyful song.

Teaching Difficult or Disruptive Children

Many children, not only those who have been labeled *difficult*, sometimes display overactive or disruptive behavior. Therefore, it is important that all religious education teachers acquire the skills necessary to work with disruptive behavior.

The child who is out of control or just being difficult can be frightening to both the teachers and the other children. Teachers may feel they are failing and that everything will end up in chaos if they do not control the situation. Some volunteer teachers easily panic because they do not have the training and experience to deal with difficult behavior. Some people avoid volunteering precisely because of their fear of handling such situations.

Yet some people always seem able to handle children who are being disruptive. Without discounting experience and adequate preparation, the attitude of the teacher seems to be the critical

factor for a successful experience. When the teacher is able to empathize and connect with the child who is being disruptive, he or she is better able to look at what changes can be made in the environment and the teaching style in order to direct the behavior of the child to become more positive.

Children who constantly act out are usually performing behaviors that they have learned will protect their dignity. Although their coping activities may be destructive, their behaviors are intended to maintain the last remnants of their self-esteem. In his books *The Self Esteem Teacher* and *Raising Resilient Children* (with Sam Goldstein), Dr. Robert Brooks emphasizes the idea of finding an “island of competence,” or a source of strength, in each child.⁴ Identifying that “island” or source gives us a technique for focusing on the positive and frees us to see the whole child instead of his or her limitations and disabilities. When we focus on fostering strength, hope, and resilience in our children, we can counter negative behavior and not give in to trying to control it.

We usually try to control children who are acting out with negative reinforcement, rather than figure out the reasons for their misbehavior. In *Learning to Listen*, Lovett emphasizes the importance of listening to people’s stories instead of making assumptions for treatment based solely on their behavior.⁵ We rarely listen to children who have been labeled *disruptive*; however, there is always a reason for disruptive behavior. After a disruptive episode is over, take time to listen to the child before it happens again.

Learning to empathize with a child who is acting out, to build on his or her strengths, and then to adapt the teaching style and the environment in order to change negative behavior does not mean ignoring expectations, rules, and consequences. According to Brooks, “We should never lose sight of the fact that when we discipline, we are involved in a process of education. Our goal is to assist students to become more thoughtful, responsible, and accountable and in the process to foster self-esteem.”⁶

Dr. Richard Lavoie, an expert on learning disabilities, has developed a behavior management plan for teaching children who

display disruptive behavior. The following behavior management ideas for religious education teachers have been adapted from Lavoie's program guide to the video *When the Chips Are Down*.⁷ In order for the recommended teaching strategies to be effective with disruptive children, teachers must develop positive attitudes about the difficult children they are teaching. Lavoie calls this a *positive supports philosophy*:

- *Teacher expectations make a difference.* Unfortunately, if we are told that a child in our program has oppositional defiant disorder, that will determine the behavior we will expect. Likewise, if we are told we have a child with autism in our program, then we will expect strange and isolating behavior. There is a difference between knowing a child has difficulties and expecting behaviors based on his or her perceived limitations and being prepared for a child who struggles and expecting the best from him or her. Studies have shown how children respond to teacher expectations. In one study, teachers were told that they were getting a class of exceptional students, when in fact, the students were low achievers and considered failures. During the year, the class performed extremely well, just like the high-achieving students they were believed to be.

- *A child would rather be viewed as bad than dumb.* Most children, especially adolescents, would prefer to be viewed as disruptive, disobedient, or disrespectful rather than incompetent or incapable. Children with disabilities are routinely seen as incompetent and incapable. Be aware of creating any circumstance in which a child will appear stupid in front of his or her peers. That child may automatically become disruptive and prefer to deal with the teacher's anger rather than feel humiliated in front of his or her peers.

- *Children with difficult behavior are distinguished by their regrettable ability to elicit from others exactly the opposite of what they need.* Often, the child who is most disruptive is the one who most needs compassion, empathy, and love. His or her disruptive behavior may be the only way he or she knows to get attention.

- *The hurt that troubled children and youth cause is never greater than the pain they feel.* Lavoie's words convey this idea best:

Children who are experiencing trouble at home or at school often feel powerless and hurt. Their response to these feelings is often inappropriate. . . . They become disruptive and disrespectful. The parent and professional must remain mindful that this behavior is rooted in the pain of rejection, isolation, and fear that they are experiencing. Therefore, the most effective strategy is to attempt to eliminate the causes of these feelings . . . not to attempt to simply modify the behavior.⁸

- *There is nothing more unequal than the equal treatment of unequals.* We know that to be fair to all of our children, we must treat each child differently. Recognizing their different strengths, abilities, and needs, we can respond accordingly. At times, the child with special needs will require more of our time, attention, and resources; providing those things does not mean that we are being unfair to the other children. For example, it is not fair to set up a situation in which the children who behave appropriately (the ones who usually receive positive attention) can go on a church outing, while those children who are trying very hard but still struggle with appropriate behavior are excluded.

The following techniques for encouraging positive behaviors are more effective if used with the positive support philosophy:

- *Request desired behaviors rather than focusing on undesirable behaviors.* For example, saying "Please put the book on the shelf" is more effective than "Stop throwing the book." Also, make observations instead of issuing commands. Rather than constantly telling kids to hang up their coats, listen to their grumbles and complaints and then say, "There are coats lying on the floor!" They will usually laugh and pick them up. Most importantly, label the behavior, not the child. It is more effective to say "It's distracting when you bang your foot on the table" than "You are annoying."

- *Use positive reinforcement instead of relying only on punishment.* Adults often dole out punishment without ever asking the

person why an incident happened or listening to the child's explanation. Children need to be praised, rewarded, and reinforced for appropriate behaviors. Be generous but specific with your praise. "Joan, you did a terrific job cleaning up after making chalices today" works better than "Joan, you are a good girl."

- *Providing indirect praise for desired behaviors can be effective.* Praise a child's behaviors to another adult, knowing that the child is nearby and can hear you. For example, for a child who has had difficulty getting along with the other children, one teacher can say to another, "Did you notice that Sam helped Miranda tie the string on her name tag? He is getting to be so helpful."

- *Reward direction, not perfection.* As Lavoie says,

It is important to remain mindful of the concept of successive approximations. Reflect for a moment upon the way in which a child learns his native language. The adults in the child's environment continually reinforce, praise, recognize, and reward every new word that is uttered! This encouragement causes the child's vocabulary to increase and grammar to improve. We do not wait until the child is fluent in language before we reinforce the progress. . . . We acknowledge every little step in the process. This concept is equally necessary and effective when we are attempting to change a child's behavior.⁹

- *Be generous with your attention.* A child who is being disruptive is seeking attention. "You can ignore the behavior . . . but you cannot ignore the need."¹⁰

- *Do not compare one child's behavior with that of others.* An individual child can control only his or her own behavior, so focus on how that behavior can be improved.

- *Listen to their stories.* Children who are troubled have the need to tell people who they are and what they are feeling. If we listen carefully, nonjudgmentally, and sincerely, we can often learn about these children's strengths and their unique ways of looking

at the world. They often have much to teach us. Because it may be difficult to listen so intently during the Sunday morning program, religious educators and, if appropriate, teachers can arrange for a meeting at another time, when they can give all their attention to the children who need it. This will go a long way toward establishing support and trust. It will also do wonders for children's self-esteem when they realize we trust them to help figure out what is best for them in our programs.

- *Find each child's "island of competence."* Find out what the child likes to do and feels good about, and then figure out a way to incorporate that into the church setting. For example, if the child likes to grow plants, give him or her the responsibility of watering and taking care of the plants in the church. This will be even more effective if you give him or her the official title of "Caretaker of the Plants" and let the entire congregation know about it.

- *Develop a proactive, positive behavior support plan with the group.* Have the children help you create a group list of standards or expectations of behavior. Make sure all the standards or expectations are stated positively—for example, "Listen while someone else is talking," "Only one person talks at a time," "Comments should always be positive," and "Everyone's opinion is respected." Then, make sure that these standards are enforced equally for all children. Repeat the standards of behavior at the beginning of each session, and provide constant reminders of what is expected. Have the children volunteer to say the various standards.

When a behavioral problem does occur, try the following to defuse the situation:

- *Use guided meditation to calm down an overactive group or end a session.* Guided meditation works well with almost all children and especially with hyperactive children. Be sure to darken the room and ask the children to get comfortable, whether lying on the floor, leaning against the wall, or sitting in a chair. Guided meditation engages the children's imagination while helping them

quiet themselves and connect with their inner knowing. Be sure to speak slowly and pause frequently to allow the children to do their own visioning. Maureen Garth has written a series of books containing guided meditations and visualizations with children that can be used or adapted for religious education settings. A guided meditation can be created for almost any theme or subject.

- *Use distraction to head off unwanted behaviors.* If a child begins to be disruptive, ask him or her to do something else, such as get out the supplies for the art activity. Tell the group something about what he or she is going to do after church. Take his or her mind off being disruptive.

- *Change your proximity to the child who is being disruptive.* Often, troubling behavior will stop when you move closer to the misbehaving child. Once, while I was doing a guided meditation with some eleven-year-old children, one girl started giggling uncontrollably, which started a ripple effect of giggling among the other children. I continued my meditation, quietly moved closer to her, and gently put my hand on her back. The giggling stopped immediately.

- *Limit the number of questions children can ask.* If a child chronically asks inappropriate questions, tell him or her that only three more questions will be allowed and then remind him or her. For example, “Harold you only have two more questions. Is this question important?” Then let the child make the decision as to whether to continue with the question. In discussion circles, you can also give each child a certain number of cards. When a child speaks, he or she turns in a card. This way, each child has a tangible way of knowing how many times he or she has left to talk. This also works well in making sure that no one child dominates the conversation.

- *Get the attention of overly noisy children.* Use these three techniques: (1) Turn out the lights. If this custom is established as a time to get quiet, it will be effective for stopping unwanted behaviors. (2) Clap your hands three times and say, “If you can hear me, clap your hands.” Repeat the phrase and clap your hands three

times, stopping in between, until everyone is clapping with you and no one is talking. (3) Tell all the children to close their eyes. This will quiet them instantly.

- *Get the children to commit to the behaviors you want.* Suppose that after the chalice has been blown out and the session has ended, one child, Rachel, always jumps up and runs at top speed to the door and out into the corridor. Instead of saying “Rachel, I want you to walk to the door today” at the beginning of the session, try asking before the final activity “Rachel, are you going to walk or run to the door today?” This will put the responsibility for the behavior on the child. More often than not, the child will choose the desired behavior. Then you can respond with praise.

- *Pray or meditate for your children.* For the child who pushes all your buttons and remains a constant challenge, try praying or meditating for him or her before each Sunday morning. It is more difficult to see the child’s negative behaviors as purposeful when you are holding him or her in a loving prayer or image. It is also helpful each Sunday morning to reaffirm our Unitarian Universalist Principle regarding the inherent worth and dignity of every person.

Teaching to Different Ways of Learning and Knowing

In *A Mind at a Time*, Mel Levine writes,

It’s taken for granted in adult society that we cannot all be generalists skilled in every area of learning and mastery. Nevertheless, we apply tremendous pressure on our children to be good at everything. Every day they are expected to shine in math, reading, writing, speaking, spelling, memorization, comprehension, problem solving, socialization, athletics, and following verbal directions. Few if any children can master all of these “trades.” And none of us adults can. In one way or another, all minds have their specialties and their frailties.¹¹

It is important to take into account the different ways of learning and knowing that all our children have. It is also important to remember that we do not expect *adults* to be perfect or even competent at everything. Ministering to children with special challenges is often the catalyst for more inclusive programming and more creative teaching.

In our Western culture, if you ask someone to name a very intelligent person, he or she will generally name someone who has a high IQ. Given the nature of IQ tests, someone who has a high IQ is very good at language and/or math. Yet according to the *New World Dictionary*, the definition of *intelligence* is “the ability to learn or understand from experience; use of the faculty of reasoning to solve problems.” Interestingly, research has shown that while IQ tests consistently predict school success, they fail to predict how individuals will do once they are out of school. One study of highly successful professional people indicated that fully one-third of them had low IQ scores.

Howard Gardner, Hobbs Professor of Cognition and Education at Harvard Graduate School of Education, has devoted years to the study of the nature of intelligence. He believes that our society has focused too much attention on the verbal and logical types of intelligence and neglected the many other types of intelligence, which involve a broader range of skills and ways of successfully interacting with the world. In his 1983 book *Frames of Mind: The Theory of Multiple Intelligences*, Gardner proposes that intelligence is not a quantifiable entity that can be summed up by an IQ score but that there are multiple intelligences worthy of being considered important modes of thought.¹² Gardner has now identified eight intelligences, one more than in his original published work (see pages 47–48).

Gardner’s eight intelligences do not operate in isolation but work together, with some dominating others. People use combinations of the different intelligences, and those combinations make each of us unique. Sally Grimes, an educational consultant with a specialization in learning disorders, states that the more fully

Overview of Multiple Intelligences

- *Verbal/linguistic intelligence* allows individuals to communicate and make sense of the world through language. Poets exemplify this intelligence in its mature form. Students who enjoy playing with rhymes, who pun, who always have a story to tell, who quickly acquire other languages (including sign language) all exhibit linguistic intelligence. Amy Tan, Alice Walker, and Will Rogers are good examples of this intelligence.

- *Musical/rhythmic intelligence* allows people to create, communicate, and understand the meanings of sounds. While composers and instrumentalists clearly exhibit this intelligence, so do the students who seem particularly attracted by the birds singing outside the classroom window or who constantly tap out intricate rhythms on the desk with their pencils. YoYo Ma, Ravi Shankhar, and Leontyne Price are good examples of this intelligence.

- *Logical/mathematical intelligence* enables individuals to use and appreciate abstract relations. Scientists, mathematicians, and philosophers all rely on this intelligence. So do the students who are engrossed in sports statistics or who carefully analyze the components of problems (either personal or academic) before systematically testing solutions. Albert Einstein, Madame Curie, George Washington Carver, and Henri Poincaré are good examples of this intelligence.

- *Visual/spatial intelligence* makes it possible for people to perceive visual and spatial information, to interpret this information, and to recreate visual images from memory. Architects, sculptors, and engineers need a well-developed spatial capacity. The students who turn first to the graphs, charts, and pictures in their textbooks, who like to sketch a map or web of their ideas before writing a paper, and who fill the blank space around their notes with intricate patterns are also using their spatial intelligence. While it is usually tied to the visual modality, spatial intelligence can also be exercised to a high level by individuals who are visually impaired. Nikola Tesla, Frank Lloyd Wright, Maya Ying Lin, and Georgia O’Keeffe are good examples of this intelligence.

- *Bodily-kinesthetic intelligence* allows individuals to use all or part of the body to create products or solve problems. Athletes, surgeons, dancers, choreographers, and craftspeople all use bodily-kinesthetic intelligence. This capacity is also evident in students who relish gym class and school dances, who prefer to make models rather than write reports, and who toss crumpled papers with frequency and accuracy into a wastebasket across the room. Michelle Kwan, Alvin Ailey, and Tiger Woods are good examples of this intelligence.

- *Interpersonal intelligence* enables individuals to recognize and make distinctions about others' feelings and intentions. Teachers, parents, politicians, psychologists, and salespeople all rely on interpersonal intelligence. Students exhibit this intelligence when they thrive on small-group work, when they notice and react to the moods of friends and classmates, and when they tactfully convince the teacher of their need for extra time to complete a homework assignment. Mahatma Gandhi, Martin Luther King Jr., Chief Joseph of the Nez Perce, Fanny Lou Hamer, and Bill Cosby are good examples of this intelligence.

- *Intrapersonal intelligence* helps individuals to distinguish among their own feelings, to build accurate mental models of themselves, and to draw on these models to make decisions about their lives. Although it is difficult to assess who has this capacity and to what degree, evidence can be found in how students use the other intelligences—that is, how well they capitalize on their strengths, how cognizant they are of their weaknesses, and how thoughtful they are about the decisions and choices they make. Maya Angelou, Mary Oliver, and Carl Jung are good examples of this intelligence.

- *Naturalist intelligence* allows people to distinguish among, classify, and use features of the environment. Farmers, gardeners, botanists, geologists, florists, and archaeologists all exhibit this intelligence, as do students who can name and describe the features of every make of car around them. Rachel Carson, Jacques Costeau, and Jane Goodall are good examples of this intelligence.¹³

developed intelligences can support the less developed ones. “Students with dyslexia, for example, may have strong spatial or bodily-kinesthetic intelligences which can be tapped to enhance the weaker linguistic intelligence.” She thinks that many good teachers have instinctively used aspects of multiple intelligence theory for years.

Project Zero is an educational research group at the Harvard Graduate School of Education that has continued to explore Gardner’s theory of multiple intelligences. The Project of Schools Using Multiple Intelligences Theory (SUMIT) has studied schools that use multiple intelligences theory in their teaching and reported these outcomes: improved test scores, improved discipline, improved parent participation, and improved teaching of students with learning disabilities.

How can we translate all this information into the religious education setting and convey it effectively to our volunteer teachers without burdensome and extensive training? As Unitarian Universalist religious educators, we have the freedom in our programs to challenge the traditional language-based approach to teaching. Our ministry is to appreciate and encourage the differences and creativity in all children. Putting the multiple intelligence theory into practice in our religious education programs is one way to honor, appreciate, and teach to the many different ways that children learn.

Another way is to invite teachers to assess their own strengths and weaknesses. In *Seven Kinds of Smart*, Thomas Armstrong presents an easy questionnaire for assessing strengths and weaknesses according to the different intelligences.¹⁴ Once teachers understand themselves, they begin to identify how they learn best. With this awareness, they can more easily understand some of the basic strategies for teaching to each intelligence. Teachers do not have to use all eight intelligences in every session, but they can look for opportunities, depending on the subject matter. Teachers can also use more than one intelligence each session to make sure to involve as many children as possible.

The following strategies provide easy ways to decide which intelligence to use for which lesson in a given subject area. They have been adapted from Sally Grimes's workshop materials:

- Using *verbal/linguistic intelligence* involves reading, writing, talking, and listening. Group teaching activities could include public speaking, playing word games, keeping a journal, reading, storytelling, tape recording oral language, writing poetry or stories, and writing a youth newsletter for the church. Suggested materials are books, books on tape, computers, paper and pencils, blank journals, and a tape recorder.

- Using *visual/spatial intelligence* involves seeing, drawing, visualizing, and mapping. Group teaching activities could include doing guided meditation; creating charts, diagrams, and maps; taking photographs; completing visual puzzles and mazes; and painting, drawing, collage, sculpting, pottery, three-dimensional construction, and other visual art. Suggested materials are art supplies, blocks, Lego sets, puzzles, cameras, pictures, and recyclable materials for building.

- Using *musical/rhythmic intelligence* involves singing, playing instruments, beating rhythms, and listening. Group teaching activities could include playing live music on different instruments; singing, humming, chanting, rapping, and whistling; playing recorded music; playing percussion instruments; linking songs with concepts; meditating to music; creating art from musical imagery; and making musical instruments from different cultures. Suggested materials are a tape recorder, a CD player, hymnals and songbooks, and musical instruments, including those from different cultures, such as rain sticks and percussion instruments.

- Using *interpersonal intelligence* involves teaching, collaborating, interacting, respecting, and acting. Group teaching activities could include peer teaching, mediating conflicts, interpersonal interaction, peer sharing, getting involved in the community, engaging in social justice activities or service projects, people sculpting, playing cooperative games, holding group discussions, and role-playing, performing plays, and other dramatic activities.

Suggested materials are props for cooperative games and dramatic activities. This intelligence requires fewer tangible materials but more interpersonal interaction.

- Using *intrapersonal intelligence* involves sensitivity to one's own moods and feelings, knowing one's own strengths and weaknesses, and using that self-knowledge to guide decision making and goal setting. Group teaching activities could include keeping a journal, goal-setting sessions, engaging in self-esteem games and discussions, understanding one's self and others through a personality or self-assessment test (such as the Myers Briggs), doing guided meditation, and walking the labyrinth. Suggested materials are journals, introspective games, meditations, and a labyrinth.

- Using *logical/mathematical intelligence* involves quantifying, classifying, thinking critically, reasoning, and conceptualizing. Group teaching activities could include completing logical problem-solving exercises, doing logic puzzles and games, organizing a logical/sequential presentation of subject matter, and doing quantifications and calculations. Suggested materials are calculators, Legos and blocks, and word and math puzzles.

- Using *bodily-kinesthetic intelligence* involves building, acting, touching, dancing, and doing physical exercise. Group teaching activities could include performing creative movement; taking field trips; doing mime and dramas/plays; doing crafts, cooking, and gardening; using body language and hand signals to communicate; doing physical relaxation exercises and physical awareness exercises (such as yoga); and playing cooperative games. Suggested materials are building tools, clay, manipulatives, and sports equipment.

- Using the *naturalist intelligence* involves classifying, touching, connecting, observing, and planting. Group teaching activities could include planting house plants or seeds, planting or tending a church garden, starting a compost bin, making a collage of the earth and all that lives on it, engaging in an outside cleaning project, and studying rocks, plants, trees, and animals. Suggested materials are gardening tools, seeds, plants, art materials, and books on nature.

Once teachers have a general understanding of the theory of multiple intelligences, they can adapt the curricula to use the strategies suggested here. Doing so may inspire more creativity and free teachers from the need to follow a curriculum exactly as written. Hopefully, teachers will feel encouraged to use their own strengths (preferred ways of learning) and have a more enjoyable teaching experience. Teachers should also be aware of children's preferred ways of learning, so they can plan to those strengths.

Many learning activities cross the different intelligences. For example, planting a garden is naturalist and bodily-kinesthetic and could also be an interpersonal (cooperation) and intrapersonal (personal connection with nature) activity. Therefore, with one activity, a teacher can teach to the strengths of many children and accommodate many different special needs. Jean Hackett, former co-chair of the Religious Education Committee at the First Unitarian Universalist Church in San Antonio, Texas, describes her experience with teachers' creatively adapting curricula to encompass many types of learning styles:

We have a class of third- and fourth-grade children which contains several children with [attention-deficit disorder]. After a year of trying different approaches, this has become one of the most enjoyable and innovative classes in our program. We've come to see these kids as capable of doing anything except sitting still for long periods of time. So we modify the curricula to include visual, kinesthetic, and musical approaches. We use excerpts from videos and recordings. We bring lots of picture books related to the lessons to pass around during times when we have to explain things or provide instructions.

Learning Centers

Many Unitarian Universalist religious education programs use a *learning centers model*, which is a good vehicle for using multiple intelligences theory. Setting up different learning centers for each

session does require preparation time and effort, and busy teachers may need support to implement this model in their groups. Nevertheless, many congregations have had success with learning centers. Smaller churches seem to use learning centers particularly well because they combine age groups by necessity.

The following is a description of the planning process and the programs for the initial multiple intelligences program at Winchester Unitarian Society in Massachusetts. A Multiple Intelligences Committee was formed with the charge to plan three Multiple Intelligences Sundays. The first task was to choose a theme. We decided to take advantage of the Unitarian Universalist initiative concerning “responsible consumption as a moral imperative,” which would also encompass the Principle of the interdependent web of life. We called our program Planet Keepers 2000.

Once we had the theme, the creative ideas started flowing. We discussed each intelligence and identified people whose strengths encompassed that intelligence. We brainstormed activity ideas for each intelligence, set a schedule for recruiting, and set a date for a planning meeting with the teachers. In an effort to eliminate any feeling of school, we decided to call the classes *studios* and the teachers *guides*. In addition, we decided to evaluate the three Sundays so that we would have information to plan future multiple intelligences programs.

Recruitment was easy. Not only were people excited about the ideas, but they loved knowing that they would be teaching with their strengths, that they had to commit to only three Sundays, and that they were free to be as creative as they wanted in an area in which they felt comfortable. At the planning meeting, we talked about multiple intelligences and asked whether the recruits agreed with our assessment of their strengths. (They all did.) We discussed the activities that would occur in each studio. Each was assigned two or more guides, with one guide taking the lead. We also promised to assign one teen aide to help in each studio. The studio guides already had wonderful ideas, so the planning meeting was spent refining their suggestions, answering questions, identifying resources, and reviewing the studio day schedule. The

third Sunday was planned as a spiritual service and a time for all the children to share with each other their experiences in the various studios. Displays would be set up and shared with parents during the coffee hour after the service.

Two weeks before the first Sunday, we sent a letter about Planet Keepers and multiple intelligences theory to everyone in the congregation. We urged parents to discuss with their children which studio they wanted to attend and to fill out a pre-evaluation form together. At the end of the program, we would ask them to fill out a final evaluation. On the first Planet Keepers Sunday, members of the Religious Education Committee were available to advise and guide children as they selected studios. If one studio was very popular and reached capacity, we made a list of the children who would have first choice of the studio the following Sunday. The second Sunday, children were encouraged to attend a different studio.

The project was a big hit. About eighty children attended each Sunday. Children were calling each other ahead of time to find out which studio they were planning to attend. Parents reported that their children were very enthusiastic. Many children did not want the sessions to stop when time was up. Most of the sessions did not even break for a snack, and the children never noticed because they were so engaged. The third Sunday, the children loved sharing what they had done with each other and participating in some studio activities together as a group. They enjoyed showing their parents their displays, which were most impressive.

The multiple intelligences structure allowed the guides to be enormously creative and enthusiastic, and their energy was immediately felt by the children and their parents. The evaluation forms, as well as verbal comments, testified to the success of the idea and indicated that people wanted to do it next year but for a longer period of time.

Given this completely positive feedback, the Religious Education Committee decided to commit an entire unit to a multiple intelligences program, this time on the theme of all the Unitarian

Universalist Principles. Eight Sundays were devoted to the Principles Pilgrimage multiple intelligences program. We matched an intelligence with each of our seven principles. Then we organized the Sundays so that each child could choose from four studios for the first three Sundays and then choose from four different studios for the next three Sundays. The children were encouraged to go to as many studios as possible to collect a bead for each Principle they learned about. The children who chose to stay all three Sundays in the same studio could still learn about all of the Principles and get their beads. (See pages 57–58 for a program description that can be sent to the parents and children so they can choose the studios they want to attend.) At the end of the program, we had all the children gather to share what they had learned and to create displays for adult viewing and celebration.

What makes this a successful model is that it easily creates a fun but structured environment in which children are taught to their strengths. When children who are sometimes disruptive are able to choose their learning style, they become more easily engaged and less likely to be disruptive. Some children were curious and tried new activities, while others felt safe and relieved to be repeating familiar activities. The program easily met most children's needs without requiring teachers to plan for individual children. It also created enthusiasm among our fifth- and sixth-graders, which is not always an easy task, and among the teachers, who were excited to be as creative as they wanted to be in an area they felt very comfortable teaching. While some structure was provided, there was no curriculum to follow.

A note of caution is in order, however: After the first multiple intelligences program, we discovered that the parent of two boys within the autism spectrum deliberately kept her sons home for the three Sundays. She felt that the unpredictability of the Sunday morning sessions would be detrimental to her children. Structure and routine were important for their participation, and they needed to be able to go to the same room each Sunday. Choosing where to go each Sunday was too confusing and frightening for

them. Keeping this in mind for the following multiple intelligences programs, we created one studio that stayed the same. We encouraged children who needed predictability and structure to attend this studio. This plan seemed to work well.

Each year that we did a multiple intelligences program, we learned more about what works and applied those lessons to the next year's program. Other influences on our planning included the new theme that was chosen and what else was happening in the church. Flexibility is definitely one of the strengths of the multiple intelligences program. It can be adapted to fit a congregation's particular needs.

Spirit Play

Spirit play is an adaptation of Jerome Berryman's *Godly Play*, a Christian education curriculum based on the Montessori method of teaching children.¹⁵ The structure of this program works well for some special-needs children. Berryman believes that children need to learn how to wonder in religious education and must be able to work together in order to learn the values of respect and love. Moreover, he believes that children need to be able to choose their play so they can return again and again to the images that help them work through their concerns. He writes,

Children can sense wonder is in the air when the storyteller wonders and is involved in discovering new and fundamental things about life, and the children begin to play. Play is the way children learn how to do things, from the use of language to opening and closing doors. They will also play the ultimate game of knowing when they sense that they are in a safe place and have the appropriate tools and both the competence and permission to use them."¹⁶

The basic structure of spirit play is as follows. All of the children line up at the door to the room. A doorkeeper then reminds the children that they are about to enter a sacred space and asks each child before he or she enters, "Are you ready?" When the child

Follow the Principles Pilgrimage

Collect a bead for each Principle, and make your own special keepsake.

Children's Chapel: Introduction to Multiple Intelligences

- *Principle 1: The inherent worth and dignity of every person*

Principles Pilgrimage Studios—First Half

STUDIO ONE: “It’s Not Fair,” with [names of guides] and friends

- *Principle 2: Justice, equity, and compassion in human relations*

Tired of hearing and saying that phrase? Want to live in a perfect world? What would it look like, feel like? How would people treat each other in your perfect world or utopia? Act it out, talk it out, play it out in this studio. (Parents: This is interpersonal.)

STUDIO TWO: “We’re All Amazing People,” with [names of guides] and friends

- *Principle 3: Acceptance of one another and encouragement to spiritual growth in our congregations*

It’s easy to get lost looking for ourselves, our friends, and others. We’re going to build an amazing maze with mirrors and pictures of ourselves and puzzles and then reflect on what we find and how we grow. (Parents: This is visual/spatial.)

STUDIO THREE: “Altered States,” with [names of guides] and friends

- *Principle 4: A free and responsible search for truth and meaning*

Sometimes, we need a special place to be by ourselves and think about what is important and what are our deepest wishes and dreams. We will build sacred spaces or altars that reflect what is important in our lives to help us focus on our deepest desires. (Parents: This is intrapersonal.)

STUDIO FOUR: “Boomwhackers,” with [names of guides] and friends

This studio will focus on all seven Principles, with emphasis on the first four during the first half. You can come once to this studio or stay here for three Sundays.

We will create a chant performance with boomwhackers and will use American spirituals and Native American chants that inspire and support our UU Principles. *Boomwhackers* are colorful, tuned tubes that make a myriad of wonderful sounds. (Parents: This is musical/rhythmic.)

Principles Pilgrimage Studios—Second Half

STUDIO FIVE: “Feed Yourself, Feed Us All,” with [names of guides] and friends

- *Principle 5: The right of conscience and the use of the democratic process within our congregations and in society at large*

With your help, we’ll eat well today. Together, we’ll decide what to make, how to make it—and who gets to eat it! We’ll see how much good food you can make and how much it costs. (Parents: This is logical/mathematical.)

STUDIO SIX: “Without Words,” with [names of guides] and friends

- *Principle 6: The goal of world community with peace, liberty, and justice for all*

What if we had no words? How would we express our feelings and thoughts? Let’s find out in this studio, where we will use our bodies to express the ideas of peace, justice, and freedom for all people on Earth. We will use movement, mime, and sign language too. This is a great workshop if you like to move and want to experiment with not using your voice. (Parents: This is bodily/kinesthetic.)

STUDIO SEVEN: “What’s Manure Got to Do with It?” with [names of guides] and friends

- *Principle 7: Respect for the interdependent web of all existence of which we are part*

What is the web of life? How are we all connected to the earth? What difference does it make? Come create a three-dimensional representation of the circle of life using lots of natural stuff and lots of hands-on fun. (Parents: This is naturalist.)

STUDIO EIGHT: “With Words,” with [names of guides] and friends

This studio will focus on all seven Principles, with an emphasis on the last three. You can come once to this studio or stay here for three Sundays. Do you want to be a writer, a reporter, or a radio announcer? We will create and record a newscast that describes, talks about, tells a story, sings, and informs others about our UU Principles. (Parents: This is verbal/linguistic.)

is ready, he or she enters and sits in a circle on the floor around the teacher. In a calm, quiet voice, the teacher tells a story or a parable from one of the cultural or religious traditions. While telling the story, the teacher uses manipulative play objects to help the children visualize the story.

At the end of the story, the teacher poses many wondering questions about what happened in the story. Then one by one, the children are asked what they would like to do and the teacher helps them make a choice. The room is set up with various stations containing manipulatives for acting out the story, including paints, clay, blocks, sand, dolls, and books. Many children choose to work together; some choose to work by themselves. With constructive guidance from the teacher, children may wander from one activity to the next. The teacher serves as more of a guide than a teacher, quietly interacting with the children, asking questions about what they are doing to act out the story, and listening to their insights.

At the end of the session, the chalice is lighted and there is a snack in celebration of the story and what each child has learned. Then the children are quietly dismissed as their parents come to pick them up.

Many children with special challenges do well in this structure. The atmosphere and environment of the room are designed to encourage respect and quiet play. Most overly active children respond well to this environment. Some children may need extra support; assigning teen aides to these children usually works well.

Other strengths of the spirit play method are:

- It encompasses many learning styles and allows children to learn in the way that is most comfortable for them while engaging them in play.
- It provides structure and predictability each Sunday, so the children always know what to expect. This gives them a feeling of safeness and support. Yet there is enough flexibility and freedom within the structure to allow the children to explore and follow their own inner knowing.

- It treats church as a place for wonder and the sacred. Children immediately feel the difference between church and school and know that church is the place where they can explore their own sense of wonder and work through the difficulties they may be experiencing in life.
- Through storytelling, children learn to be co-creators of their own existence.
- Once trained, the teachers do not have to prepare a lot before each session. They do need to learn the story well.
- The teachers enjoy themselves, rarely feel stressed, and volunteer to continue teaching.

The spirit play curriculum poses some challenges as well:

- The religious educator will need to be trained in the method, either from Jerome Berryman's organization or from Unitarian Universalist trainers.
- Once the religious educator has been trained, he or she will need to train the teachers.
- It takes time to make and prepare the play materials and manipulatives for the stories and the play stations.
- The room needs to be arranged by stations, which may require building shelves and dividers. This arrangement may not be possible if the religious education space is shared or rented.
- Some expense is involved in the curriculum, the training, and the materials.

Despite these challenges, the rewards of spirit play are many. The parents are very appreciative of this program, and the children enjoy themselves as they foster their sense of wonder. (To learn more about Godly Play and how to receive training, visit www.godlyplay.net or call 1-800-445-4390.)

Teacher Training

Most religious educators have wonderful ideas and activities for teacher training, and many resources are available on this subject as well. You should assess your teachers' knowledge and skills concerning ministry to children with special needs in order to determine what type of training is needed. Remember to start small, taking on one task at a time. Change usually happens gradually. Completing the training exercises described below will help move your congregation slowly forward to inclusion. One effective model for teacher training is to structure the training the way the religious education program sessions are structured. The following ideas will help you get started.

Theme: *Assessing Attitudes*

When working with parents and other adults interested in teaching, never assume that they are comfortable with the idea of including children with special needs in the religious education program. While most adults would never intentionally exclude a child because of his or her disability, many teachers' good intentions falter after their first efforts at inclusion. A well thought out plan is needed to include a child with difficult behavior. Some of the teaching strategies already discussed in this book can help. (See pages 38–45.)

Even so, teachers' attitudes will affect whether or not they can use the teaching strategies effectively. It is helpful to understand how teachers feel about ministering to children with special needs. The following exercise provides an opportunity for participants to think about and openly discuss these feelings.

Activity: *Case Scenarios*

Write the following statement on a flipchart: "My church is a faith community that welcomes all children who come into the church." Ask the teachers whether they feel this is currently true. If it is not true, ask the teachers whether they want it to be true. Ask

what they would do if faced with the situation in which one difficult child's behavior was causing other families to leave the church.

After a brief discussion, share the following case scenario. If the group is larger than seven, divide participants into groups of four or five to discuss the scenario. Then bring the whole group together to share ideas and feelings.

Case Scenario: Fred is ten years old. He has difficulty understanding social cues and behaving appropriately in differing circumstances. In his religious education group, he will pick out one child, cling to him or her, and demand his or her attention for the entire session. Fred also has difficulty transitioning from one activity to the next and ends up screaming if he gets too frustrated. He constantly interrupts the teacher and the other children when they are talking. As a result, many of the other children do not feel comfortable coming to their Sunday morning group anymore.

During the discussion, you may want to ask the initial questions again. As people share their ideas, list on newsprint ways that the child could be included as well as ways to help the other families who are thinking about leaving.

Theme: *Creating Moments of Transcendence*

Prepare the following quotation as a handout for the teacher training activity:

Often we want to “give the ocean” to young children when splashing in the “puddle” is enough. We fall into this trap by the ways we choose to share our adult faith with our youngest children. In our hurry to communicate our faith, we often assume that words are the most effective vehicle. Yet by using only words, we may fail to engage children in those common mud-puddle experiences where God is most visible, such as sitting on a loved person's lap and hearing a story, helping to bake bread, sharing a doughnut, or going with someone for a walk. These are the simple ways by which adults nurture and tend to the religious experiences of children.

The institutional church, unfortunately, often overlooks such participatory experience and substitutes a canned curriculum for such common, ordinary happenings. “Canned curriculum” here means a printed, generic curriculum that assumes anyone can use it. The question then becomes, Who can “fill the slots” to “teach the curriculum”? Such an approach often avoids the necessity of providing ongoing relationships and does not promote experiential interaction on the basis of the adult’s familiarity with and understanding of a child’s world.¹⁷

—Barbara Kimes Myers and William R. Myers,
Engaging in Transcendence

It is important to realize that so-called mud-puddle experiences cannot always be planned. Many times, they emerge from serendipitous moments. These moments are unique to each individual. That is, what will be meaningful for one child will not be meaningful to another.

As teachers, we can create a nurturing atmosphere in which moments of transcendence can emerge. The structure and environment of the spirit play program, with its emphasis on fostering a sense of wonder, is a good example of this type of atmosphere. In order for teachers to create the circumstances in which moments of transcendence happen, it is important that they examine what transcendence means to them.

Activity: *Spiritual Moments*

Ask the teachers to think of spiritual moments they experienced as children or youth—moments when they felt completely content, connected to people, or joyful. (Sometimes people do not relate to the word *spiritual*, so it is best to emphasize feelings of happiness and contentment.) Invite the teachers to share their spiritual moments, if they feel comfortable doing so. If the group is large, only a few people may have time to share. Notice how many of the spiritual moments occurred in a church or other religious setting.

Divide participants into groups of three or four. Ask each group to choose one person's spiritual moment and create a religious education session around it. Then have each small group share with the large group the session they created. Finally, hand out the Myers and Myers quote and discuss it in light of the spiritual moments activity.

This exercise can be wonderfully freeing. The teachers begin to realize that they have the imagination to teach without relying completely on the curricula. They also get in touch with what is spiritually meaningful to them. Inevitably, the sessions they create take into account many different learning styles and tend to be very experiential.

Theme: *Charismatic Teachers*

According to Robert Brooks and Sam Goldstein in *Raising Resilient Children*, a *charismatic adult* is someone who cares and loves a child unconditionally, who advocates for the child, and from whom the child gathers strength. Charismatic adults provide opportunities that reinforce "islands of competence," or individual strengths, and that foster self-esteem.¹⁸ (For more information on charismatic adults, refer to "Ideas for Teaching," pages 137–139, in the chapter on mood disorders.)

All of us can be charismatic adults in children's lives. In order to feel comfortable in the role, we need to regain a sense of who was important in our lives when we were children.

Activity: *Recalling Special Adults*

Ask the teachers to make a list of adults who were important to them when they were children and youth.

Ask "What traits, attributes, or characteristics did these adults have that made them special?" and record the teachers' responses on newsprint. Responses might include traits such as being a good listener, being nonjudgmental, showing compassion, and demonstrating trust.

A goal of this exercise is to demonstrate that every adult has the ability to be a charismatic adult. We are not all wonderful all of the time, but we are much of the time. Moreover, we can never predict when providing a kind word or listening thoughtfully to a child's story can change a bad day into a good day for that child. We may never know when we have had a positive affect on a child or were instrumental in creating a moment of transcendence. But as we feel ourselves making a difference, we also change.

Theme: *Seeing the Whole Child Instead of the Limitations*

Children with disabilities do not have the luxury of defining themselves; they have already been labeled by their disease, behavior, impairment, or limitation. We often expect the child to behave in the ways the label implies. We may actually see something that is not there, and our expectations will produce it.

Many psychology courses and workshops use pictures that can be seen as two different images, depending on what one looks for. There is one famous picture that looks like an old woman if viewed one way but like a young woman if viewed another way. Find some of these pictures for the following activity.

Activity: *A Matter of Perspective*

Select a dual-perspective picture, and label the top of the picture with one of the images that can be seen. For example, if you are using the old woman/young woman picture, label the top "Old Woman." Show the picture to the teachers, and ask them what they see. Most likely, all will see the old woman because that is how the picture has been labeled.

Next, show the teachers a dual-perspective picture of another subject that has not been labeled. Again, ask them what they see. This time, people will probably see either or both of the images in the picture.

Discuss how labeling directed them to look for a particular image in the first picture. Discuss how this can happen to children with disabilities.

Have the teachers describe a child in the religious education program whose behavior is disruptive or difficult. Notice how many negatives the teachers use. Next, have the teachers describe the life of that child—what his or her family is like, what school is like for him or her, whether he or she has many friends. Finally, have each teacher name something he or she likes about the child. If someone cannot come up with anything, discuss why this is so and what he or she can do to find the positive in this child.

This exercise addresses how our perceptions and expectations shape our behaviors toward *all* children. The child who does well in school, who is a leader, and who behaves well toward others is constantly reinforced for positive behavior. Moreover, we come to expect that behavior. Conversely, we come to expect bad behavior from children who are labeled as *difficult*. These children are more easily judged as acting out and more frequently reprimanded. The resulting insecurity leads to more bad behavior. To change this pattern, we need to find each child's "island of competence" (see page 39) and build on it.

**Theme: *Developing Empathy
and a Welcoming Faith Community***

An effective way to help people develop empathy for a child with a disability is to have them imagine what it would be like to be that child. The following exercise not only engages the imagination and develops empathy but also identifies what mechanisms and attitudes in the congregation might prevent a child with a disability from feeling welcome.

Activity: *Visualization*

Hand out to each participant one of the descriptions of children with disabilities (see pages 70–74). Give each person a different description until all of the descriptions have been distributed.

Ask each participant to read his or her description and to take a few minutes to imagine being that ten-year-old coming to a new church on Sunday morning. Ask each person to visualize walking

through a typical Sunday morning experience through the eyes of that child. Consider the following:

- How is your family greeted? Is someone there to help you and your parents find your religious education room?
- How does your teacher react to you? How do the children react to your disability and to your strange behavior?
- Can you easily participate in the activities that are planned, or are they too complicated or intimidating? Are you confused?
- Do the children talk to you or ignore you? Do you feel like everyone is staring at you, or are they comfortable with your presence?
- Does the teacher pay too much attention to you or not enough? Do you feel included?
- At the end of the session, do you feel like you want to return?

Jot down a few ideas on how you, as this child, would create the best possible religious education experience for yourself.

After everyone has visualized this experience and jotted down some suggestions on how the church should change, have each person share with the group how it felt to be this child. In addition to creating empathy, hearing about the various types of disabilities should educate teachers about these common conditions. In discussing how the church can be more welcoming to children with disabilities, many participants become very creative in their suggestions. If there is time, redistribute the descriptions and repeat the activity.

Theme: *If the Child Is Safe, Everyone Is Safe*

When a congregation works at making all children feel safe, loved, and trusted, it creates a community in which all adults also feel safe, loved, and trusted. For example, a child will not feel safe if several elders in the congregation are uncomfortable being around children. Understanding what has wounded these elders so that they feel this way and providing healing for them would then become a goal of the faith community.

Activity: *Envisioning an Intergenerational Community*

Have the teachers create an ideal intergenerational faith community that ministers to all. Ask them to imagine what their community would look like if all decisions, programs, and ministries had the purpose of making children feel safe and loved. Invite them to express this vision on construction paper with crayons, paints, or colored pencils.

When the participants have had time to reflect on their vision and express it in images or words, invite them to share it with the group. Record on newsprint responses to the following questions:

- Who would be involved in the ideal intergenerational faith community?
- What would it look like?
- What would have to happen to make it come true?
- What might be the first steps toward realizing your vision?

Theme: *Know Your Own Learning Style*

Before teachers can teach to children's different intelligences and preferred ways of learning, they must first understand their own primary intelligences and preferred ways of learning. What they see as their strengths will often be what they depend on in teaching. Sometimes, we are so used to the school model, which relies heavily on lecture and discussion, that we lose sight of our own strengths and preferences.

Activity: *Applying Multiple Intelligences Theory*

Distribute copies of the overview of Howard Gardner's multiple intelligences theory (see pages 47–48), and give teachers a few minutes to become familiar with the eight types of intelligence.

When they are ready, have the teachers talk about which intelligences are most dominant for them and how this might affect their teaching style. Then ask the teachers to identify which intelligences are not their strongest and how this might affect their teaching style.

Next, give the teachers a theme and have them create a session about it based on their own preferred ways of learning. This can be done in small groups of participants who share the same dominant intelligences. Then ask them to design a session based on an intelligence that they would not ordinarily use.

When one teacher finished teaching after several Sundays, he announced that he would never do it again. Yet after another man finished his first teaching experience, he told the congregation that it had transformed him. Clearly, teaching children is not for everybody, but it may be right for more people than will give it a chance. One enthusiastic teacher can generate a lot of recruits.

Part of a teacher's success comes from being well prepared and well supported. Part of a teacher's enthusiasm comes from the freedom to use his or her imagination and multiple teaching styles. If teacher training accomplishes these goals, it will provide a successful start to serving the needs of all our children.

Child Descriptions

A child in a wheelchair

You have a spinal injury, such that you have the use of your arms with braces but no use of your legs. Sometimes, you involuntarily jerk forward. You like sports and reading poetry.

“The last church I went to did not have any ramps, so I had to be carried everywhere. It was humiliating. After I was brought upstairs with my chair, I could not move around much because there was furniture everywhere. The teacher was nice and the kids were curious because I was different, which I did not mind. But they had this circle meditation and talk, and all the kids and the teacher sat on pillows on the floor and I had to sit in my chair and look down on everyone. People have a tendency to think I am stupid just because I am in a wheelchair, so the teacher and kids talked to me as if I was three years old. Every time I jerked forward, everyone stopped and stared at me. I wish I had been made to feel more welcome. I hope my experience in the new church is better.”

A child with Down syndrome

You have the obvious physical attributes of a Down syndrome child, and so you know everyone looks at you funny if they do not know you. Sometimes, you cannot follow what is going on, but if someone explains it to you, you feel more comfortable. You like caring for small children and singing.

“The last church I went to did not think I belonged with other kids my age, so they gave me a special tutor that invented activities for me. I missed being with the other kids. I know I look different and some kids think I’m dumb and fat and they make fun of me, but still I’d rather be around other kids. Sometimes, I’m clumsy and too loud, so the teacher and kids get upset, which is why they gave me my own special tutor. I hope in this new church I get to be with kids.”

A child who has attention-deficit disorder

You have always had a lot of energy and can't stand to sit still. You like to talk about everything. You know adults think you are often disruptive and uncontrollable, but you don't understand why everyone gets so upset. Other kids think you're weird and deliberately trying to be bad. You like to build things and climb trees.

"It was awful at the last church. I got kicked out of the program three times. They kept doing these boring discussion groups, so I invented stuff to do to keep me busy, which is when I got into trouble. Some of the kids liked doing those things with me, and then they got into trouble, too, and couldn't be friends with me anymore. I don't understand why this happens, and it makes me so angry. No one understands. I don't think this new church will be any better. No one ever likes me."

A child with Asperger's syndrome (high functioning)

You know you are different, but you don't know why. You don't understand people; they're like alien objects. It makes you very uncomfortable to be touched. You focus on one thing at a time but not for long. You like consistency and get very confused when the rules or plans are changed. You like dinosaurs and know everything about the different species—when they lived and what they ate. You wish they still lived so you could have one as a pet.

"Mommy and Daddy are making me go to another church. I would rather stay home and build dinosaurs or read books about dinosaurs. I don't understand why the other kids aren't interested in dinosaurs like I am. The kids annoy me. Anyway, I would much rather play by myself. At the last church, they wouldn't let me talk about dinosaurs, and they wanted me to hold hands all the time. They were always changing what they were doing each Sunday, and I got terribly confused. Sometimes, it was too much and I got angry. Then they made my parents come and get me. I like to do stuff, though. I hope I can bring my dinosaurs to this new church."

A child with a learning disability

Sometimes, you feel like you must be from another planet because when you talk, people look at you as if you are strange and not making any sense. You try so hard to understand, but evidently you don't because you're always screwing up. You think you're creative and intelligent, but you have real difficulty reading the words and doing the math. You're always inventing things in your head, and you love to draw.

“I hate school! Everyone there thinks I’m dumb, except for my tutor. I have all these special classes, so the kids know I’m stupid. In the regular classes, I get so anxious I’m going to screw up that I almost always have a stomachache. The last church we went to was not much better than school. They kept having the kids read these stories, and everyone knew that the reason I never volunteered to read is because I don’t read very well. The discussions were interesting, but whenever I was asked for my opinion, I would get so scared that I couldn’t say anything. I always had an answer afterward, but then it was too late and they would be talking about something else. I have good ideas, so I hope I can share what is inside of me at the new church.”

A child with obsessive-compulsive disorder

You and your parents are just beginning to understand the extent of your problem. You know you're very odd, but you can't help doing certain things over and over again, like counting every crack in the sidewalk, turning three circles every time you go through a door, and arranging your food all in a line before you can eat it. You know no one else has to do these things, but you have to in order to feel safe.

“My last Sunday school teacher tried to stop me every time I walked into the room and turned three circles. It made me so anxious that I would be in tears. Even when I knew the kids were staring at me, I would have to go out and turn three circles and then come back in and try to turn three circles. The teacher would finally give up in disgust. It would start all over again when we had snack, and I would line up all the crackers in a row. The teacher would try to joke me out of it, but all it did was make the kids notice more what I was doing. They all teased me later. I hated being there. My parents are taking me to a new church, but it won't be any better. I have to do these things; I have no choice. It will start when we arrive, and my parents will be frustrated because I will have to count the cracks in the sidewalk leading to the church. At least I can do that without too many people noticing. Maybe there will be some kids I already know in this church who already know I'm odd and will just ignore me.”

A child with blindness

You have never been able to see, so you have learned about your world primarily through touching and hearing. You're very bright and independent and get around well with your cane. You don't understand why people keep calling you brave or courageous because being blind is normal to you—it's part of living. You do get upset, though, when someone says your eyes look funny or when they talk loudly to you, as if you're deaf. You hate it when people tell you that you can't do something because you're blind without even asking you what you think.

“The last church my parents took me to didn't know what to do with me. They said that there was absolutely no way the teachers could accommodate me because I wouldn't be able to do all the activities the other children were doing and I might fall and hurt myself. When my parents assured the minister that I could take care of myself and that I would let people know when I needed assistance, he reluctantly let me attend the Sunday school. Everyone treated me as if I was going to break. The teacher introduced me as “a very brave little boy.” Then she gave the children something to read but did not offer to read it to me. When I asked the kid next to me to read it to me, he got into trouble for talking out loud when he was supposed to be reading quietly. When the group was talking about all living things being related, the teacher brought in a bunny. Everyone but me was allowed to hold the bunny. The teacher said that she was afraid I would hurt the bunny because I couldn't see. I explained that I am very gentle because touching is a big part of how I learn about my world. So she let me hold the bunny for a second and then snatched it away. I felt her anxiety. I never want to go back to church.”

Learning Disabilities

I think that when I was born, I was put in a rocket ship and taken to another planet earth. I never felt that I was like anyone else here. From the time I was five, I can recall feeling like an outsider. I first remember feeling like an alien when I tried to communicate. People would raise their eyebrows and make other facial expressions of confusion when I tried to express myself. . . . Constant rejection created feelings of isolation and isolation created anger and anger created self-defeat.

—Larry B. Silver, *The Misunderstood Child*

OURS IS A CULTURE THAT PRIZES the verbal and logical modes of learning, and these modes dominate the approach to teaching in our schools. Children who succeed in school are those who can master these preferred ways of learning. Most children who learn and think in significantly different ways receive less support in school and may come to consider themselves deficient and even stupid. Many times, these feelings are reinforced by adults who think that these children are lazy or unintelligent. The struggles of children with learning differences are profound and their true gifts often go unnoticed.

This problem is becoming even more acute with the use of standardized testing to determine educational competence. Given

the importance of these tests, teachers often resort to “teaching to the test.” When this happens, the teacher’s ability to support children’s different learning styles and foster creativity is severely jeopardized. This situation threatens to solidify intolerance in our culture for diversity of learning and knowing and forces more and more children into special education.

To understand the children in our faith communities who have been identified as *learning disabled*, we have to look at the prevalent perceptions about learning disabilities. Dr. Thomas Armstrong, an education specialist, states that it is the *society* that defines who is disabled. He gives the example of the Anang culture in Nigeria, in which children learn hundreds of songs and play numerous percussion instruments. In this society, someone who is not very musical is considered unintelligent.¹

In *Our Labeled Children*, Robert Sternberg and Elena Grigorenko write, “Learning disabilities are labeled as such through the interaction of an individual with the environment. Virtually all individuals have disabilities of one kind or another, but society chooses to label only some of these learning disabilities.”² Children labeled as *learning disabled* are frequently treated as if there is something wrong with them, and this is how society defines them. We often see the results of this labeling in church when children act out and demonstrate low self-esteem.

Description

There is no easy way to define a *learning disability*. Most professionals view learning disabilities as an overall category that contains many different types of learning problems. In popular usage, the label *dyslexia* is sometimes seen as synonymous with *learning disability*. However, most professionals designate dyslexia as only one type of learning disability. Some professionals place pervasive developmental disorders (PDDs), autism, and Asperger’s syndrome

into this category because children with these conditions have multiple learning problems.

The federal definition of what comprises a specific learning disability, as defined in the Individuals with Disabilities Education Act, is the basis for determining which children qualify for special education services in school systems. However, this definition leaves room for immense disagreement and conflict.

The website LDOnline offers the most simple, understandable definition of a *learning disability*:

LD is a disorder that affects people's ability to either interpret what they see and hear or to link information from different parts of the brain. These limitations can show up in many ways: as specific difficulties with spoken and written language, coordination, self-control, or attention. Such difficulties extend to schoolwork and can impede learning to read, write, or do math.

Since professionals in this field do not have a standard set of labels with which to designate different types of learning problems, it is easy to get confused. LDOnline organizes the various types of learning disabilities into three categories:

- developmental speech and language disorders, including developmental articulation, expressive language, and receptive language disorders
- academic disorders, including developmental reading, writing, and arithmetic disorders
- other learning differences, including motor skills disorders and specific developmental disorders not otherwise specified³

Developmental reading disorder, often referred to as *dyslexia*, is the most prevalent learning disorder and the one the general public hears most about. Because speaking, listening, reading, writing, and arithmetic use many of the same brain functions, people are

usually diagnosed as having multiple learning disorders. Some common labels associated with learning disabilities are:

- *dyslexia*—difficulty understanding words, sentences, and paragraphs
- *dyscalculia*—difficulty solving arithmetic problems and grasping math concepts
- *dysgraphia*—difficulty with letter formation and writing within a defined space
- *auditory and visual processing disabilities*—difficulty understanding language despite normal hearing and vision⁴

Recently, the condition known as *nonverbal learning disorder (NLD)* has received a lot of attention. People with this poorly understood disorder have strong skills in verbal rote memory but difficulty processing information; they also have poor physical coordination and social skills. Some professionals consider children with NLD to have a mild form of Asperger's syndrome, while others see NLD as a distinct disorder. Whatever the diagnosis, children with NLD have difficulties similar to those of children with learning disabilities *and* children with Asperger's syndrome. If the developmental and learning disorders could be placed on a continuum, NLD might be placed between dyslexia and Asperger's syndrome. (This issue will be revisited in the chapter on autism.)

Dyspraxia is another poorly understood disorder that is generally placed in the learning disabilities category. There are two types of dyspraxia. A person with *generalized motor dyspraxia* has problems with coordination—both large and small body movements. Children with *verbal dyspraxia* have marked difficulty producing and sequencing speech sounds into words, and their development of expressive language is often delayed. Children can have one or both forms of dyspraxia.

Children with learning disabilities do not often fit within a discreet category. For instance, a child can have dyslexia, dyscalculia, and dysgraphia. Similarly, a child can have difficulty speaking and

controlling his or her movements but have no problems reading. Children with any of the learning disorders can have sensory integration problems. Sometimes, sensory integration is their only problem, such that they are identified as having *sensory integrative dysfunction (SID)*.

Given the complexity and diversity of learning disabilities, diagnostic labels are no substitute for getting to know the individual child. Relying on clinical terms not only limits understanding of a child but it can become a self-fulfilling prophecy. Adult expectations of certain behaviors can be powerfully motivating, both positively and negatively.

Discussion

Much has been written about dyslexia because it is the most common of the learning disabilities. Some learning disabilities professionals have concentrated their research on how dyslexic (or language-disordered) people think, and they have formed theories that challenge the traditional view of what makes a person smart.

Dyslexia actually means “trouble with (*dys*) words (*lex*).” Priscilla L. Vail, an expert in this field, lists several general characteristics of people with dyslexia in her book *About Dyslexia*. In explaining their unique way of interacting with the world, she describes dyslexic people as creative and imaginative. They have trouble with words but often know how to make the world work. Vail says, “Dyslexics can learn to compensate but their learning style is permanent. Although this is inconvenient in school years, let us rejoice that no one ‘cured’ Leonardo da Vinci.”⁵

In The Mind’s Eye, by Thomas G. West, is a liberating book for rethinking the way we view people with learning disabilities. West’s theories challenge us to reconsider the traditional views of learning. Like Vail, West believes that people with dyslexia are visual/spatial thinkers, rather than linear/verbal thinkers. This relates to how people use the right and left hemispheres of the

brain. The left hemisphere thinks in words and numbers in linear fashion, while the right thinks in pictures and images in three-dimensional space.

Our culture and our educational institutions are dominated by and reward the mental processes of the left side of the brain. But West posits a relationship between creativity and the visual/spatial or right-hemisphere mode of thought. He also says that people with dyslexic traits have always been part of the gene pool. These traits have come to our attention as a disability as our culture has become more and more dependent on the left-brained way of thinking.

A number of people have achieved success despite some form of dyslexia or learning difficulty. According to West, this group includes Hans Christian Anderson, Albert Einstein, Thomas Edison, Auguste Rodin, Nikola Tesla, Leonardo da Vinci, George Patton, William James, Woodrow Wilson, Nelson Rockefeller, Winston Churchill, and William Butler Yeats. Contemporary figures with a learning disability include Walt Disney, Cher, Greg Louganis, Whoopi Goldberg, Henry Winkler, Danny Glover, Henry Ford, Charles Schwab, and Bruce Jenner.

A major hypothesis of West's book is that many of these individuals achieved success or greatness not *in spite of* but *because of* their apparent learning difficulty. That is, they achieved success not because they compensated for some disability but because they could not fully compensate and instead embraced their unique talents. West suggests that having a learning disability is essentially a gift. He presents several profiles of famous people with well-documented learning difficulties and describes the mode of visual/spatial thinking that led to their achievements. Interestingly, many professionals believe Einstein was not only dyslexic but also had many of the symptoms associated with Asperger's syndrome or high-functioning autism. Visual/spatial thinking is a very strong characteristic of people within the autism spectrum. (See the chapter on autism.)⁶

In *The Gift of Dyslexia*, Ronald D. Davis supports West's view of learning disabilities: "The mental function that causes dyslexia is a gift in the truest sense of the word: *a natural ability, a talent*. It is something special that enhances the individual." Not every dyslexic person is a genius, but if we understand how children with dyslexia think, then we can help their gifts emerge, whether in art, athletics, science, or another field. Davis lists the following abilities that all dyslexic people possess:

- the brain's ability to alter and create perceptions (the primary ability), a highly developed awareness of their environment
- intense curiosity, the ability to think in pictures instead of words
- intuition and insightfulness, the ability to think and perceive using all the senses or multi-dimensionally
- the ability to experience thought as reality
- a vivid imagination

Davis suggests that dyslexia is a perceptual talent that, in some situations, can be a liability; for instance, it can cause problems in learning to read, to write, and to do math. He explains the thinking process of people with dyslexia with his *theory of disorientation*. Briefly, it involves the idea that dyslexic children conceptualize of things nonverbally with mental pictures and become disoriented when they are forced to think with words, for which meanings cannot be pictured. Thus, the letter symbols that make up individual words mean nothing; they do not look like any known objects and so do not generate mental pictures. In West's language, these children think from the right side of the brain. Davis believes that controlling the disorientation will help dyslexic children overcome their learning problems and allow their talents to flourish.⁷

There is a major effort among many learning disabilities professionals, people with learning disabilities, and parents of children with learning disabilities to use the word *difference* instead of *disability* in designating this condition. The primary reason for

this new terminology is to change the general public's perceptions about what it means to have a learning disability. Using the word *difference*, instead of *disability*, promotes a vision of a world in which each person has a mixture of strengths and weaknesses and can make his or her own special contribution.

However, many professionals in this area see the trend toward using the word *difference* as harmful. They feel it will undo all the years of struggle it took to recognize that these children have special problems that require special educational services. In order for children who significantly struggle with learning in school to be represented under the Education for All Handicapped Children Act, it was essential that learning disability be seen as a handicapping condition. Using the word *difference* would not have accomplished this goal.

The Learning Disabilities Association (LDA) has been a leader in the fight to have children with learning disabilities protected by federal law and to ensure that the public education system will continue to serve them. Dr. Larry Silver of the LDA comments,

Using the term Learning Difference rather than Learning Disability *is not just a semantic difference*. It feeds right into the arguments that too many superintendents of schools and principals are using to control their budget. Why do we need special services or specially trained teachers or special materials for students who learn differently? Our special education funds are for students who have real disabilities. If they only learn differently, we can teach them in general education. It is this very real and urgent need that causes our organization to speak out so loudly to organizations and individuals who want to use the term Learning Differences.⁸

Mel Levine, an expert on learning disabilities, feels that labels served their purpose in the past by indicating that children's and youths' learning problems were not their fault. But now, he feels, labeling has gone too far, so that every variation in thinking is labeled a *deviance* or *disorder*. Labels are harmful, Levine says,

because they are often misleading, pessimistic, simplistic, and dehumanizing, particularly when they are used to define a person's total identity: "I am dyslexic, I am ADD, I am autistic." Levine asks us to imagine proclaiming, "I am bronchial asthma."⁹

Students at the Eagle Hill School for children with learning disabilities responded to Silver and the LDA on the issue of terminology. In their view, it is unreasonable to assume that there is a single point on the continuum of school success that indicates when a child learns differently and should be considered learning disabled. The students write,

We recognize the danger in a rapid, unconsidered shift from the use of *learning disabilities* to *learning differences*, and we appreciate your foresight in calling attention to this in your article. It is a real concern and one that we share. However, we do not accept the notion that persons with *learning disabilities* are qualitatively different from others who have difficulty in school or from those who do not have difficulty in school, for that matter. We recognize that most uses of the term *learning differences* depend upon the same assumptions about the world (and about people) that we have argued against here. In the end, we suggest an even more radical shift in perspectives and in terminology to *learning diversity*, which can value multiple ways of learning and allow every student greater access to success in school.¹⁰

The issue of whether to use *disability*, *difference*, or *diversity* is important because it affects how we view children who think differently. Howard Gardner feels that our schools have come to teach uniformly in a one-dimensional way, relying heavily on linguistic and logical problem solving while ignoring other ways of learning and thinking.¹¹ This has created a culture in which children who think and learn differently are considered disabled.

For the purpose of getting needed educational services for their child, it is necessary for parents to use the word *disabled*. It is not necessary, however, for involving the child in religious education programming.

Ministering to Families

When ministering to families that have children with learning disabilities, it is important not to minimize the pain and anger that they frequently experience. Many of these parents have to fight an unyielding school system in order to get needed services for their child. That fight can be very expensive, including the costs of hiring advocates and lawyers. Many parents give up because they cannot handle the expense, only to watch their child suffer from the lack of proper services. The resulting anger and frustration can be overwhelming and debilitating. It can spill over into the church environment, especially if parents feel they have to continue to fight for what their child needs. It is therefore critical that parents feel their child will be safe in church and free from the struggles he or she faces in school. Creating a learning environment that does not rely on reading and writing is essential.

Sometimes, a child's struggle in school indicates other problems, such as depression, bipolar disorder, or an anxiety disorder; these conditions can go hand in hand with learning disabilities. But many times children are diagnosed incorrectly. Parents who seek pastoral care need to receive not only support but also help in finding the proper resources for their child. Richard Lavoie, a learning disabilities expert, says that the biggest challenge for both parents and professionals is not educating the child with learning differences but educating other people.

Ideas for Teaching

If children struggle too much to learn to read, write, and do math, they are often diagnosed with a learning disability. And no matter how this diagnosis is conveyed or countered with talk about their "gifts," the message to the children is that they are defective in some way. Their hurt, frustration, and pain from being viewed as different may be invisible, but they bring it all with them to our faith communities.

Dr. Harold Levinson, an expert on learning disabilities, calls these children the “upside-down” kids. Like the figure 8, which looks the same rightside up or upside down, these children look like other kids. But their whole world has been turned upside down because their learning needs do not match the predominant teaching method.¹² As a result, they can feel stupid and frustrated in school.

Specific ideas for teaching children with learning disabilities can be found in the section “Make Religious Education Less Like School” in the chapter on religious education (pages 31–34) and in the “Ideas for Teaching” section in the chapter on attention-deficit disorder (pages 92–95). Key strategies include using storytelling instead of asking the children to read out loud; using visual cues in the religious education classroom to represent session themes; and providing one set of information or directions at a time for children who have difficulty remembering too many directions or the sequence of events. With younger children especially, avoid activities involving writing, or have each child share his or her thoughts while the teacher writes them down. For example, in an activity that asked the children to share how they were going to help at home during the week, the teacher wrote each child’s response on a balloon to take home.

Attention-Deficit Disorder

Those carrying this gene [the gene associated with ADD] . . . often find themselves in environments where they're coerced, threatened, or shoehorned into a classroom or job that doesn't fit. The Edison-gene children aren't recognized for their gifts but instead are told that they're disordered, broken, or failures; a great emotional and spiritual wounding occurs. This wounding can bring about all sorts of problems for children, for adults they grow into, and for our society.

—Thom Hartmann, *The Edison Gene*

CHILDREN WITH *ATTENTION-DEFICIT DISORDER (ADD)** rarely have the opportunity to feel good about themselves, to follow their dreams, and to be appreciated for their strengths and gifts. These are the children who learn at an early age that they are different from other children, and they are reminded of that fact throughout their lives.

Children with ADD have difficulty controlling their impulsive and distracting behaviors. And rather than allow themselves to be thought of as odd or stupid, many choose either to withdraw completely or to get into trouble on a regular basis. Many of these chil-

* In this chapter, the term *attention-deficit disorder (ADD)* is used exclusively and includes *attention-deficit hyperactive disorder (ADHD)*.

dren learn quite young that they can disrupt, control, and cause fear in well-meaning adults. If they also have a learning disability, they receive a double dose of misunderstanding and negative reinforcement. Even those children with concerned and loving parents grow to hate themselves, because no matter how hard they try, they do not fit in.

Description

Dr. Edward M. Hallowell and Dr. John J. Ratey are two of the foremost experts on diagnosing and treating people with ADD. In their book *Answers to Distraction*, they describe ADD as a neurological syndrome that is characterized by one or more of three symptoms: impulsivity, distractibility, and hyperactivity.¹ Today, about 15 million Americans have ADD, although many do not know it. It occurs in children and adults of both sexes and all racial and ethnic groups, socioeconomic strata, levels of education, and degrees of intelligence. ADD is not a learning or language disability, nor is it associated with low intelligence.

Given this information, diagnosing attention-deficit disorder would seem to be straightforward, but it is not. Many people are at times impulsive, distracted, or hyperactive. Some people consider themselves to have ADD with only one or two symptoms and not necessarily the same symptoms that others with ADD experience. In an effort to aid diagnosis, several clinicians have developed a diagnostic checklist, but it does not always work.

Many of the problems common to children can cause the symptoms of ADD, such as depression or bipolar disorder, a dysfunctional family situation, and poor nutrition. Many children with learning disabilities also have attention problems that make them seem at times to have ADD. To complicate matters, ADD occurs more frequently among people with dyslexia than in the population at large. It is estimated that between 50 and 90 percent of students with ADD also have a learning disability² and that between 6 and 10 percent of the school-age population have ADD.³

Discussion

Given the number of American children who have been diagnosed as ADD in recent years, it seems as if this condition has swept across the nation, bringing upset and confusion with it. A conservative estimate is that between 6 and 10 percent of American children have been diagnosed with ADD.⁴ It is also intriguing to consider that ADD appears to be a phenomenon of Western countries.

But do all of these children really have ADD? In *Answers to Distraction*, Hallowell and Ratey discuss what they call *pseudo-ADD*, an ADD-like syndrome caused by our fast-paced, visual, electronically wired, impatient, violent and action-prone, over-stimulating urban culture.⁵ Hartmann believes that the reason we are seeing more children with ADD in American schools is that underfunding and teacher overload are bringing them to our attention.⁶

In large classrooms and under increased pressure to teach standardized materials, teachers no longer have the opportunity or time to work creatively with children who have learning differences. Because children with ADD are primarily visual, not auditory, learners, they become bored easily and begin to act out. It then becomes easier to label, blame, and medicate the child rather than change the school culture. Jeffrey Freed, in his book *Right-Brained Children in a Left-Brained World*, believes that all American children are becoming more visual and right-brained from living in our highly stimulating, electronically based culture.⁷ He believes we are a left-brained society that is in the process of becoming more visual. Our schools are being flooded with right-brained, visual/spatial children, but they continue to be dominated by a teaching style that has historically emphasized a left-brained, linear mode of learning. The more visual, right-brained students have difficulty learning in this environment and are often labeled as nonlearners or as having ADD and/or learning disabilities.

Another professional who questions the prevailing view that ADD is a problem or disorder is Dr. Thomas Armstrong. In his

book *The Myth of the ADD Child*, he proposes that ADD is not a medical disability, which means this label is not helpful in understanding the behaviors of a given child.⁸ He suggests other possible explanations for ADD-type behaviors. Perhaps it is a social invention, a symptom of societal breakdown, a product of a short-attention-span culture, a response to boring classrooms, a reflection of normal gender differences, a bad fit between parent and child, or a different way of learning.

Although some people feel that ADD is simply the latest excuse used by parents who do not discipline their unruly children, scientific research shows that ADD is a biologically based disorder that can be inherited and may be due to an imbalance of neurotransmitters or abnormal glucose metabolism in the central nervous system, according to the organization Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD).⁹ While a biological explanation may confirm that ADD is not a myth, it does not explain why the disorder is in the human gene pool.

Hartmann proposes the hunter/farmer model to address this question. He believes that ADD is a vestigial survival mechanism that has been handed down to us from our hunter/gatherer ancestors. As he explains,

ADD . . . is something that was once an adaptive psychological and physiological mechanism providing our hunter/gatherer ancestors with an edge over the world in which they lived. Their distractibility was actually a continual scan for danger or opportunity in the world of the forest or jungle, their sense of doom was a hypervigilance that protected them from predators or enemy warriors. Their impulsivity eliminated the problem of indecisiveness which could cause them to miss out on a meal if they were busy doing a task while something edible ran by; their seeking out of sensation and risk facilitated their hunt, leading them into areas where food could be found (along with the other predators also attracted by that food).¹⁰

For about six million years, our ancestors were hunters. Then, with the agricultural revolution, farming societies developed and flourished. Farming became a more efficient way to produce food than hunting. Having more food allowed the population to grow and specialize. Those people with the patience to grow crops evolved into farming and eventually industrial societies and tried to eliminate the impulsive, sensation-seeking hunters among them. Hartmann concludes that ADD is part of our genetic heritage and therefore should not be viewed as a disorder. (In his latest book, *The Edison Gene*, Hartmann describes the scientific research that has identified the DRD4 gene, the one most often associated with ADD, and its appearance in human populations around the world.¹¹)

From Hartmann's view, we are still attempting to eliminate the hunters among us by telling our children with ADD there is something wrong with them, medicating them so they behave differently, and forcing them into school systems that do not appreciate their skills and gifts. Hartmann, however, sees the hunter people as keeping our society from ossifying. The hunters in our society are often our entrepreneurs, leaders and risk takers, and most creative people. He sees the hunter/farmer model as a continuum, with *hunter*, or ADD-type behavior, on one end and *farmer*, or careful and methodical behavior, on the other end. This could explain the difficulty in diagnosing ADD because many people have both farmer and hunter characteristics.

Regardless, the hunter/farmer model allows us to look at children with ADD from a different perspective. Instead of telling them that they have a disorder, which suggests that they are damaged in some way and thus lowers their self-esteem, we can tell them that their personality traits are well adapted for some areas but that they may experience difficulties in other areas, which leaves their self-esteem intact. In fact, children with ADD may be more successful and functional in some areas than their peers without ADD. We can nurture these positive aspects of each child's uniqueness at home, in school, and in our religious education programs.

Ministering to Families

One of the most controversial issues in the treatment of children with attention-deficit disorder concerns the use of certain medications. As ministers and religious educators, we should not advocate one way or another to treat children with ADD, but we need to be aware of the related issues. The medical community has sponsored limited information about natural alternatives and interventions, so unless parents are proactive in researching all of the possibilities, they may make a decision based on partial information. In providing pastoral care for a family, we can encourage parents to seek out all available information in order to make an informed decision.

In ministering to the family of a child with ADD, be sure to realize that the accuracy of the child's diagnosis will affect what happens as he or she grows up. For example, children with ADD who are not diagnosed and treated may develop other severe problems, such as depression and anxiety, conditions that can mask the underlying ADD. Children with bipolar disorder are sometimes mistakenly diagnosed as having ADD. Some professionals suggest that boys are being overdiagnosed with ADD because they are usually active and that girls are being underdiagnosed because they are less likely to be disruptive. And research, along with increased awareness, has shown a high incidence of drug and alcohol abuse among people with ADD who have received little support and help.

A friend with ADD said to me, "Once you know what ADD is, then you intuitively know when you see it in someone else." Many of us who work with children feel we know when we have children with ADD in our religious education programs. In some cases, the parents will tell you, and in others, it is obvious. Either way, we need to be careful in making assumptions when working with overly active, distracted, or disruptive children. The same is true for ministering to the parents of an overactive and/or disruptive child. As noted earlier, many reasons besides ADD can explain why a child is hyperactive or inattentive.

While some people do not agree with Armstrong's view that ADD is a myth, his ideas about other causes of ADD-type behavior are worth considering. According to Armstrong,

One of the biggest difficulties with the ADD myth is that its holy trinity of symptoms—hyperactivity, distractibility, and impulsivity—are sufficiently global as to be likely to result from any of a wide number of potential causes. A child can have trouble paying attention or behaving, for example, because his schoolwork is boring, because his family is going through a crisis, because his way of learning doesn't match the school's way of teaching, because he's allergic to milk, because his temperament doesn't match that of his parents, or because he's anxious or depressed.¹²

Ideas for Teaching

The majority of us in Unitarian Universalist religious education have had experience with children whom we believe to have ADD. Often, these are the children we have the most difficulty serving. When there is consistently disruptive behavior in a religious education program, it is often from a child who has been diagnosed with ADD. This is the child who makes some volunteer teachers decide never to teach again. This is the child whom other children become angry with and frequently shun.

To be sure, our churches cannot be the place of primary intervention and service delivery for children with ADD. However, we can have a significant impact on the self-esteem of these children by providing a sacred place where they feel protected and free to explore their own potential.

Richard Lavoie was headmaster of a school for boys with attention-deficit disorder and learning disabilities on Cape Cod in Massachusetts and is now director of the Schwab Foundation Learning Center. A wonderfully compassionate, insightful

professional who also has ADD, Lavoie provides a wealth of information on how to work with children with this condition. The following overview of his understanding of and approach to working with these children has been compiled from one of his day-long workshops and adapted for religious educators.

Distractibility. People with ADD are constantly looking for stimulation, and if they cannot find it, they will create it. Plan sessions so that there is always some activity in which a child with ADD can participate. It is a misconception that children with ADD have difficulty paying attention to anything. Quite to the contrary, the distractible child with ADD pays attention to *everything*. Hartmann says that a better way to describe the distractibility of ADD is to use the term *scanning*. Children with ADD notice everything, such that they are constantly bombarded with stimuli. They hear all the noises going on both inside and outside the room. They notice what the teacher is wearing while she is talking to the class and that her hair is combed differently from last week. They notice the spider crawling across the ceiling and that one of the books has been removed from the shelf by the window. In fact, children with ADD give all these stimuli equal importance. As a result, they are poor at selective attention, a tendency that can lead to impulsivity.

Impulsivity. Children with ADD handle all of life's problems less effectively than their peers. Specifically, children with ADD do not have sequential thoughts, so they often appear reckless and thoughtless. They are more likely to get into trouble, more likely to get caught, more likely to respond to the wrong stimuli when confronted with their misdeed, and more likely to suffer a stiffer punishment. Unfortunately, what appears to be misbehavior is actually part of their automatic functioning. Most children learn an inhibitor response that says "Think it but don't say it or do it!" Children with ADD immediately say or do what comes to mind.

Punishing them does nothing but create anxiety because these children do not understand why they are so different and why they behave the way that they do.

Self-Esteem and Success. A major myth associated with children who have ADD or learning disabilities is that they would do better if they only tried harder. The truth is, according to Lavoie, “If they only did better, they’d try harder!” Children need to know what it feels like to succeed before they will want to work more diligently. Dr. Robert Brooks, who works with highly difficult children, says that they need to develop an “island of competence.” (See the section “Teaching Difficult or Disruptive Children” in the chapter on religious education, pages 38–45.) Children with ADD and learning disabilities rarely get the opportunity to demonstrate competence. In school, they are constantly asked to participate in activities that are difficult for them but are rarely asked to participate in activities that they can do well. Imagine what this does to a child’s self-esteem and willingness to keep trying. In our ministry, we can create opportunities for these children to succeed and to receive positive recognition. In particular, we can achieve this by believing in them and helping them learn to be moral, kind human beings and seekers of truth.

Anxiety. Children with attention-deficit disorder and learning disabilities also have performance inconsistency; in other words, they have good days and bad days. The bad days are usually full of comments and criticisms from everyone around them, including their peers. On these days, the best these children can do is go unnoticed. When they have good days, children with ADD and learning disabilities often feel guilty because they do not understand why they cannot always do so well. Over time, they may feel that no matter how hard they work, they will still fail. The result is intense anxiety. Children with ADD and learning disabilities are usually anxious, not depressed. Depressed people worry so much

about the past that the future looks bleak, whereas anxious people worry constantly about what is going to happen. Anxiety can be extraordinarily debilitating, inhibiting the ability to listen, to learn, and to act. For children who are already struggling, being anxious can cause intense stress. A ministry that incorporates meditation techniques and getting in touch with the sacred can be enormously beneficial in helping these children reduce the anxiety and thus the stress in their lives.

The Autism Spectrum

To understand autism, or any other human condition, you must observe the individuals, not just the stereotypes. Our most talented teachers agree when they say, “To reach a child with autism, you must first learn the world through the student’s eyes.”

—Charles Hart, *A Parent’s Guide to Autism*

THE WORLD THAT IS EXPERIENCED by children with autism or Asperger’s syndrome is very different from that which most of us experience. In order to understand the children within the autism spectrum, imagine moving to a new world. You learned the language, so you think you hear what people are saying to you, only to discover that you do not understand. Imagine trying to figure it out by repeating the words, only to be yelled at for being rude. Imagine talking about a subject dear to your heart, only to discover that you are boring everyone. You try very hard to understand how to behave in this new world, but people are inconsistent and confusing. There are no set rules in this world. They change from one set of circumstances to the next, so you never know which rules to follow. You like your daily routines. They are comforting and predictable. But in this strange world, someone is always asking you to change.

Sometimes in this world, there is too much noise, too many people talking at once, very bright lights, and confusion

everywhere. All of this makes you anxious, so you retreat inside your head. You calm yourself by rocking back and forth and turning around in circles. But for some reason, doing these things makes the people in this world frantic and they physically force you to stop. This makes you very angry. Sometimes you hit whatever is closest to release your rage at being intruded upon when you are just coping the best way you know how. You wish the people in this new world could see who you are.

Our ability as a faith community to minister to each child from a place of understanding and support helps children within the autism spectrum. When we can understand their behavior as a way of coping with a strange world, then we can create a welcoming program and minister to their needs.

Description

Autism is a neurological disorder that affects brain functioning in the areas of social interaction and communication skills. It is a *spectrum disorder*, which means that its symptoms and characteristics can present themselves in a wide variety of combinations, from mild to severe. As a result, professionals often disagree about what to call the overall category of this spectrum disorder. In 1994, the American Psychiatric Association (APA) grouped disorders characterized by severe and pervasive impairment in several areas of development under the overall category of *pervasive developmental disorder (PDD)*. But some use the term *autistic spectrum* or *autistic continuum*. The term *PDD* is frequently used to describe children with mild autistic symptoms, and the term *autism spectrum* is often used to describe the full range of symptoms and characteristics.

The Autism Society of America (ASA) also uses *PDD* as an overall term, although it continues to use *autism* to refer to the range of disorders. An excellent source for understandable information on the autism spectrum, the ASA describes autism as a complex developmental disability that typically appears during

the first three years of life. Children and adults with autism typically have difficulties in verbal and nonverbal communication, social interaction, and leisure play activities. Specifically, the disorder makes it hard for them to communicate with others and to relate to the outside world. They may exhibit repeated body movements (such as hand flapping and rocking), unusual responses to people, attachments to objects, and resistance to changes in their routine. They may also experience sensitivities in sight, hearing, touch, smell, and taste. In some cases, people with autism are aggressive or injure themselves.

Dr. Lorna Wing, an expert on autism, believes that people within the autism spectrum have limitations in three common areas: language, social understanding, and imagination.¹ And while the range of symptoms and behaviors can vary dramatically from one individual to the next, sources generally agree on these common areas of difficulty:

- *Communication:* Children with autism show difficulty in the use and understanding of language. Their language develops slowly and sometimes not at all. Approximately 20 percent of individuals with autism will not learn to speak but will learn sign language or typing. The term *apraxia* is often used to describe children who cannot speak and whose condition is not a language delay. Those who do learn to speak often use words inappropriately with incorrect meanings. Sometimes, children with autism engage in *echolalia*, repeating of someone else's word.
- *Social interaction:* Children with autism have difficulty interacting with others or making friends and often show a preference for being alone. They are less responsive to social cues than most people and may avoid eye contact or show of affection.
- *Sensory impairment:* Children with autism may show unusual responses or reactions to sounds, visual stimuli, tastes, touch, or smells. They may be more (hyper) sensitive to or less (hypo) sensitive to sensations than others.

- *Developmental abilities:* Children with autism often have some skills that are normal or even superior for their age but others that are significantly delayed.

Several types of disorders fall within the overall autism spectrum:

- *Autistic disorder or classic autism:* The children with this condition have impairments in social interaction, communication, and imaginative play prior to the age of three. They have stereotyped behaviors, interests, and activities and little or no flexibility in thinking and behavior. People with classic autism also have difficulty imagining what others are thinking, even when the cues are obvious. Individuals identified as *savants* are considered part of this disorder. Savants are autistic people who have extreme developmental delays overall but display a highly unusual ability in an area such as math or music. The character of Ray, played by Dustin Hoffman in the film *Rain Man*, is a good example of a savant. Savants make up about 10 percent of people with classic autism.

- *Asperger's disorder, often called Asperger's syndrome (AS):* Named after Hans Asperger, this diagnosis includes children who have symptoms similar to those with autistic disorder but who are more able. Many professionals use *high-functioning autism* as another term for Asperger's syndrome.² The main clinical features of Asperger's syndrome are described by Wing as lack of empathy; naiveté; inappropriate or one-sided interaction; little or no ability to form friendships; pedantic, repetitive speech; poor nonverbal communication; intense absorption in certain subjects; and clumsy and ill-coordinated movements and odd postures.³ Many people with Asperger's syndrome are never diagnosed and may be the adults we see as highly eccentric with poor social skills. There is also evidence to suggest that Asperger's syndrome is more common than classic autism, and it may be diagnosed in children who have not been previously considered as having autism.⁴

- *Pervasive developmental disorder—not otherwise specified (PDD–NOS)*: Commonly referred to as *atypical autism*, this diagnosis is applied to children with mild symptoms who do not fit into one of the other categories. Doctors sometimes use a PDD–NOS diagnosis to avoid using the more harsh term of *autism* and to decrease the stress on parents. However, some professionals do not see this as a separate disorder and feel these children should be placed within the Asperger’s syndrome category.

- *Nonverbal learning disability (NLD)*: Some professionals use this diagnosis for individuals who have symptoms similar to those of PDD–NOS, whereas others consider NLD a learning disability. The leading authority on NLD, Sue Thompson, sees it as related to Asperger’s syndrome.⁵ Children with NLD have remarkable rote memory and reading skills but have difficulty with coordination, visual/spatial organization, and social skills.

- *Childhood disintegrative disorder*: Children with this diagnosis have normal development in speech and social skills for at least the first two years of life but then regress and lose previously acquired skills, leaving them with autistic symptoms.

Discussion

Describing autism is complicated because professionals do not agree on definitions and behavioral criteria for autism are constantly being changed. A number of other factors also cloud our understanding of autism:

- Symptoms and behaviors vary from child to child.
- Negative attitudes and old beliefs are still very prevalent, producing an immense fear of the diagnosis of autism. That fear has spawned the creation of other labels to avoid the stigma of the autism label.
- Most doctors, teachers, and psychologists have limited experience with autism.

- Some children are labeled autistic when their behavior can be attributed to other causes, such as severe allergies, poor nutrition, or brain injury.
- New research is changing perceptions and language around autism.

One of the primary areas of debate among professionals is the treatment of autistic children. The various therapies reflect the philosophies of those who propose them. For example, some professionals believe that a child diagnosed with severe autism will forever lead a very limited life and will probably need to be institutionalized. Others believe that a child with autism can function more appropriately and learn to succeed in many tasks.

Certainly, the most thought-provoking information about the autism spectrum comes from those people who consider themselves to be living with high-functioning autism or Asperger's syndrome and from parents who believe this about their children. Their stories are as varied as the autism spectrum itself. And while they reflect the confusion and pain that continue to surround autism, they also reflect enormous advances in the perception and treatment of children with autism. Viewed as a whole, these stories offer testament to the human spirit and hope that inspires many to transcend diagnostic labels. Consider these examples:

- With the help of a loving mother, Temple Grandin earned a Ph.D. and went on to enjoy a highly successful career as an animal scientist. She not only learned to cope with her autism but also became a well-known spokesperson for people with autism. She has written a book about her experiences, *Thinking in Pictures and Other Reports from My Life with Autism*.⁶

- Once a severely abused autistic child, Donna Williams completed a remarkable and compelling journey of recovery to self-awareness as an autistic person and a successful career as a college professor. She tells her story in *Somebody Somewhere, Breaking Free from the World of Autism*.⁷

- In *Pretending to Be Normal, Living with Asperger's Syndrome*, Liane Holliday Willey talks about how she coped with Asperger's syndrome throughout her life and became an advocate and spokesperson for others like her.⁸

All three people are within the autism spectrum, but their stories illustrate the many differences and abilities among autistic people. A review of the current literature reveals that most professionals would conclude that Grandin, Williams, and Willey were able to cope with their autism successfully because they are highly gifted and intelligent. An overwhelming majority of professionals agree that there is no cure for autism and that the most someone with autism can achieve is a strategy for living with the condition. This position is challenged by some parents, however, who claim to have cured their children.

The word *cure* means different things to different people. Grandin states, "If I could snap my fingers and be non-autistic, I would not. Autism is part of what I am."⁹ Williams says, "The most important thing I have learned is that autism is not me. Autism is just an information-processing problem that controls who I appear to be."¹⁰ And Willey says,

Yet, no matter the hardships, I do not wish for a cure to Asperger's Syndrome. What I wish for is a cure for the common ill that pervades too many lives; the ill that makes people compare themselves to a normal that is measured in terms of perfect and absolute standards, most of which are impossible for anyone to reach. I think it would be far more productive and so much more satisfying to live according to a new set of ideals that are anchored in far more subjective criteria, the fluid and the affective domains of life, the stuff of wonder, . . . curiosity, . . . creativity, . . . invention, . . . originality. Perhaps then, we will all find peace and joy in one another.¹¹

The issue of *curing* versus *copying* takes on new meaning when it involves a severely autistic child. Who can ignore children locked into their own worlds, silently flapping their hands, twirling and

excessively focusing on objects, resisting and often avoiding human touch? The debate concerning appropriate intervention strategies is intense, but desperate parents will often try whatever is suggested.

On the other hand, there are compelling testimonies offered by parents who have ignored the advice of the professionals and apparently cured their children. In *Son-Rise: The Miracle Continues*, Barry Neil Kaufman recounts how he and his wife, Samahria, brought their son Raun out of autism.¹² Raun was diagnosed at eighteen months as severely autistic and neurologically damaged with an IQ of 30. Ignoring the recommendations of professionals who counseled them to institutionalize their son, the Kaufmans created an innovative, home-based, child-centered program and transformed Raun into an outgoing, social boy with a near-genius IQ. Today, he is a highly intelligent, competent, and well-balanced adult who lectures, writes, and teaches about the Son-Rise Program that began with him.

Similarly, in her book *Let Me Hear Your Voice*, Catherine Maurice describes how her child triumphed over autism through intensive behavioral therapy.¹³ Her daughter started that therapy very young and is now a happily functioning child.

Dietary changes can also have a meaningful impact on the treatment of children with autism. Bernard Rimland, director of the Autism Institute, is the leading authority and proponent of diet and nutrition as an effective way to treat children with autism. He claims that vaccines, food intolerances, and yeast conditions can trigger autistic behavior. In addition, Rimland offers research that identifies autism as a possible immune system disorder.¹⁴ Donna Williams claims that a change in her diet and the inclusion of certain types of vitamins helped her recover from autism.¹⁵ Likewise, Karyn Serousi describes how dietary changes cured her son of autism in *Unraveling the Mystery of Autism and Pervasive Developmental Disorder: A Mother's Story of Research and Recovery*.¹⁶

Sensory training has also proven effective for some individuals. In *A Sound of a Miracle: A Child's Triumph over Autism*, Anabel

Stehli tells her story of seeking treatment for her autistic daughter.¹⁷ She eventually rejected much of the professionals' advice and found two alternative treatments—visual retraining by Dr. Melvin Kaplan and auditory integration training (AIT), pioneered in France by Dr. Guy Bérard.

Due to the complexity of behaviors and symptoms among children within the autism spectrum, it is extremely difficult to predict who will cope successfully with autism and who will need supervised care all their lives. Some approaches work with some children, and some work with others. Most parents try many different therapies to find the one that best matches the needs of their child, and some children learn how to function on their own, as Williams and Willey did. No matter what approach to treatment a family chooses, maintaining hope and seeing the world from the child's eyes is essential.

Ministering to Families

Even though much progress has been made concerning the diagnosis, treatment, and prognosis for autistic children, autism is still a frightening label for most parents. According to Kathleen Dillon in *Living with Autism*, most people cannot comprehend the harsh, unyielding nature of autism.¹⁸

The complexity of the available information about autism can overwhelm parents, and fear and unhappiness can keep them from thinking creatively. Having an autistic child does not have to be a tragedy. Treating it as such will only ensure that it stays one. Kaufman's *Son-Rise: The Miracle Continues* and Stehli's *Dancing in the Rain* are wonderful books for helping parents think positively about their autistic child.¹⁹

Given the amount of negativity that surrounds autism, we can help most by providing hope, understanding, and a nonanxious presence for families. Ministering to parents who are just realizing that their child is autistic will be different from ministering to parents who have accepted their child's autism and are now struggling

to find appropriate intervention programs or therapies. For a more in-depth discussion about the difficulties, challenges, stress, and grief that families experience, please refer to the chapter “Ministering to Families.” The section on “Ministering to Families” in the chapter on mental retardation will also be helpful, as these parents’ experiences are similar to those of parents with autistic children.

Ideas for Teaching

“We have a child with autism, and we would like to bring him to church to participate in the religious education program”—a statement like this is likely to send many religious educators into a state of understandable panic. The words *autistic child* often conjure up images of an uncontrollable, sometimes violent child locked into his or her own world.

There are so many misconceptions about autistic children that it is difficult to know how to minister to them. We know that the autism spectrum includes a very wide range of behaviors. While professionals disagree about diagnosis and treatment or therapy, autistic children can be included in programs with appropriate knowledge and planning.

The following story from Connie Grant, a religious educator at the Countryside Church in Palatine, Illinois, illustrates the benefits of involving children within the autism spectrum in our programming:

Jason has Asperger’s syndrome and is now eighteen. He has been coming to the church since he was eight, participating in our church school classes to the extent he was able. He found his own comfort level with the understanding and quiet encouragement of his teachers and classmates. In his affirmation statement to the congregation at the conclusion of our Coming of Age program, he spoke about how important the church has been in his life commenting, “No one makes fun of me here.” There was not a dry eye in the house. This is my idea of a success story.

When we understand the world of an autistic child, we can help him or her learn to live in our world successfully. Consider these factors when creating a ministry for children within the autism spectrum:

- *Dispel the myths.* The proliferation of misinformation and stereotypes about autistic children can seriously affect a church's ability to be a welcoming place. Members of the congregation, including the children, may need to receive awareness training in order to become better informed. Learning to include and accept an autistic child can be a life-affirming experience for all involved.

- *Let go of the fear.* Many adults are uncomfortable around autistic children because they feel that they need to stop these children's behaviors and fear that they cannot. By not judging the child's behavior as weird but accepting that he or she is coping as well as possible at the moment, we can release the fear that negatively affects how we minister to autistic children.

- *Ignore the labels.* Many of our attitudes and expectations are based on what the label of *autism* implies and thus limit how we relate to autistic children. For example, it is generally recommended to avoid eye contact with these children because it can make them uncomfortable. Children with Asperger's syndrome, especially, may not understand that making eye contact is a way to get information about a person. While this is certainly true for a number of children, it is not true for others. Moreover, reacting this way to a child who is just beginning to make eye contact with people would negate the very behavior we wish to encourage. Seeing beyond the label and treating each child as an individual is critical.

- *See the world from the child's perspective.* The behavior of autistic children has baffled people for many years; we cannot hope to figure out such complex behavior when no one else has. We can, however, accept that these children are behaving as well as they can and not deliberately being bad. For instance, a child with

Asperger's syndrome often experiences high anxiety in social situations. If there are too many interruptions in a session, too much noise, and not enough structure, he or she may panic, become angry, or hit something.

- *Create a climate of love and acceptance.* The need for a loving, accepting community cannot be overstated. Children within the autism spectrum who function well enough to go to school are bombarded daily with stress and high anxiety. They know that most children and adults think they are weird, and trying to fit in can be confusing and painful. Our job is to recognize that these children have many gifts and to encourage them and celebrate their uniqueness.

Mental Retardation and Developmental Delays

Some people treat me differently because I have Down syndrome, but I just want to be treated like anyone else. And some people think that just because I have Down syndrome, I'm stupid or handicapped. I don't feel that way. My Down syndrome never kept me from doing anything I wanted to do. Everybody is different. I don't like it when people say I am a victim, or when they say I suffer from it. It's not a disease. I don't like it when they show the pictures of the little chromosomes, because it's personal to me. But I think it's great to have an extra chromosome and I like talking about it. It doesn't make me feel "down." Actually, I call it "Up syndrome" because I am happy and excited about my life.

—Chris Burke, *A Special Kind of Hero*

MOST DISABILITIES ARE MISUNDERSTOOD and generate fear and prejudice. However, people with mental retardation seem to be particularly feared, mistrusted, and even reviled. People with mental retardation have been mistreated throughout history, at times enslaved, killed as witches, subjected to systematic extermination, and deemed to be criminally defective. Except for a few attempts to provide them with education, these individuals were typically isolated and institutionalized. The most fortunate ones were cared for by their families.

The language used to describe people with mental retardation has reflected society's misunderstanding about them. In years past, the terms *mongoloid*, *cretin*, and *imbecile* were all considered acceptable and used with no harmful intent. Today, they are considered derogatory and inappropriate, as is the word *retard*. The accepted label of *mental retardation*, which is used to describe cognitive limitations, often has the same, although unintended, affect.

Despite this evolution in terminology, negative attitudes persist. In a culture that prizes intellectual ability, children with mental retardation are sometimes seen as defective and as a drain on educational resources. In addition, most people still feel uncomfortable around those with mental retardation because they may look or act in unusual ways.

Most people have never had the opportunity to know a child like Chris Burke, whom many know as the star of the television program *Life Goes On*. In that program and in real life, Burke has been able to counteract negative attitudes about people with mental retardation. He has demonstrated that people with mental retardation have much to offer if we allow them to develop their strengths.

One mother of a daughter with a cognitive delay described her experience in her church's religious education program. Because of her daughter's unflinching love for everyone and consistently positive attitude, she was seen as a beloved and beneficial influence for all the children. They eagerly accepted and wanted her in their program, fully recognizing her unique traits and abilities. In recognizing the uniqueness of all children with mental retardation, we can find ways to include them in our religious education programs.

Description

The language used to describe people with mental retardation continues to evolve. In recent years, there has been a growing trend to use the term *developmental delay*, instead of *mental retardation*. The American Association of Mental Retardation (AAMR) also uses the term *intellectual impairment*.

Some professionals and parents find the term *developmentally delayed* more humanizing because it implies that children with mental retardation have limitations but are still capable of learning. Children with mental retardation can certainly continue to learn and develop. However, according to some, using the term *delayed* gives the false impression that these children will eventually grow out of or be cured of their cognitive delays. Thus, the term *mental retardation* is the one most frequently used by the AAMR and special-needs professionals.

The AAMR has provided the most widely accepted definition of *mental retardation*:

Mental retardation is a particular state of functioning that begins in childhood and is characterized by limitation in both intelligence and adaptive skills. Mental retardation reflects the “fit” between the capabilities of individuals and the structure and expectations of their environment. Mental retardation refers to substantial limitations in present functioning. It is characterized by significantly sub average intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, home-living, community use, health and safety, leisure, self-care, social skills, self-direction, functional academics, and work. Mental retardation manifests before age eighteen.¹

To put it more simply, a child is considered to be mentally retarded if he or she performs significantly below age level in two areas—intellectual functioning (or intelligence) and adaptive functioning (or the ability to act independently and function in social situations). In *Children with Mental Retardation: A Parent’s Guide*, Romaine Smith writes,

Perhaps the best way to understand mental retardation is in relation to normal development. As a developmental disability, mental retardation means a significant and lifelong impairment in development, for example, in the acquisition of

language, thinking, self-help, social and other skills. It does not mean, however, that development and learning is impossible. Rather, mental retardation means that the *rate* of development is slower than in a child with *normal* intellectual and adaptive skills.²

Mental retardation is the most common of the developmental disorders, and like most developmental disorders, it can be difficult to diagnose, particularly when it occurs in conjunction with other disabilities such as autism, cerebral palsy, or epilepsy. The most common diagnoses of mental retardation include the following:

- *Down syndrome* is the most common noninherited cause of mental retardation. According to the National Down Syndrome Society, it affects people of all ages, races, and economic levels, occurring in about 1 in 800 to 1,000 live births.³ The diagnosis of Down syndrome is usually made shortly after birth and based on the appearance of the infant. Most children with Down syndrome fall within the mild to moderate range of mental retardation. However, some children have more severe mental retardation while a few have normal intelligence.

- *Fragile X syndrome* is the most common cause of inherited mental retardation. The condition results from an abnormal or defective gene on the child's X chromosomes. Because girls have two X chromosomes, an abnormality on one of the X chromosomes may not cause severe symptoms. As a result, fragile X syndrome predominately affects boys. While most boys with fragile X syndrome have mental retardation, only one-third to one-half of girls with fragile X have significant intellectual impairment. The rest of the girls have either a normal IQ or some learning disabilities. Sometimes children with fragile X syndrome are misdiagnosed with autism because the presenting characteristics are similar. Genetic testing is important for a correct diagnosis.⁴

- *Fetal alcohol syndrome (FAS)* is currently the leading cause of mental retardation in the Western world, occurring in an estimated 1 in 500 to 700 births.⁵ Doctors have not been able to

determine what constitutes a safe drinking level for mothers during pregnancy, as the amount of alcohol that can cause full-blown FAS varies from mother to mother. Moderate to excessive alcohol consumption during any stage of pregnancy can cause damage to the developing fetus. Children with FAS generally have mild mental retardation. However, some have normal intelligence and some have severe mental retardation.⁶

- *Prader-Willie syndrome (PWS)* is a complex genetic disorder that includes short stature and incomplete sexual development. It is the most common genetic cause of obesity.

- *Phenylketonuria (PKU)* is a single-gene, inherited metabolic disease that leads to mental retardation if left untreated in infancy. All babies in the United States are routinely screened for PKU.

- *Childhood lead poisoning* is the most common environmental health problem affecting children in the United States. Large amounts of lead in a child's body can cause brain damage and mental retardation.

Other types of mental retardation may be caused by serious injuries during pregnancy, a serious disease such as AIDS or Reye's syndrome, neural tube defects (NTD) such as spina bifida or anencephaly, or birth trauma resulting in cerebral palsy. (NTDs and cerebral palsy are discussed in the chapter on motor disabilities.) Children may also become brain damaged or mentally retarded after birth as a result of an accident or serious disease; for example, shaken baby syndrome can cause mental retardation. Exposure to toxic substances and malnutrition can also cause mental retardation to a fetus or child.

Discussion

Four major issues always seem to emerge in discussions about mental retardation: historical and cultural attitudes that continue to influence the treatment of people with mental retardation; the

definition of *mental retardation* and the implications of labeling; the sentimentalization of children with mental retardation; and ethical, moral, and legal dilemmas concerning issues such as abortion, prenatal testing, genetic discrimination, and medical treatment.

These issues are emotional and intellectual minefields and can profoundly affect us morally and spiritually. It would be easier to ignore them and focus solely on the mechanics of how to include children and youth with mental retardation in our ministry. However, to do so would be an enormous disservice to families who have children with mental retardation, as they live with these issues every day. Moreover, these issues affect how people with mental retardation are accepted in our churches. While discussions of these topics can be polarizing, there is no better place than within a spiritual community to talk about them, for they can influence how we ultimately view and value all life.

Over the past thirty years, U.S. society has followed a policy of deinstitutionalization. Parents today can receive early intervention services for their children and place them in the public school system, both in special education programs and in regular inclusive classrooms. More and more children with mental retardation live at home with their families, except for those who have severe medical needs. Many adults with mental retardation live in group homes and have jobs and other responsibilities.

Yet many negative cultural attitudes are still prevalent. Book after book, article after article tells of the understandable devastation and grief parents feel when they learn that their child has mental retardation and the unrelenting prejudice of people whose attitudes about mental retardation have changed little over the years. In *Expecting Adam*, Martha Beck describes what it feels like for a parent to experience this prejudice:

Just as I feared, Adam and I have experienced mockery and judgment and exclusion, and they have all been painful. It hurts every time people look at Adam and see only the defor-

imity of their own perceptions, instead of the beauty before their eyes. But more and more, I feel this pain not for my son but for the people who are too blind to see him. The lessons I have learned from Adam have hurt more than just about anything else I ever felt in my life. And it's been worth it, a thousand times over.⁷

Consideration of people with mental retardation adds moral complexity to discussions about abortion, prenatal screening, priorities for organ donor programs and other expensive medical procedures, and the identification of defective genes by the Human Genome Project. The issues of prenatal testing and abortion are sometimes linked with discussions of Down syndrome and fragile X syndrome. Many people believe parents have the right to terminate a pregnancy when these syndromes are identified, while others believe that prenatal screening should be banned because its results can lead to a decision to abort a child. Still others point out that banning prenatal screening does not take into account the woman who wants to know if her child will be born mentally retarded in order to prepare herself to be accepting and loving when the child is born. Some advocates for people with Down syndrome believe that a woman should never abort a fetus just because it has Down syndrome. Other advocates, including parents of children with Down syndrome, such as Martha Beck and Michael Berubé, feel that the choice to abort should be the mother's and that doctors, in particular, should stay out of the decision-making process.

Another area of contention and moral complexity involves the highly expensive medical procedures and treatments that children with mental retardation often need. What is the humane thing to do if there is one liver donor and two children who need a liver transplant to save their lives—one who is severely mentally retarded, with little likelihood of ever being able to care for himself, and one who is bright and inquisitive with unbounded potential? There are no right or wrong answers to questions like these.

As ministers and religious educators, the best support we can provide is to make sure that parents faced with this decision receive all the available information. We should also be sensitive to the fact that parents of children with mental retardation are very aware of the controversies and prejudices surrounding their children.

Ministering to Families

In an effort to counteract the stigma often associated with mental retardation, some promote a vision of children with mental retardation as gifts from God, sent to make us better people. This sentiment is difficult to contradict without sounding callous.

In her book *Differences in Common*, Marilyn Trainer suggests that these children are “special . . . in the truest sense of the word.” But she and her husband strongly object to patronizing descriptions of their son, Ben, who has mental retardation:

How many times have we winced inwardly, saying nothing while listening to those dreadful clichés about “Heaven’s Special Child,” or “Little Gift from God,” or “Angel Sent from Above” just for us? The idea that Ben is a gift from heaven is totally offensive to us. Worse, it is demeaning to our son. Ben is not a cute little kid any more, nor unaware of things said about him. He is a young adult functioning pretty well in the real world. And that’s exactly what he wants to be, no more, no less.

We’ve come to the conclusion that if we are to be true and effective advocates for our son, we have a *duty* to tell it like it is. How can we, his parents, expect society to accept him in a realistic way—to respect him as a person, flawed perhaps, but a person nevertheless—if we insist on adorning him with a mantle of the supernatural.

Realistic acceptance is what we all should be striving for. Sentimental glop is not going to do it for our kids. In fact, we’re convinced that it promotes the continuation of negative and outdated images.⁸

We do not want to deny the humanity of children with mental retardation. They are human beings with their own traits and abilities.

But the idea of children with mental retardation as gifts from God contains an element of truth, in that many parents of such children view them as wonderful blessings and feel that their children have changed their perceptions and visions of life dramatically. In *Life as We Now Know It*, Michael Berubé suggests a compelling vision:

Even if you don't think that biology is destiny, and even if you don't believe evolution follows any plan, there's still something very seductive about the thought that Down syndrome wouldn't have been so prevalent in humans for so long without good reason. Indeed, there are days when, despite everything I know and profess, I catch myself believing that people with Down syndrome are here for a specific purpose—perhaps to teach us patience, or humility, or compassion, or mere joy. A great deal can go wrong with us *in utero*, but under the heading of what goes wrong, Down syndrome is among the most basic, the most fundamental, the most common, *and* the most innocuous, leavening the species with children who are somewhat slower, and usually somewhat gentler, than the rest of the human brood. It speaks to us strongly of design—if design govern in a thing so small.⁹

There is much in the literature to support the view that children with mental retardation can bless a family's life. After the initial feelings of grief, parents who accept and love their child often feel that they have been given a special gift. Whatever the parents' view, we need to tread very carefully. In particular, we must avoid blaming parents who decide they cannot keep their mentally retarded child at home. Most children with Down syndrome are mildly to moderately retarded and do well in a loving home environment. But the more severely retarded and medically dependent the child is, the more difficult it will be to have him or her live at

home. Just as it is incorrect to assume that all children with mental retardation should be institutionalized, it is incorrect to assume that all children with mental retardation belong at home with their families. Each child is born into this life with his or her own set of circumstances, needs, and support systems, and all those factors should be considered when selecting the best form of care. Where the child lives must be the family's decision.

Appropriate ministry to a family with a mentally retarded child depends on what stage the parents are at in terms of accepting their child's condition. Parents who are just coping with the news that their child is mentally retarded will need different support than parents who have accepted their child's diagnosis. The parents of children with Down syndrome often learn of this condition either before or just after the child is born. Some parents may think there is something wrong with their child's development but not receive the diagnosis of mental retardation until months or even years after birth.

Whenever they receive the news, the parents will probably be faced with conflicting and confusing information and experience emotional overload. They will need consistent and gentle support during this time. This is the stage when parents are feeling bad for themselves and for their child. Helping them get through this stage so they can focus more on the needs of their child will begin the healing process.

Smith describes what parents typically feel about their child with mental retardation. Pastoral care may focus on helping parents accept and work through these feelings:

- *Helplessness*: Parents feel helpless when they sense something is developmentally wrong with their child but they can get no answers. Parents may also feel helpless after the diagnosis because of feelings of inadequacy.
- *Denial*: Some parents pretend that there is no problem when they feel that there is nothing they can do to make the situation better. While denial is a normal reaction, pretending too long can jeopardize the ability to obtain critical services for the child.

- *Guilt*: Most parents blame themselves for their child's mental retardation. In an effort to answer the question "How did this happen?" the mother may review her pregnancy and history to see if she did anything wrong. The most important thing to remember is that unless parents were heavy drinkers or drug addicts, they are not the cause of their child's mental retardation, just as they are not the cause of earthquakes or tornadoes.

- *Uncertainty*: Parents who do not know the cause of their child's mental retardation may ask endless questions about why and whether there was anything they could have done to prevent it. The fact is that one-third of parents never find out the cause of mental retardation in their child. This may be small consolation, but focusing only on finding out the cause will not help in moving forward and focusing on the needs of the child.

- *Resentment*: Having a child with mental retardation when others around you have normal children creates endless opportunities to feel resentment. When other parents talk about their children's struggles, it is understandable to think that they do not have a clue as to what it really means to struggle. As parents learn to know, love, and accept their child, these feelings of resentment usually fade over time.

- *Anger*: People get angry about things they cannot control. A diagnosis of mental retardation is definitely one of these. Parents may become angry periodically if their child does not receive the services he or she needs or is treated unjustly or cruelly.

- *Relief*: Parents who have spent months or years of uncertainty about why their child cannot keep up with other children will usually feel relieved when they finally receive the diagnosis of mental retardation. Now they can finally move on and focus on what the child needs for services.

- *Grief*: Parents of a child with mental retardation will probably experience feelings of grief over and over again. That sorrow can be a constant companion. Parents grieve for the child they wanted and for the fact that no matter how much they love their child, the

mental retardation will not go away. Grief can become more manageable when parents learn to focus on who their child really is and take pride in his or her achievements.

- *Betrayal*: Parents who learn later that their child has mental retardation may feel a sense of betrayal because the doctors and other professionals did not figure it out sooner. Some professionals hesitate to tell parents because they feel an accurate diagnosis for many children cannot occur before age five and because they do not want to be the bearer of bad news.

- *Shame*: Although attitudes are improving, the label *mental retardation* still carries a lot of stigma. So even though parents know that there is nothing to be ashamed of about having a child with mental retardation, they are acutely aware of other people's negative attitudes and they may still feel embarrassed by their child's behavior in public.¹⁰

Ideas for Teaching

As Unitarian Universalist religious educators, we should ensure that our focus is on what children with mental retardation can bring to our faith communities, not only on what we have to do to include them in our religious education programming. Children with mental retardation have many of the same feelings, desires, abilities, and expectations as other children. Rather than make assumptions, we must listen to these children, for they can tell us what they need. Welcoming a child with mental retardation into a religious education program also requires educating both the other children and the adults in the congregation.

We need to establish excellent communication with the child's parents to determine at what level he or she is functioning. This comment from a parent illustrates just how important communication is in creating an effective program:

My child is invisible. The minister supports me, but does not understand how to include my developmentally disabled son. Jonathan is never part of the services when the children

receive recognition for milestones. He will never be part of Coming of Age. Why isn't there a place for my son!

Consider the following factors when creating a ministry for children with mental retardation. Many are similar to those described for children within the autism spectrum:

- *Attitudes may need to change.* Prejudice and discomfort about people with mental retardation is pervasive even today, due largely to misinformation and unfamiliarity. Including a child with mental retardation in the religious education program provides an opportunity to talk about how every person has differences and strengths. Assume that both adults and children will need some awareness training. If the parents of a child with mental retardation are willing, they are often the most appropriate people to explain to the other children about their child.

- *Ignore the labels.* If we are not careful, the label *mental retardation* can cause us to expect too little from a child. We should not let a label limit a child's opportunities or potential.

- *Let go of the fear.* As with autistic children, children with mental retardation can generate a lot of fear among those who are asked to work with them. Generally, this fear comes from unfamiliarity. Focusing exclusively on the child's problems causes anxiety. Help teachers and others focus on strengths and gifts.

- *See the world from the child's perspective.* The best antidote to fear, this is particularly helpful in working with children who have temper tantrums or aggressive tendencies. Do not make assumptions; rather, talk to the child and the parents to determine why he or she is acting inappropriately.

- *Recognize strengths.* All children have strengths and abilities, but it is easier to see these qualities in some children than in others. Helping a child find what Robert Brooks calls his or her "island of competence" can be transformational for both teacher and child.¹¹ Once a teacher starts seeing what is positive in a child, the

child will gradually blossom and his or her inappropriate behavior can be handled without fear or tension. Children with mental retardation know they are different and slower than other children. Helping them find an area of success in which they can shine will be a tremendous boost to their self-esteem as well as a wonderful learning experience for all children.

Most children with mild to moderate mental retardation function easily in regular religious education programming with children their own age, especially if the curriculum includes hands-on learning and teaches to different learning styles. Sometimes, these children need aides. Providing a separate and more structured learning environment may also be needed, especially if the child is hyperactive. Older children with mental retardation may like to help out in the nursery with younger children, or they may be more comfortable in the church service.

In closing, remember these words from Brett Webb-Mitchell: “The important thing to remember about any definition of mental retardation is that it is a definition of *people*. They are first and foremost human beings, and because they are human beings, they have the capacity to be engaged by rituals like worship.”¹²

Mood Disorders

Depression is certainly the most widespread mental and emotional disorder afflicting humankind, and very probably the oldest.

—Leon Cytryn and Donald McKnew, *Growing Up Sad*

WHEN WE THINK ABOUT MOOD DISORDERS, we usually think of depression. Most of us have felt depressed at some time in our lives. Some people believe it is an inevitable consequence of living. Fortunately, for most of us, depression is a temporary state, but for people with bipolar disorder (or manic depression), it is a chronic condition. Depression and bipolar disorder are related, but they differ dramatically in how they affect people's lives.

Children with depression and bipolar disorder are most often misdiagnosed because many of them have serious behavioral problems that suggest other diagnoses. For example, depression and bipolar disorder can co-exist with other conditions, such as attention-deficit disorder (ADD), learning disabilities, oppositional defiant disorder (ODD), and anxiety disorders. Professionals call these other disorders *comorbid conditions*. In many cases, a comorbid condition is diagnosed but not the underlying mood disorder, making it impossible to obtain the necessary treatment.

Misdiagnosis can have heartbreaking consequences. Children with mood disorders are frequently explosive and defiant, which can cause parents and siblings endless worry and trauma. The

children themselves experience the agony of not knowing why they act the way they do.

As ministers and religious educators, we very often know of a child who is situationally depressed (*reactive depression*) because of a major life change or tragedy. But we are less likely to know of a child with a mood disorder unless his or her parents have been fortunate enough to receive an appropriate diagnosis. What we may see instead is a child who is angry a lot and difficult to manage.

Ministering to explosive, inflexible children is difficult, but the church setting may be one of the few places where these children can be accepted for who they are. Interacting with children who have mood disorders takes a lot of compassion, tact, understanding, flexibility, and often a willingness to minister outside the church building. While we are challenged to our utmost abilities and resources, we must remember that spiritual healing should be available to everyone, including our most difficult children.

Description

Major depression is sometimes called *unipolar disorder* or *clinical depression*. According to David Fassler and Lynne Dumas, the authors of *Help Me, I'm Sad*, depression often takes different forms in children, depending on their ages.¹ Frequently, the symptoms are masked because the child is too young to express his or her feelings. Instead, he or she may start bullying others, picking fights, or complaining about unexplained aches and pains. These are not symptoms ordinarily associated with adult depression.

Another difficulty is that depression often changes in adolescence. Young children who are depressed repeatedly complain of physical problems, such as stomachaches and restlessness, and they experience great anxiety when separated from their parents. Adolescents who are depressed, however, tend to sleep more, feel hopeless, lose or gain weight, or abuse drugs or alcohol. Many of these symptoms can be indicators of other disorders, complicating the depression diagnosis.

In his book *When You Worry about the Child You Love*, Dr. Edward Hallowell identifies several signs that may indicate a child is depressed:

- chronic, ongoing complaints of being sad
- feelings of helplessness and emotional pain
- loss of interest in usual friends and activities that used to be enjoyable
- unusual irritable and cranky behavior
- much less attention paid to dress and personal hygiene
- loss of memory and shortening of attention span
- atypical changes in weight and sleep patterns
- substance abuse
- involvement in new, potentially self-destructive behavior
- family history of depression or other brain disorders²

Dysthymia is a mild form of depression, in which the symptoms are less severe but may last longer. Children and adolescents with dysthymia are generally unhappy or dispirited all the time. They are gloomy and brood a lot about not being loved, and they have little self-esteem. In fact, these individuals' depressive symptoms become so deeply ingrained that they seem to be personality traits.³ Dysthymia often occurs as a consequence of a pre-existing condition, such as ADD, a conduct disorder, a learning disability, an anxiety disorder, or a physical disability.

The majority of young people with dysthymia eventually develop major depression and go on to have recurrent episodes of depression or bipolar disorder. It is therefore critically important to identify and treat children with dysthymia in order to prevent later, more severe depression.

Bipolar disorder is commonly described as *manic depression*. There are several types of bipolar disorder; however, all of them include the basic symptom of extreme and debilitating mood swings that can cause a serious lack in judgment. Diagnosing a particular type of bipolar disorder is based on which moods a

person experiences and how often they occur.⁴ The moods associated with bipolar disorder are as follows:

- *Depression*: People with bipolar disorder experience clinical depression as one of their moods (see earlier explanation of clinical depression).

- *Mania*: This mood is characterized by excessive energy and frenzied thoughts and behaviors over a long period of time, such that a person's ability to function is impaired. Specific symptoms include heightened mood, exaggerated optimism and self-confidence; decreased need for sleep without experiencing fatigue; grandiose delusions and an inflated sense of self-importance; excessive irritability and aggressive behavior; increased physical and mental activity; racing speech, flight of ideas, and impulsiveness; poor judgment and distractibility; reckless behavior such as spending sprees, rash business decisions, erratic driving, sexual indiscretions; and in the most severe cases, hallucinations.

- *Hypomania*: This is a sense of heightened awareness and activity that tends to spin out of control. Specific symptoms are inflated self-esteem or grandiosity; decreased need for sleep; pressured speech; flight of ideas; difficulty paying attention; agitation, hyperactivity, and a feeling of being driven to pursue activities; and involvement in reckless activities.⁵

- *Mixed state*: This mood has symptoms of both mania and depression. Symptoms may occur together at one time or sequentially over a period of a few days. Thus, the person may swing between depression, hypomania, and mania. The mixed state is more common in children and adolescents than hypomania or mania. Given this, children and adolescents are often misdiagnosed with ADD because of the similarities between its symptoms and the mixed state. Two-thirds of the people with bipolar disorder experience mixed states.⁶

Bipolar disorder is different in children than in adults. Children cycle back and forth between moods more often than adults do. Sometimes, the cycling is so rapid that it is difficult to tell what is happening. More often than adults, children experience manic states in which they are depressed at the same time they are displaying manic behavior. According to Mitzi Waltz in *Bipolar Disorders*, children's symptoms emerge gradually over the years, such that parents are shocked when the more dramatic symptoms finally occur.⁷ This is one of the reasons that early diagnosis of bipolar disorder is so difficult.

Dmitri and Janice Papolos, authors of *The Bipolar Child*, feel that almost all children who are bipolar share certain temperamental and behavioral traits:

- *Difficulties in infancy:* Infants have a surprising lack of need for sleep, are extraspirited, seem precocious, and do everything early and with gusto.
- *Separation anxiety:* Infants and small children become extremely anxious if they are separated from their mother or primary caregiver even for a moment.
- *Night terrors:* Children have terrifying dreams of blood, mutilation, and fighting.
- *Fear of death and annihilation:* These fears accompany night terrors. Many times, these children are overcome by abject terror.
- *Raging:* These children frequently erupt into out-of-control rages. They often look like they are in a trance-like state. These rages can be traumatic for both the child and the family.
- *Oppositional behavior:* Many bipolar children are incorrectly diagnosed with oppositional defiant disorder because they can be hostile, disobedient, and negative. Bipolar children cannot cope well with transitions, so they respond negatively and become highly inflexible. The stress they feel often leads to rages and meltdowns.

- *Rapid cycling*: These children rapidly cycle from depression to mania and back again. Some cycle over a period of days, and some seem to alternate mood states several times during the day. Some children in the mixed state cycle so rapidly that they get trapped in the switch process. This results in marked agitation, high energy, and constant restlessness. When this happens, many children are misdiagnosed with ADD. Rapid cycling is much more characteristic of bipolar children than bipolar adults. This is one reason it is so difficult to diagnose bipolar disorder in children.

- *Sensitivity to stimuli*: Bipolar children are excruciatingly sensitive to stimuli of many types: "It's as if the arousal system of the child is set at such a threshold that any kind of physical sensation that is not 'just right' is extremely irritating and threatens a sense of bodily integrity."⁸

- *Problems with peers*: Bipolar children are usually not very popular with their peers. They are seen as bossy and intrusive. They miss social cues and can be overwhelmingly aggressive.

- *Temperature dysregulation*: These children are reactive to cold and heat. For example, in the winter, they may be always hot even when everyone else is cold.

- *Cravings for carbohydrates and sweets*: Bipolar children have excessive cravings for sugar and desserts. They also have food aversions. This pattern is similar to the findings about children with developmental and learning disorders. Clearly, children who are struggling have difficulties with their nutritional balance. It is unclear whether this nutritional imbalance is caused by the disorder or triggers certain behavior common to specific disorders. For example, sugar cravings may indicate an underlying *Candida* problem (an imbalance of the healthy bacteria in the colon exacerbated by high levels of sugar intake), or children may be subconsciously using sugar to give them a needed boost when they are depressed. What is clear is the need for good nutritional support.

- *Bed wetting and soiling:* Why these children have difficulties with bed wetting or soiling is not understood. However, the problem can persist for years.

- *Impending mania:* As bipolar children start to become manic, they shift dramatically and frequently, so their families can never know what to expect.

- *Hallucinations:* Not all children who become manic suffer from hallucinations, but some do. Children and adolescents are more likely than adults to have the psychotic features of hallucinations, grandiose thinking, and delusions. Children can experience both auditory and visual hallucinations. Their hallucinations are different, however, from the hallucinations of schizophrenia. Unlike someone with schizophrenia, bipolar children are more likely to realize that what they are experiencing is not normal. In addition, bipolar children's swings are sudden, and their affect is more emotional than the blunt affect of the person with schizophrenia.⁹ The schizophrenic person's disordered thoughts, hallucinations, and delusions are much more persistent and incapacitating than those of someone with bipolar disorder.

- *Suicidal ideas:* The rate of suicide among people with bipolar disorder is high. One study found that 58 percent of patients with manic depression tried suicide at least once.¹⁰ Suicide is the third-leading cause of death for people between the ages of fifteen and twenty-four.¹¹ One-third of people with bipolar disorder commit suicide, and some believe the figure is even higher if we include people with bipolar disorder who overdose with drugs.¹² Therefore, it is especially critical to be ever vigilant for signs of suicidal thinking in bipolar adolescents.

While eating disorders are not usually included with mood disorders, they are closely related to depression and its associated feelings of anxiety and anger. Moreover, the prevalence of eating disorders has reached an epidemic level in the United States. The National Association of Anorexia Nervosa and Associated

Disorders (ANAD) estimates that 7 million women and 1 million men have an eating disorder. Adolescents are particularly prone to these disorders; approximately 1 in 2,400 are affected. More than 90 percent of anorexics are female, and 86 percent report the onset of an eating disorder by the age of twenty. About 6 percent of the most serious cases end in death.¹³

There are three categories of eating disorders:

- *Anorexia nervosa* is often characterized as self-starvation. Girls and boys with anorexia nervosa are afraid of gaining weight and have an intense need to be thin. Their body image is poor and often distorted, so that they feel they look fat when they are actually extremely thin. Youth with anorexia nervosa control their weight through excessive dieting, self-induced vomiting, and/or misuse of diuretics and laxatives.

- *Bulimia nervosa* is characterized by recurring episodes of binge eating, in which large amounts of food are consumed in a short time period, usually followed by purging through self-induced vomiting or misuse of diuretics and laxatives. Some youth do not purge but go on extreme diets to control the weight gain. People with bulimia nervosa know that they are overeating but cannot stop themselves. They feel guilty and depressed afterward, which leads to the purging. Unlike someone with anorexia, a person with bulimia usually has normal weight.

- *Compulsive overeating (or binge-eating) disorder* is characterized by uncontrollable overeating without purging. Compulsive overeaters become overweight. Some consume large amounts of food in one sitting, while others eat steadily throughout the day.

Discussion

The idea that children can become depressed goes against all our feelings about childhood. Childhood is supposed to be a time of innocence—a time for play, curiosity, and learning. We want to

believe that children have not experienced enough of life or are not emotionally mature enough to become depressed. We know that children become sad, but we hope and expect that they move on. Unfortunately, they don't always, and we now know that children can suffer major depression and bipolar disorder.

In fact, the last ten years have seen a dramatic increase in the number of people, particularly children, treated for these conditions. A current theory suggests that some people are born with a predisposition to mood disorders and that a combination of environmental and social events can trigger debilitating mood disorders in children. What causes this predisposition to mood disorders is open to debate and interpretation.

Some experts believe that children's brain chemistry predisposes them to depression or bipolar disorder, while others believe that these conditions are a response to overwhelming stress. Many factors can enter into a child's mood disorder, including nutrition, environmental and social factors, brain chemistry, and a bad fit between temperament and parenting styles. The identification of these factors often directs which therapies will be used to treat the child's disorder. The most common treatments are medication and cognitive, interpersonal, play, behavior, family, and group approaches to psychotherapy.

The common use of medication reflects the widespread belief among experts that the chemistry of the brain underlies depression. This is why mood disorders are often treated with medications that affect the neurochemical functions in the brain.

Many people taking such medications experience improvement in behaviors and feelings. Some feel they would not be able to participate in other therapeutic strategies without medication. However, others have found medication ineffective or even counterproductive. Medicating children is especially controversial.

Not all of the experts who believe that brain chemistry affects depression advocate medication. Some offer different approaches to healing. In *Toxic Psychiatry*, psychiatrist Peter Breggin says that depression and bipolar disorder are responses to a psychospiritual

crisis—a moral and social phenomenon that can be understood in the context of basic human needs and strivings.¹⁴ He believes that psychiatric labels refer to human conditions that cannot be pigeonholed because they are not diseases but subjective experiences. In contrast to many psychiatrists, Breggin feels that medication cannot solve these problems and often makes them worse because they can damage the brain.

Barry Neil Kaufman suggests that we can change the chemicals in our brains by choosing to think positively. In his book *Happiness Is a Choice*, he writes,

The human organism is not simply a lifeless heap into which the soul breathes life. We can put aside the antiquated view of body separate from mind and replace it with more valid perception—bodymind! . . . Thinking has physical substance in the form of neurotransmitters and neuropeptides, visible chemical substances which are not confined to the brain but operate body-wide. . . . In creating new thoughts or revising old ones, we change the actual physiology of the entire body system in an instant. Atoms and molecules realign and readjust immediately. New biochemical and cellular configurations pop into existence. The mind is everywhere, and we can change ourselves dramatically and profoundly by simply changing our minds.¹⁵

Interestingly, research has borne out this idea. In an experiment by Dr. Andrew Leuchter at the University of California in Los Angeles, people who took placebos for depression showed marked improvement, but when they discovered they were taking a placebo, their depression returned.¹⁶

Kaufman's premise is similar to the philosophy behind *cognitive therapy*, which the mental health community commonly uses to treat children with mood disorders. Cognitive therapy is based on the belief that how a person thinks can create depressive or manic thought patterns, negative self-images, and false assumptions that affect behavior. The goal of cognitive therapy is

therefore to help the child break free from these negative thought patterns and emotions in order to stop the recurrence of the mood disorder. Strategies include using positive affirmations, substituting positive thoughts for negative thoughts, and consulting with a trusted adult when negative thoughts arise. According to Waltz, there is growing evidence that cognitive therapy can produce physical changes in the brain, such as changes in the production and absorption of neurotransmitters.¹⁷

In his book *There's a Spiritual Solution to Every Problem*, Wayne Dyer offers this explanation:

In the low energy of depression, we identify or diagnose the chemical imbalances that result and conclude that we need to restore that chemistry to its natural harmonious level. We pour chemicals into our bodies and we see some changes, less despair, more harmony, less tension, more cheerfulness. We conclude that depression is cured with drugs and chemicals. Why the body-mind is out of balance should have been the first question. Depression, like stress, is internally generated by one's attitudes. Could it be that one crucial ingredient that represents a spiritual solution to this massive problem of depression is hope?¹⁸

Debra Whiting Alexander agrees that nurturing the spiritual life of a child who is depressed or suffering from trauma can help restore his or her heart, mind, body, and soul. In her book *Children Changed by Trauma*, she suggests three basic strategies: listen carefully, respond genuinely, and restore hope continuously.¹⁹ Dyer says, "When your emphasis is the inner spiritual energy of love, peace, rejoicing, cheerfulness, celebration, and kindness, you cannot know debilitating depression. . . . In a sense, hope is the restoration of the appetite for life itself."²⁰

We can provide spiritual nourishment and a sense of hope in our ministry to children and their families. And in doing so, we can also replenish our own sense of optimism.

Ministering to Families

Depression in children was not officially acknowledged until 1980. Blaming parents for children's mood disorders was common practice and still occurs today. This blame can cause parents immense heartache and prevent them from obtaining effective treatment for their children. While parenting obviously has an effect on the emotional health of children, mood disorders are caused by a combination of biological, environmental, psychological, spiritual, social, and familial factors.

Religious educators and ministers need to be aware that stigma and misunderstanding continue to surround behavioral and emotional disorders. It is still easy to feel that people who are depressed are weak and just need "to get their act together." Friends and family may get frustrated or angry with them when they cannot turn things around on their own. As a result, many people who are depressed feel ashamed about seeking help. Parents, in particular, may hesitate to seek treatment for their children out of fear that they will be judged as bad parents who caused their child's mood disorder. As religious educators and ministers, we need to be aware of these fears. Our support, acceptance, and understanding are critical.

While we need to be careful about assigning a label to a child, an accurate diagnosis is vitally important in order to obtain effective treatment for a mood disorder. Bipolar children can be helped tremendously with early and accurate diagnosis and subsequent treatment. But without treatment, self-esteem plummets, the manic and depressive moods become much more severe, and eventually substance abuse and/or suicide become possibilities.

Usually, manic depression is diagnosed when a child is in his or her teens. By that time, however, the child and his or her family have been through years of agony with many diagnoses and little relief. In *His Bright Light*, Danielle Steel writes compellingly of her son's struggle with manic depression from infancy, to his diagnosis at age fifteen, to his suicide at nineteen.²¹ Her son, Nick Traina,

cycled back and forth between states of incredible creative energy and anger and deep, dark depression. Steel's story of her constant struggle to find help for her son conveys how difficult it is for parents to find help for their children with bipolar disorder from professionals with differing methods of treatment.

Even an appropriate diagnosis does not necessarily ensure acceptance or compliance with treatment. Carrie Fisher, the actress best known for her role as Princess Leia in *Star Wars*, talks about her continual struggle with accepting her diagnosis of manic depression. Although she started seeing a therapist at the age of fifteen, she was only diagnosed with bipolar disorder at age twenty-four. She recalls,

I didn't like the diagnosis. I couldn't believe the psychiatrist told me that. I just thought it was because he was lazy and didn't want to treat me. I was on drugs, too, at the time, and I don't think you can accurately diagnose bipolar disorder when someone is actively drug addicted or alcoholic. Then I overdosed at 28, at which point I began to accept the bipolar diagnosis. . . . So maybe I was taking drugs to keep the monster in the box.²²

Many people in the psychiatric recovery movement feel that their diagnoses made them *worse* because others then focused on their disorder instead of on them as individuals who were coping the best way they knew how. Any odd behavior was seen as evidence of the disorder, when it would have been tolerated in another person.

In the case of an eating disorder, both the individual and his or her family are often in denial about the condition. This means that it is usually hidden and surrounded by guilt, shame, and unhappiness. Given the severe health consequences of eating disorders, as well as the mental and emotional pain they cause, it is critical to get help for anyone who might be suffering from such a disorder. In our roles as ministers and religious educators, we can seek advice from professionals or contact ANAD about their CONFRONT program on how to approach the individual and his or her family.

We do not have the training to make diagnoses, but our experience working with children should give us a sense of when something is not right. Acting on that sense can be difficult, however, especially when ministering to parents who are in denial about their child's mood disorder. Denial is more common when the child is young, as parents find it easy to believe that he or she will outgrow the disturbing behavior. As religious educators and ministers, we have to tread very carefully with parents. All we can do is gently suggest that they seek a professional opinion and then support them no matter what they decide.

Our opinion may be better received if it is well informed; namely, we need to be aware of the factors that place a child at risk for developing depression. In *Help Me, I'm Sad*, Fassler and Dumas describe eleven risk factors and point out that the interaction and cumulative effect of these risk factors is of critical importance. Some of these risk factors are influenced by family dynamics and therefore will affect how we minister to families:

- A child is more likely to develop depression if one or both parents have a history of depression.
- Stressful life events—such as hospitalization, an illness in the family, going to a new school, a change in the parents' financial situation, breaking up with a girlfriend or boyfriend, and failing in school—can cause a child to feel depressed. This kind of depression usually passes, but if a child experiences a series of traumatic losses (such as the death of a parent or sibling, the parents' divorce, a natural disaster, or violence), he or she may develop serious depression.
- Child abuse, inconsistent or unstable caregiving, parental substance abuse, and conflict between parents can cause a child to be depressed.
- Children who have been diagnosed with a disability or are otherwise seen as different can experience isolation, unpopularity, and loss of self-esteem, which make them more vulnerable to depression.

Of course, the most serious worry about someone who is seriously depressed is that he or she will commit suicide. We need to be aware of the risks for child and adolescent suicide.

We have limited time with the children in our religious education ministry and may not have the opportunity to observe the signs of depression. However, when we know that a child has a mood disorder that puts him or her at risk for suicide, we can be sensitive to changes in that child. For instance, a dramatic change in a child's behavior—say, from engagement to listlessness—over several Sundays is reason to talk with the parents.

The American Foundation for Suicide Prevention suggests the following steps if a child is suspected of being at risk for suicide:

- Take the child's actions seriously.
- Talk to the child's parents.
- Insist that the parents get help from a medical or mental health professional or help them to do so.
- Support the child and encourage the parents to listen to him or her.
- Avoid undue criticism and remain connected.²³

Tuning in to the observations of peers is also useful in determining if a youth is at risk, as adolescents often know when something is wrong with their friends. Teach youth groups about suicide prevention. General guidelines include taking a friend's actions seriously; encouraging the friend to seek professional help and accompanying him or her if necessary; talking to a trusted adult; and not trying to help the friend on one's own.²⁴

It is also critical to provide a support network for children and youth coping with a peer's suicide, as all of them will experience symptoms of posttraumatic stress disorder (PTSD). According to the National Center for Post-Traumatic Stress Disorder, these symptoms can be debilitating and must be taken seriously.²⁵ (More information on PTSD is provided in the chapter on anxiety disorders.)

Ideas for Teaching

Unlike physical and developmental disabilities, mood disorders are often attributed to a lack of emotional well-being. Thus, it is appropriate for a faith community to minister to children with mood disorders from a spiritual perspective. This will not resolve or eliminate the factors behind the mood disorder but instead will provide a context for exploring the human condition.

As religious educators and ministers, we all know children and youth who see the world as a negative, unforgiving place. Ironically, it is these pessimistic children, who are trying to protect themselves from disappointment, who are often susceptible to depression. Helping them connect to the divine within and to see the world as a sacred, wondrous place can help lift the pain of their mood disorder. And for those having difficulty with personal relationships, being part of a faith community can promote feelings of acceptance and understanding. As religious educators, we can create a climate in which all children are loved and cherished.

In *Raising Resilient Children*, Robert Brooks and Sam Goldstein describe how one *charismatic adult* can make a positive difference in the life of a struggling child. That adult is someone who listens, cares and supports, sees the strengths in the child rather than just the problems, and is consistently present in the child's life. Often, it takes only one charismatic adult in a troubled child's life to lift him or her out of despair and stop self-destructive behavior.

Ideally, that adult is a parent, but it can be someone else. A religious community can be an excellent source of charismatic adults. We can *all* play this role in children's lives by following these suggestions:

- *Listen carefully.* If a child is having serious difficulty fitting in or is posing a behavior problem in the religious education program, listening carefully to his or her explanation of the situation without judgment is absolutely necessary for understanding the child's perspective and ministering to him or her. Listening

patiently to one struggling child can be difficult if there are only two adults in a room full of children. And if there is only one adult, it will be impossible. Thus, we need to make sure that enough adults are present in religious education groups that we can meet the needs of all our children. If we cannot provide a patient listener within the program, we must be sure that someone listens to the child outside the program.

- *Respond genuinely.* Difficult children need to know that people care about them. In particular, they need to know that we can dislike their behavior but still care about them as people. Try to look beyond the behavior to identify what you like about each child, and then tell him or her about it. Also be clear about what behavior is expected and what you and the other adults in the program can do to help the children. If, for some reason, a child is removed from the program, let that child know that you will not give up on him or her and that you will stay in contact until everyone agrees that he or she can comfortably return.

- *Love and support the real child, not the troublesome behavior.* Some children become very good at hiding their true selves because they have come to believe that they are bad, uncontrollable, difficult, and worthless. Our ministry can help them reshape that perception and see themselves as unique children of the universe and that there is nothing they can do to destroy our love for them. As members of our faith community, they need to hear our spiritual thoughts and beliefs of hope.

- *Create ways to understand others.* Some children with mood disorders are so embroiled in their own difficulties and depressing thoughts that they have no understanding of what other children are experiencing. Finding ways for them to help others can open doors of understanding and ease their own pain.

- *Work with parents.* Many parents are quite knowledgeable about their children's needs and what does or does not work in encouraging acceptable behavior. Work with parents to recognize the

signs that explosive or troublesome behavior is imminent and defuse it. For example, an older child may be able to recognize when something is about to trigger a bout of rage, and his or her strategy may be to leave the room and find a quiet place to calm down. As teachers, we need to be aware of this and provide a safe place for the child to retreat. In addition, we need to ensure that the other children in the group know why it is acceptable for this child to leave the room.²⁶

- *Practice visualization, guided meditation, and prayer.* Helping children connect with a higher power or sense of transcendence can provide hope and a connection with what is sacred and meaningful in their lives.

- *Restore hope continuously.* It cannot be stated too many times that hope helps people heal. Children depend on adults to provide that vision of hope. We can provide hope by believing in each child and by providing ways for him or her to feel accepted, loved, and worthwhile. Children gain hope by experiencing positive results from their actions. We can set up a win/win situation for every child.

Anxiety Disorders

Toxic worry is a disease of the imagination. It is insidious and invisible, like a virus. It sets upon you unwanted and unbidden, subtly stealing its way into your consciousness until it dominates your life. As worry infiltrates your mind, it diminishes your ability to enjoy your family, your friends, your physical being, and your achievements because you live in fear of what might go wrong. It undermines your ability to work, to love, and to play. It interferes with your starting a new task or even enjoying the completion of an old one.

—Edward Hallowell, *Worry, Hope and Help
for a Common Condition*

MOST OF US KNOW HOW IT FEELS to be anxious or worried. We can feel anxious about a new job, speaking in public, waiting for our teenage child to come home, driving in an unfamiliar city, meeting new people, or handling an unfamiliar situation. Anxiety is tied into our basic biological survival mechanism. It can keep us alert in a potentially dangerous situation.

Most of us have the internal coping skills to reassure ourselves before anxiety becomes debilitating. We know the anxious moment will pass without doing us harm. But children often do not have enough life experience to cope with their anxiety. They need adult intervention and support to teach them how to cope and to realize that anxiety can sometimes be useful and that it will always go away.

Given the prevalence of high anxiety in our culture, it is more than likely that we have children with anxiety disorders in our religious education programs. In most cases, because we see the children in our programs for a limited amount of time, highly anxious children pose no problems. If the anxiety becomes severe, however, the child may want to avoid church. Many parents will stop bringing their children rather than face a constant struggle. To minister to these children and their families, we can provide clear expectations while fostering a sense of connectedness to self and others and offering imaginative and creative programs that engage and support the children.

Description

Professionals use many terms to describe children who need professional intervention and treatment, such as *extremely anxious*, *overly worried*, *overly sensitive*, and *very fearful*. Children have an *anxiety disorder* when their fears are out of control and interfere with their daily activities.

There are a number of types of anxiety disorders, and as with mood disorders, the types are not discreet, which makes diagnosis a subjective process. Moreover, some children experience more than one anxiety disorder, further complicating diagnosis. Children may exhibit their anxious feelings with behaviors such as crying, tantrums, freezing, clinging, avoidance, and headaches or stomachaches—none of which are unique to anxiety disorders.

So, when does normal anxiety reach the level of a disorder? An anxiety disorder is distinguished by its debilitating effect in terms of limiting daily activities. These disorders can be successfully treated, however, provided an accurate diagnosis is made. The following are the basic types of anxiety disorders.

Specific Phobias. According to the Anxiety Disorders Association of America (ADAA), a *specific phobia* is diagnosed when a fear becomes a central part of an individual's life after six months and starts to interfere with his or her daily activities.¹ In more general

terms, a specific phobia is an intense reaction to or irrational fear of a specific object that is generally not considered dangerous and avoidance of that object. For example, a small child may fear large dogs. Even if a specific dog is friendly, the child will avoid that dog and then all large dogs and eventually all dogs. When adults struggle with phobias, they usually realize that their fears are irrational. However, most children have difficulty articulating their fears and do not realize when those fears are irrational or out of proportion to the situation. Thus, common childhood phobias include animals, storms, heights, water, blood, the dark, and medical procedures. Specific phobias in children are most common between the ages of six and nine years old and are not usually debilitating. They generally disappear as children grow older.

Agoraphobia. This anxiety disorder is sometimes defined as an anxiety disorder distinct from specific phobia. It affects one in twenty in the general population.² Agoraphobia is an all-encompassing anxiety that renders people unable to participate in most social situations. According to John S. Dacey and Lisa B. Fiore in *Your Anxious Child*, agoraphobia is actually about the fear of losing control in public places.³ People with this condition feel so anxious about being vulnerable in unfamiliar surroundings that they are reluctant to leave their own homes. Agoraphobia is uncommon in early childhood and usually begins to appear in adolescence or young adulthood. Most children and adolescents with agoraphobia experience panic attacks.

Social Anxiety Disorder (SAD). Sometimes called *social phobia*, SAD is characterized by persistent anxiety in social situations, usually because of the threat of embarrassment, scrutiny, or humiliation. Individuals with this anxiety disorder are intensely self-conscious and concerned about what other people think of them. And even though they may realize that these feelings are exaggerated, they cannot control them. Among children, SAD is most common in middle childhood and adolescence, although it can be

found in preschool and grade school children who are excessively shy. If left unresolved, SAD can lead to isolation, depression, and substance abuse.

Selective Mutism. This condition is considered a symptom of SAD or a severe form of SAD. Some younger children avoid certain social situations by shutting themselves out verbally; thus, they will speak in some social situations but not others. The onset of selective mutism usually occurs before age five but is not considered serious until a child enters school. Although children are generally diagnosed between the ages of four and eight, they were probably extremely shy previously. Selective mutism can also be a symptom of posttraumatic stress disorder (PTSD) resulting from sexual abuse. Maya Angelou's book *I Know Why the Caged Bird Sings* is a classic story of selective mutism due to sexual abuse.⁴

School Phobia. Children who refuse to go to school may have one or more anxiety disorders. Sometimes refusal to go to school is considered a single anxiety disorder referred to as *school phobia*. Some professionals place school refusal in the SAD category. It can also be a response to agoraphobia or part of separation anxiety disorder, obsessive-compulsive disorder, or generalized anxiety disorder. In general, most professionals view school refusal as a symptom or behavioral response to anxiety, rather than a single anxiety disorder.

Anxiety-based school refusal affects 2 to 5 percent of the school-age population. If left untreated, it can lead to serious consequences in socialization skills, self-esteem, and school performance. The most common stressors leading to school refusal are separation anxiety, concerns about academic performance, anxieties about making friends, and fear of a teacher or a bully. Common school fears include being separated from caregivers; riding on the bus; eating in the cafeteria; using the school bathroom; being called on in class; changing for gym; interacting with other children or teachers; and being picked on by peers or older children.⁵

Separation Anxiety Disorder. It is normal for very young children to feel anxious when separated from their parents or caregivers. Usually by the age of four, children can cope with this anxiety or be distracted from it. When children over the age of four are unable to or exhibit excessive anxiety about leaving their parents over a period of at least four weeks, they are probably experiencing separation anxiety disorder. In younger children, this disorder exhibits itself as crying, clinging, and/or panic. In older children and adolescents, the signs of separation anxiety disorder include unrealistic worry about potential harm to loved ones or fear that they will not return home; reluctance to sleep alone; refusal to attend school; and physical symptoms such as stomachache or headache. These children and youth may refuse to sleep over at a friend's house or show reluctance to go anywhere by themselves.

Generalized Anxiety Disorder (GAD). The characteristics of GAD are excessive or unrealistic anxiety about a variety of situations. People with GAD cannot handle anxiety; therefore, they develop anticipatory anxiety when they're even thinking about being put in an uncomfortable situation. Dacey and Fiore describe the person with GAD as someone who "worries about worrying."⁶ In many cases, people with this disorder are perfectionists, who constantly repeat tasks until they think they have done them just right.

GAD usually begins to affect children between the ages of six and eleven and can continue into adolescence and adulthood if left untreated. These children are often easy to identify because anxiety dominates their lives. Their physical symptoms may include restlessness, tiredness, difficulty concentrating, irritability, unusual muscle tension, and sleep disturbance. For a specific diagnosis of GAD, one of these physical symptoms must occur regularly over the course of six months. Many children and adolescents with GAD also experience panic attacks. GAD is a frustrating condition because children generally do not know the source of their anxiety; they just feel overly anxious. If they have a panic attack, they do not know why.

Panic Disorder. This anxiety disorder is rare in young children, with the onset usually occurring in the midtwenties. However, it does occur more often among older children and adolescents. A diagnosis of panic disorder is made when an individual experiences at least two unexpected panic attacks followed by at least one month of worrying about having another panic attack. A *panic attack* is a short episode of intense fear or discomfort that lasts approximately twenty to thirty minutes and peaks after about ten minutes. In order to be classified as a panic attack, four or more of the following symptoms must develop abruptly and peak within ten minutes:

- a feeling of imminent danger or doom
- the need to escape
- palpitations
- sweating
- trembling
- shortness of breath or a smothering feeling
- a feeling of choking
- chest pain or discomfort
- nausea or abdominal discomfort
- dizziness or lightheadedness
- a sense of things being unreal, depersonalization
- a fear of losing control or “going crazy”
- a fear of dying
- tingling sensations
- chills or hot flashes⁷

About half of adults with panic disorder had SAD as children, which has prompted some researchers to propose that SAD is an early manifestation of panic disorder.⁸ Agoraphobia can result from panic disorder when a child starts to avoid places in which she or he has experienced or might experience a panic attack.

Posttraumatic Stress Disorder (PTSD). Many people associate posttraumatic stress disorder with military conflict, but in fact, this disorder can occur in the aftermath of any trauma, such as a

serious accident or natural disaster. In particular, individuals who have experienced an event that involved a threat of death or serious injury to themselves or others are at risk for developing PTSD. PTSD can result if the person felt such intense horror, fear, or helplessness that the trauma is imprinted in such a way that he or she continuously relives the trauma in his or her mind.

Identifying PTSD in children and adolescents can be difficult because they often do not know how to effectively communicate their feelings and emotions. With children who have experienced trauma, it is important to watch for the signs that might indicate PTSD, such as frequent headaches and stomachaches and extreme agitation. Other symptoms and behaviors that may indicate that children and adolescents are re-experiencing the trauma include these:

- dramatic play behaviors that act out the traumatic events
- repeated bad dreams
- thoughts or recollections
- avoidance of the activities, situations, or people associated with the trauma
- detachment from others or numbness and loss of interest in surroundings
- difficulty remembering the details of the trauma
- inability to sleep and irritability
- difficulties in focus and concentration⁹

Children who have experienced sexual abuse are at particular risk for developing PTSD. According to the National Center for Post-Traumatic Stress Disorder (NCPTSD), 10 percent of boys and 25 percent of girls will be sexually abused by the time they are eighteen years old, and 90 percent of these children will experience some symptoms of PTSD. Early warning signs that a child has been sexually abused can resemble the symptoms of anxiety disorders as well as depression and behavior disorders. Whatever the cause of the trauma, Dacey and Fiore strongly recommend that children receive professional intervention immediately, as the consequences of letting this disorder go untreated can be dangerous.¹⁰

Obsessive-Compulsive Disorder (OCD). OCD is a complex psychoneurophysiological disorder characterized by fearful and repetitive thoughts that drive individuals to perform senseless rituals in order to reduce the fearful thoughts. *Obsessions* are recurrent, persistent thoughts, images, and impulses that are frightening in nature; they generally revolve around the fear of hurting oneself or others. The most common obsessions are about contamination, such as fear of dirt or germs, and persistent doubts about having performed some necessary act, like turning off an appliance. Obsessions can also take the form of extreme discomfort when things are out of order or horrific impulses such as thinking about hurting someone. *Compulsions* are repeated behaviors or mental acts that are used to decrease the fear and anxiety caused by obsessions. Common compulsions include:

- *Cleaning*: Individuals concerned with contamination and germs will constantly clean their hands or their homes. Many avoid touching things they think are dirty, such as shoes, doorknobs, chalk, and other people.
- *Checking*: Checking several times to make sure that doors and windows are locked or that the stove and other appliances are turned off or unplugged.
- *Symmetry*: Doing things the same way every time, such as making sure eating utensils are lined up, exiting a room the same way one entered it, and making sure all the pictures on the wall are lined up perfectly.
- *Hoarding*: The inability to throw anything away—even useless items. People with this compulsion often spend hours sorting items.
- *Repeating*: Repeating a name, phrase, or action over and over again, such as turning the lights on and off or rewriting a school assignment over and over until it is perfect.
- *Praying*: Praying constantly, confessing every bad thought, and praying for everyone so they will not come to any harm.

The cycle that characterizes obsessive-compulsive disorder works like this: Obsessions, or fearful and repetitive thoughts,

cause a high level of anxiety, which leads the individual to act out compulsions, or repetitive behaviors, in an effort to neutralize the anxiety. And while the individual may feel immediate relief, he or she will eventually feel worse, at which point the anxiety will return and the cycle will begin again. Thus, the person with OCD never learns what most of us know—that the anxiety will go away on its own. Obsessive-compulsive disorder is particularly prevalent among children, affecting one out of every hundred American children, or over one million in all. This makes OCD more prevalent than diabetes, although it is rarely discussed. Children as young as age four can develop OCD. Today, through cognitive behavior therapy (CBT) and medication, children and adolescents can learn to successfully treat and manage their OCD.¹¹

OCD Spectrum Disorders. The term *OCD spectrum disorders* was first used in the 1990s by psychiatrist Eric Hollander, who posited that there were other disorders that presented characteristics similar to those of OCD—for instance, trichotillomania, or compulsive hair pulling; body dysmorphic disorder (BDD), or preoccupation with an imagined body defect; hypochondriasis, or the belief that one has a serious physical illness despite medical advice to the contrary; kleptomania, or compulsive stealing; severe nail-biting; compulsive gambling; and compulsive buying or spending. The difference between OCD and the OCD spectrum disorders is the feeling associated with the behavior. People with OCD may feel some fleeting relief upon completing a compulsion but no pleasure. Someone with an OCD spectrum disorder, on the other hand, often feels both pleasure and relief while performing the compulsive behavior, followed by distress when he or she sees the damage that the compulsion caused.¹²

Tourette's Syndrome. Tourette's syndrome is not an anxiety disorder, but there is a high prevalence of Tourette's among children with OCD. About one-third of children with OCD also have Tourette's syndrome, and about half of children with Tourette's

have obsessive-compulsive symptoms.¹³ Tourette's syndrome is a neurological disorder characterized by involuntary movements and vocalizations (or tics). Usually, this disorder emerges around age seven, although it can start earlier or later. In addition to OCD, Tourette's syndrome is often accompanied by conditions such as ADD, specific learning disabilities, and sensory integration problems.

Discussion

The causes of anxiety disorders vary and may involve a combination of factors, including genetics, brain chemistry, personality, and life events. Children and adolescents can experience any of the major types of anxiety disorders that adults can experience, although some are more prevalent in childhood and tend to be age specific in terms of onset. And while adults and children may experience similar symptoms of anxiety, children often display and react to those symptoms differently. These differences can create problems in diagnosis, including determining whether a child's behavior is just a phase or an actual disorder.

Despite the fact that anxiety disorders are highly treatable with psychosocial therapy and medication, only about one-third of the people struggling with anxiety disorders receive treatment, according to the Anxiety Disorders Association of America.¹⁴ Professionals who work with overly anxious children use a combination of treatments to help them develop coping skills and resilience and learn how to interact more successfully with their environment.

In our work with these children, we need to understand the rigid thinking patterns and often debilitating behaviors that they use to cope with their intense fears. A fearful child experiences three basic reactions:

- a *physical reaction*, such as a pounding heart, shortness of breath, sweaty palms, lightheadedness, and tightness in the chest

- a *cognitive reaction* involving the images that promote the fear, such as inaccurate and overblown perceptions that make a harmless event seem threatening
- a *behavioral reaction*, or the tendency to avoid the situation that is perceived as frightening

Most experts agree that the physical reaction to a stressful situation, sometimes called *the fight-or-flight response*, is hardwired into the human body. This response was essential in our ancestral days of hunting and gathering. However, most of the stressful situations children face cannot be resolved by attacking or running away. For example, a twelve-year-old girl may feel that everyone is staring at her and thinking she is odd whenever she is in a room full of people. At birthday parties, she may become so anxious that she leaves. Eventually, she may avoid all parties, social gatherings, and maybe even school. Ultimately, she may refuse to leave her home. A child like this needs to learn how to calm her nervous system, so she can think clearly and creatively in stressful situations.

Even if children can manage to calm themselves, many exhibit distorted thinking when highly stressed. That is, they have a faulty understanding of what they are experiencing and feeling, accompanied by inflexible thinking due to stress. These children do not seem to know how to access their imaginations to find creative coping strategies for their fears. They need to learn to become better problem solvers.

Children who are master worriers tend to magnify and distort their fears. The following list, adapted from Katharina Manassis's book *Keys to Parenting Your Anxious Child*, identifies common cognitive distortions:

- *Arbitrary inference*: interpreting situations or events without factual information. For example, John does not say hello to Mary at lunch, so Mary immediately thinks that he is mad at her and avoiding her, even though John was friendly in class.
- *Selective abstraction*: focusing on a negative detail out of context and ignoring other more prominent features. For example,

Harry receives resounding applause after playing his piano recital piece without any mistakes. But when his teacher talks with another student first before congratulating him, he worries about what he did wrong.

- *Overgeneralization*: forming a general conclusion on the basis of a single event. For example, Joan falls once during her ice skating lesson and decides that she is a terrible skater.

- *Minimization or magnification*: gross underestimation of an event and gross exaggeration of an event to see the worse possible outcome. For example, Tom, who is afraid of dogs, feels that all the dogs in his neighborhood are vicious and that there is nothing he can do to protect himself.

- *Dichotomous thinking*: an either/or interpretation of events with little tolerance for ambiguity. For example, Rachel's older brother told her that he could not go to the movies with her because he was scheduled to play with his friend Jacob. Rachel decides her brother likes Jacob better than her.

- *Personalization*: an unsupported perception that an event reflects on one's self. For example, Mario overhears a brief conversation describing someone who dresses badly, and he immediately assumes they are talking about him.

- *Emotional reasoning*: equating feelings with facts. For example, Shawna feels anxious talking to Sue in a group of people, so she concludes that she can never talk to someone unless he or she is alone.¹⁵

Even if they develop a plan for coping, highly anxious children tend to avoid anxiety-producing situations or give up after initial attempts to face their fears. If the anxiety becomes severe, these children may start avoiding not only the situation that caused the initial anxiety but also other situations where the anxiety may occur again. Sometimes, they generalize from the initial fear so much that it gets lost. But by then, their avoidance of situations may be so profound that they cannot go to school or even leave

home. The avoidance that originated with the now-lost initial fear has become so extensive that it is seriously debilitating. Children need to be taught to have faith in themselves and their ability to deal with their anxiety before it gets out of control.

Ministering to Families

Because anxiety is often a silent affliction, we as ministers and religious educators will most likely be unaware of the children in our program who have anxiety disorders. Additionally, families often deny that there is a problem or work hard to hide the problem from the public; many will be unwilling to talk about their child's excessive anxiety.

We can reasonably suspect that there is a problem if a child never talks while participating in a religious education group, insists on performing certain rituals before participating, or often becomes terrified for no apparent reason. When we suspect that a child has an anxiety disorder, talking with his or her parents is the necessary first step. We must be very careful, however, not to diagnose but only to suggest that the parents talk with a professional about their child's anxiety. Some parents are actually relieved to have an outside observer confirm their suspicions. They can experience enormous stress trying to decide if their child will grow out of a dysfunctional behavior pattern or if it is a more chronic condition.

While all anxiety disorders affect the dynamics of the family, OCD is especially powerful in this regard. Given this, we need special understanding in order to minister to the family of a child with OCD. Some professionals refer to OCD as the "hidden epidemic."¹⁶ Children with OCD try to hide the symptoms, and many professionals are not trained to diagnose this disorder. To further complicate diagnosis, a child may have mild symptoms of OCD for years before some outside stress or trauma triggers a major obsessive-compulsive episode. OCD also waxes and wanes over

a lifetime. As described by Herbert L. Gravitz in his book *Obsessive Compulsive Disorder*,

It is like riding a roller coaster without ever stopping. The sufferer may be relatively symptom-free for days or weeks, even months, when suddenly the disease strikes again. Symptoms often come from out of nowhere and the sufferer feels like he or she has been blindsided.¹⁷

It is essential to understand that OCD is a problem with brain chemistry and biologically driven. According to Tamar E. Chansky in *Freeing Your Child from Obsessive-Compulsive Disorder*,

Simply stated, OCD comes from a biochemical mishap in the brain. Part of the brain sends out a false message of danger and rather than going through the proper “screening process” to evaluate the thought, the brain gets stuck in *danger gear* and cannot move out of it. The emergency message circuit keeps repeating and is “immune” to logical thought.¹⁸

While OCD does run in families, it can occur in an individual with no genetic predisposition. Moreover, it is no one’s fault. OCD in children is not the result of poor parenting or inappropriate behavior. Children do not engage in compulsions because they want to but because doing so is the only way they know how to cope with the awful obsessions locked in their brains. When they understand that OCD is caused by a sort of misfiring in the brain, then they can start to realize that they have a choice in how to respond. The child realizes, “I don’t have to listen to this message—it’s not real—it’s a brain trick. I can fight this.”¹⁹ The goal is not to make the OCD disappear but to change the child’s response to it. Children can learn to cope with their fears and to recognize that their obsessions and compulsions are a result of the OCD. OCD is a trap; it is not who they are.

The other anxiety disorders may be caused by a combination of factors, including genetics and brain chemistry as well as

personality and life events. Whatever their individual causes, these disorders share the effect of bringing shame to the children who experience them. Children with anxiety disorders are often stigmatized by their bizarre behavior, such that they and their families will do anything to keep the disorder a secret. These children know that their peers do not have to do the things they do to maintain control or to stay safe, and they are usually ashamed of their lack of self-control.

With these dynamics, the family coping with a child with an anxiety disorder is in many ways similar to the family coping with an alcoholic member. In our religious education programs, we need to let the parents and if possible the children know that there is no shame involved and that effective treatment is available. Again, our role is to suggest, not to diagnose.

When the family acknowledges that there is a problem, they can move toward healing what Gravitz calls a “traumatic wound.” According to Gravitz,

We are never fully cured of our traumatic wounds. In contrast to curing, our traumatic wounds may or may not be eliminated when we heal. But the suffering is gone. We discover we are not separate but are part of the unity of the universe. Healing goes deeper than symptoms; it involves becoming clear about our real self and purpose in life.²⁰

Thus, through healing their severe anxiety, children and their families can learn to embrace life.

Ideas for Teaching

Children with excessive anxiety may need additional help in the religious education classroom. For information on how to support these, review the section “Teaching the Anxious Child” in the chapter “Religious Education That Welcomes All Children.”

Another good resource is John Dacey and Lisa Fiore’s *Your Anxious Child*, which describes the COPE method for helping

overly anxious children address their fears. The ideas presented in this book will be useful in developing our programs because all children will benefit from activities that enhance problem-solving abilities, flexibility in thinking, self-worth and faith in self, and the ability to live in the present. In addition, some of the techniques Dacey and Fiore suggest for calming the nervous system will be helpful to all children.

Humor is an excellent way to distract a child who is becoming overly anxious, and performing exercises in visualization and guided mediation can increase a child's visual ability to see himself or herself in a calming scene. The recitation of a prayer with powerful meaning can calm an overly stimulated system and bring peace to a troubled mind. The famous prayer by St. Francis of Assisi ("Lord make me an instrument of peace") is an example of this type of prayer. Dacey and Fiore also talk about helping children create a "bank of goodwill," in which they regularly perform acts of caring and helping others.²¹ This "bank" can help them during difficult times.

Finally, imaginative thinking is a critical tool for children with high anxiety, who often believe they must rigidly follow all of the rules and even make up rules in order to feel safe. Problem-solving activities that foster flexible, imaginative thinking can help anxious children begin to cope. Moreover, encouraging the positive side of children's imaginations can help them develop persistence in the face of obstacles and failures.

Disruptive Behavior Disorders

I've yet to meet a troubled child who wasn't, above all else, terribly lonely. I presume loneliness even before I see the child. The misbehavior of troubled children is seldom what it first appears to be. Understanding this, I believe, is the only place to start. No child has a need to create a life of conflict. Think about it—what need is the child trying to express?

—L. Tobin, *What Do You Do With a Child Like This?*

WE ALL KNOW KIDS WHO JUST HAVE TO SAY NO, even when it is in their best interest to say yes. They seem angry and resentful all the time; some are disrespectful. These are the children who can readily blame others but cannot take any criticism themselves. They seem to fail deliberately at everything they try. They seem unhappy with life and with themselves. Sometimes, these children are impossible at home but function well in school. Sometimes, their behavior gets them into trouble wherever they are—even legal trouble.

These children are often described as having *oppositional defiance disorder (ODD)*. More extreme, destructive behavior is considered a manifestation of *conduct disorder (CD)*.

The children who are oppositional, defiant, and explosive may pose the biggest and most complicated challenge for a congregation and its religious leaders. Certainly, a major part of that challenge is to balance the needs of all the children in the religious education program with the needs of a child who may be a constant disruptive influence. When ministering to such a child, we

must always remember that behind his or her troubling behavior is a person longing for love, community, connection, self-esteem, and competence.

Even when it is necessary to remove a disruptive child from a group situation, it is critical to continue ministering to him or her and to seek other ways that he or she can participate in church activities. In fact, the church may be the best place for this type of child to learn what it means to be part of a community of love that will never give up on him or her.

Description

Disruptive behavior disorders is the overall category that generally includes *oppositional defiance disorder (ODD)* and *conduct disorder (CD)*, for children and adolescents, and *antisocial personality disorder*, for people over age eighteen. *Attention-deficit disorder (ADD)* is also sometimes placed in this category; however, it is important to remember that most children with ADD are not oppositional.

As we will discuss later in this section, there is significant behavioral overlap between oppositional defiant disorder and conduct disorder. The most significant difference between the two is that extreme, destructive behavior is considered a manifestation of CD. For instance, youth with CD are often cruel to animals and people. Most youth with ODD eventually outgrow their oppositional behavior, although about one-third go on to develop conduct disorders.¹

As Ross Greene points out in *The Explosive Child*, a diagnosis does not tell us much about the precise difficulties a child is experiencing or what is needed to help the child.² Some experts believe that most children's behavioral disorders are triggered by biochemical/neurological causes that may be genetically transmitted. Whatever the cause, there is a group of children and youth whose disturbing behavior can be termed as either *oppositional defiance disorder* or *conduct disorder*, according to the *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)*, published by the American Psychiatric Association.³

Oppositional defiance disorder is characterized by behavior that is consistently hostile and aggressive over a long period of time and detrimental to family, social, and school life. According to the American Academy of Child and Adolescent Psychiatry (AACAP), children with ODD have an ongoing pattern of uncooperative, defiant, and hostile behavior toward authority figures that lasts at least six months. The specific symptoms of ODD include:

- frequent temper tantrums
- excessive arguing with adults
- active defiance and refusal to comply with adult requests and rules
- deliberate attempts to annoy or upset people
- blaming others for mistakes or misbehavior
- often being touchy or easily annoyed by others
- frequent anger and resentment
- mean and hateful talking when upset
- seeking revenge⁴

It is rare for a child to have ODD alone. Usually, he or she also has some other neuropsychiatric disorder or comorbid (coexistent) condition, such as ADD, depression, bipolar disorder, Tourette's syndrome, or an anxiety disorder. The most common pattern of comorbidity is ODD with ADD, which occurs in about 30 to 40 percent of children with ADD. The next most common combination is ODD with depression or anxiety. According to Jim Chandler, many young children with ODD go on to develop ADD or a mood disorder.⁵

Conduct disorder usually manifests itself in late childhood or early adolescence. ODD appears to be a precursor of conduct disorder. In many ways, CD is a more dangerous version of ODD. It is considered the most serious of the childhood psychiatric disorders and the most difficult to treat. Approximately 70 percent of adolescents with CD will grow out of it, but a comorbid condition, such as bipolar disorder, may worsen and continue into adulthood.

Conduct disorder is a repetitive and persistent pattern of behavior in which the basic rights of others or the major rules and

values of society are violated, causing significant and recurring problems in the adolescent's family, social, and school lives. This disorder is demonstrated by the presence of three or more of the following behavior patterns in the past twelve months, with at least one behavior pattern present in the past six months:

- aggression toward people and animals
- frequent bullying, threatening, or intimidation of others
- frequent initiation of physical fights
- use of a weapon that can cause serious physical harm to others (for example, a bat, brick, broken bottle, knife, gun)
- physical cruelty toward people
- physical cruelty toward animals
- stealing while confronting a victim (for example, mugging, purse snatching, extortion, armed robbery)
- forcing someone into sexual activity

Conduct disorder is often characterized by destruction of property, involving acts such as these:

- deliberately setting a fire with the intention of causing serious damage
- deliberately destroying others' property (other than fire setting)
- deceitfulness or theft
- breaking into someone else's house, building, or car
- frequent lying to obtain goods or favors or to avoid obligations (in other words, "conning" others)
- stealing items of value without confronting a victim (for example, shoplifting, forgery)

The serious violations of rules typical of CD include:

- staying out at night despite parental prohibitions, beginning before age thirteen
- running away from home overnight at least twice while living with parents or parental surrogates (or once without returning for a lengthy period)
- frequent truancy from school, beginning before age thirteen⁶

Children with conduct disorder seem to have difficulty reading the intentions of others; they often imagine that other people are threatening them or putting them down. They typically react to perceived threats with aggression and very little show of regret or remorse. They do not tolerate frustration and tend to behave recklessly. Children with conduct disorder frequently threaten suicide, and these threats should be taken seriously.

Boys with CD are more likely than girls to fight, steal, and participate in acts of vandalism. Girls with CD are more likely than boys to lie, run away, and act out sexually, including engaging in prostitution. All children with CD are at extremely high risk for substance abuse.

Many people equate CD with juvenile delinquency, even though youth who get into trouble with the law are not always oppositional and do not always display the extreme antisocial behaviors of CD. In fact, however, most young people with CD will eventually end up in the juvenile justice system.

Discussion

The disruptive behavior disorders are complicated, and there is professional disagreement about both their causes and diagnoses. Children with ODD may also have attention-deficit disorder (ADD) or another learning disability that may exacerbate or even be the cause of negative, uncontrollable behavior. Research is also beginning to show that behaviors often attributed to ODD and CD may be motivated by a mood disorder, and there is increasing evidence that conduct disorder may be a component of bipolar disorder.

If you have a child in your program with excessive behavior problems, it is important to read the chapters on ADD and mood disorders. The child may be acting in explosive, negative ways because he or she does not know how to deal with an undiagnosed condition. Some professionals believe that ODD is not actually a discrete disorder but the result of other problems.

Children and youth with disruptive behavior disorders may be in families who are coping with their behavior, or they may be in families that have given up on them. They may be on the fringes of school, or they may roam the streets, coping the best way they know how. Some of the youth who have dropped out do not fit the exact definition of ODD but are alienated from their families, school, and themselves. Society's response to these alienated youth is often negative, controlling, and punitive. They are seen as lazy, aggressive, unteachable, and unreachable. Moreover, people tend to blame them rather than look at what led to the disruptive behavior. And this is exactly what the youth want adults to know—that they cannot be controlled.

Research appears to support the theory that a combination of genes and environment produces disruptive behavior disorders. In *When You Worry about the Child You Love*, Edward Hallowell suggests that some children's brains cause them to have significantly less inhibition than others, so that they seem to be born thrill-seekers and risk-takers. These children may be under-aroused physiologically and thus seek excitement in the external environment in order to become engaged or activated.⁷

Greene indicates that many of these children have sensory integration problems that lead to low tolerance for frustration. Boys are more likely to be aggressive than girls, and this difference becomes even more pronounced in adolescents with conduct disorder.

A child's ability to manage anger is dependent on his or her ability to process language, both verbally and nonverbally. If children have difficulty understanding all the verbal information they are receiving, they can become confused and frustrated. Some children have difficulty managing emotions, thinking through sequences of events, solving problems, or reflecting on what they have heard. These weaknesses in language processing can lead to misunderstandings and difficulties in social interactions. Eventually the frustrations build up until the child becomes overwhelmed and explodes out of frustration. When we can recognize that these children have serious cognitive and emotional deficits,

then we can change our vision of them to see their behavior as their way of coping with confusing and frustrating stimuli. As Greene observes, it is difficult to view a child's behavior as purposeful when we know that he or she is coping with extremely frustrating circumstances and not thinking rationally:

It's harder still to imagine why a child would intentionally behave in a way that makes other people respond in a manner that makes him miserable. I also don't think these kids are especially angry, though I do think they're extremely frustrated. When the term anger applies to them, it's often because they're angry at being misunderstood. They typically don't understand their own behavior, but they're quite certain no one else does either.⁸

Ministering to Families

Children and youth develop oppositional behavior as a way of protecting themselves from what they see as an unreasonable and hostile world of adults. While many oppositional children come from families that are struggling with addiction, abuse, and neglect, some come from intact families where there seems to be a poor fit between the temperament of the child and the parenting style of the parents. In *Treating the Disruptive Adolescent*, Eduardo Bustamante explains,

A good fit with a difficult child is a patient and flexible parent. A poor fit is a demanding, aggressive, and controlling parent. A good fit with an easy child is a parent who is reasonably easy to satisfy. A poor fit is a parent who is excessively difficult to satisfy. Difficult children turned out just as healthy and successful as others when raised in an environment that provided goodness of fit.⁹

Parents may ask why they should be the ones to change their behavior when it is their child's behavior that is causing all the

pain and grief. Russell Barkley and Christine Benton, in *Your Defiant Child*, state that the child's environment offers the greatest potential for changing the oppositional behavior.¹⁰ Of course, the parents control an enormous part of the child's environment. This does not mean that they are to be blamed for their child's behavior, only that they are the people most able to affect it. When ministering to parents of oppositional children, it is important to understand that they may feel too overwhelmed to take on the task of changing their child's environment and their role as parents. They may feel defensive about learning new skills if they feel blamed for their child's problems. All we can suggest is that they seek professional help in order to look at their relationship with their child in a different way.

Experts are beginning to realize that the causes of the destructive and defiant behavior of oppositional children are very complex. Oppositional behavior is now seen as a precursor or an indicator of other conditions, such as ADD, depression, bipolar disorder, Tourette's syndrome, learning disabilities, and obsessive-compulsive disorder. In fact, ODD rarely exists by itself. Whatever the label assigned to these children, they are characterized by inflexibility and a very low tolerance for frustration. Hallowell describes five general causes of aggressive behavior: biological and genetic factors, inability to use language well and to put feelings into words, insufficient structure, parental influence, and peer group influence.¹¹ Most of the experts working with these young people agree with this assessment.

The lack of structure in children's lives can be one of the accumulative causes of explosive and/or oppositional behavior. *Structure* can be rephrased as *consistency*. Barkley and Benton say that consistency in childrearing is more important than creativity. For parents living with an oppositional child, they strongly suggest that consistency in rule setting, expectations, consequences to bad behavior, and encouragement of good behavior are key to breaking the pattern of oppositional behavior.¹² Hallowell says that many children do not understand rules because they change from

situation to situation and there is no overall influence in their lives to explain and enforce structure and consistency. As result, they may become confused and angry and act without a good set of values as a base.¹³ No matter what the cause for oppositional behavior, the parents' ability to learn techniques to create a "goodness of fit" environment is essential for healing the child.

Ideas for Teaching

The children and youth in our religious education programs who have disruptive behavior disorders are perhaps our greatest challenge. They are the most difficult of the difficult children. A story by Emily Green, a former director of religious education, illustrates this difficulty:

This year, we have in our religious education program a highly intelligent eight-year-old boy who has been diagnosed with oppositional defiant disorder. He is a handful and seems to take delight in being inappropriate. He will ask people about their sex life, make silly sounds during quiet times, and grab and pinch other kids. His mom's advice is to ignore him. But does this seem fair to the other kids?

As with all children, our teaching strategies and interactions with difficult children must begin with the understanding that they are not defined by a label or behavior. (It would be helpful to review the teaching strategies suggested for difficult children in the chapter "Religious Education That Welcomes All Children." Also review the teaching ideas described in the chapter on mood disorders, which are appropriate for all troubled children.)

In *Reclaiming Youth at Risk*, Larry K. Brendtro, Martin Brockenleg, and Steve Van Bockern describe what they call the "seeds of discouragement" in our society, which have caused a crisis of alienation among too many of our youth. They try to shift the focus away from the negative traits of children at risk and instead

focus on the transactions within their environment that cause their alienation, including destructive relationships, climates of futility, learned irresponsibility, and loss of purpose. Brendtro et al. apply the wisdom of the Native American child-centered culture to help heal the wounds of youth at risk:

Native American philosophies of child management represent what is perhaps the most effective system of positive discipline ever developed. These approaches emerged from cultures where the central purpose of life was the education and empowerment of children.

These authors also describe how a “circle of courage” created an environment in which Native American children could grow and flourish. Belonging, mastery, independence, and generosity are the central values in this circle:

- experiencing belonging in a supportive community, rather than being lost in a depersonalized bureaucracy
- meeting one’s needs for mastery, rather than enduring inflexible systems designed for the convenience of adults
- involving youth in determining their own future, while recognizing society’s need to control harmful behavior
- expecting youth to be caregivers, not just helpless recipients overly dependent on the care of adults

These values are the components for creating an environment that reclaims lost youth. Again, quoting Brendtro et al., “The reclaiming environment is one that creates changes that meet the needs of both the young person and the society. To reclaim is to recover and redeem, to restore value to something that has been devalued.”¹⁴

The authors also write, “We believe the philosophy embodied in this circle of courage is not only a cultural belonging of Native peoples, but a cultural birthright for all the world’s children.”¹⁵ When the circle of courage is broken, children become alienated

and are put at risk. The authors offer four approaches for working with alienated children and bringing them back into the circle of courage:

- *Relating to the reluctant*: establishing positive relationships with youth whose lives have been marked by alienation
- *Brain-friendly learning*: learning experiences that reverse patterns of failure and futility
- *Discipline for responsibility*: management approaches that counter irresponsibility and rebellion by mobilizing positive youth involvement
- *The courage to care*: fostering prosocial values and behaviors in youth whose lives are self-centered and lacking in purpose¹⁶

The chapter on mood disorders in this book discusses the positive influence that a “charismatic adult” can have on a child’s life. As Robert Brooks and Sam Goldstein point out,

We can all serve as the charismatic adults in children’s lives—believing in them and providing them with opportunities that reinforce their islands of competence and feelings of self-worth. This is not only a wonderful gift to our children but also an essential ingredient for the future. It is part of our legacy to the next generation.¹⁷

Our Unitarian Universalist churches and programs of ministry to children can be important resources for creating reclaiming environments for children at risk and for providing them with the loving oversight of charismatic adults. We can provide these children and all children with belonging, mastery, independence, and generosity.

Schizophrenia

Schizophrenia is a cruel disease. The lives of those affected are often chronicles of constricted expectations. It leads to twilight existence, a twentieth-century underground man. The fate of these patients has been worsened by our propensity to misunderstand, our failure to provide adequate treatment and rehabilitation, our meager research efforts.

—E. Fuller Torrey, *Surviving Schizophrenia*

WHEN PARENTS FIND OUT THAT THEIR CHILD has been diagnosed with some type of disorder, their response is usually one of shock and dismay. That is particularly true with a diagnosis of schizophrenia, which is often made when the child is well into adolescence.

Misconceptions about schizophrenia are fueled by media portrayals of people with schizophrenia as violent, predatory, totally delusional, and homeless. Many people erroneously believe that people with schizophrenia are weak and choose to behave bizarrely. The stigma of schizophrenia in our society can be a barrier to obtaining help.

A young person diagnosed with schizophrenia will most likely present a considerable challenge for ministry and religious education programs. The parents and family will also need extra support, as caring for a person with schizophrenia is an all-consuming task. Religious professionals and the entire congregation are called to minister to these young people and their families with understanding, patience, and flexibility.

Description

According to the National Institute of Mental Health, there is no exact definition of *schizophrenia*.¹ Most experts recognize it as a complex set of conditions that may be one disorder or many disorders with different causes. Symptoms are not the same for all people who are diagnosed with schizophrenia.² One widespread but incorrect belief is that schizophrenia is the same as split personality, the condition suffered by Dr. Jekyll and Mr. Hyde. Another is that people with schizophrenia are violent and dangerous. Yet less than 1 percent of people with schizophrenia will commit violent acts. They are more likely to have violence committed against them.³

Schizophrenia is found primarily among adolescents and adults. Childhood schizophrenia is less than one-sixth as common as the type that occurs in adolescents and adults. This disorder is rarely observed before the age of twelve, but the incidence increases at sixteen. Most children diagnosed with schizophrenia show developmental delays in language and other functions before the age of seven, when the psychotic symptoms of hallucinations, delusions, and disordered thinking begin to occur. Psychosis usually develops gradually, with children talking about strange ideas and fears and saying things that do not make sense. Other early warning signs of schizophrenia are:

- trouble discerning dreams from reality
- seeing things and hearing voices that are not real
- confused thinking
- vivid and bizarre thoughts and ideas
- extreme moodiness
- peculiar behavior
- belief that people are out to get them
- behaving younger than chronological age
- severe anxiety and fearfulness
- confusing television or movies with reality
- severe problems in making and keeping friends.

Schizophrenia can develop gradually or rapidly. When schizophrenia develops over a long period of time, it is called *gradual-*

onset or *insidious schizophrenia*. When very dramatic changes in behavior occur over a few days or weeks, it is called *rapid-* or *sudden-onset schizophrenia*. The gradual-onset type may or may not lead to what is called an *acute* or *crisis episode*, but the rapid-onset type usually does. Some individuals develop *chronic schizophrenia*, which is a “severe long-lasting disability characterized by social withdrawal, lack of motivation, depression, and blunted feelings. In addition, moderate versions of acute symptoms such as delusions and thought disorder may be present in the chronic disorder.”⁴

Schizophrenia: A Handbook for Families, published by Health Canada in cooperation with the Schizophrenia Society of Canada, has identified these symptoms:

- *Hallucinations*: Hallucinations are thought to result from excessively acute senses and the brain’s inability to interpret and respond appropriately to incoming messages. Someone with schizophrenia may hear voices or see visions that are not there or experience unusual sensations in his or her body. Auditory hallucinations, the most common form, involve hearing voices that are perceived to be inside or outside the person’s body. Sometimes, the voices are complimentary, reassuring, and neutral. Other times, they are threatening, punitive, and frightening and may command the individual to do harmful things.

- *Delusions*: A *delusion* is a strange and steadfast belief that is held only by the person having the delusion and that remains intact despite obvious evidence to the contrary. For example, someone with schizophrenia may interpret red and green traffic signals as instructions from a higher power. Many people with schizophrenia who suffer from persecution delusions are termed *paranoid*. They believe that they are being watched, spied upon, or plotted against. Common delusions are that one’s thoughts are being broadcast over the radio or television and that other people are controlling one’s thoughts. Delusions are resistant to reason. It is of no use to argue that they are not real.

- *Thought disorder*: People with schizophrenia have problems processing and organizing their thoughts. For example, they may

be unable to connect thoughts into logical sequences. They may have “racing thoughts” that come and go so quickly that it is impossible to grasp or process them. Because these individuals’ thinking is disorganized and fragmented, their speech is often incoherent and illogical. Moreover, they may have inappropriate emotional responses, such that their words and moods do not appear in tune with each other. For instance, they might laugh when speaking of somber or frightening events.

- *Altered sense of self:* This term is used to describe the blurring of the ill person’s feeling of who he or she is. He or she may feel bodiless or nonexistent, or he or she may not be able to tell where his or her body stops and the rest of the world begins. It may feel as if the body is separated from the person.⁵

Discussion

The popular understanding (or misunderstanding) of schizophrenia has come from portrayals of this disorder in the mass media. Fortunately, the success of the recent movie *A Beautiful Mind*, about Nobel prize–winning scientist John Nash, provided a more accurate portrayal of schizophrenia and helped bring this subject into the public discourse. And while the movie showed that John Nash learned to function well in his life, his ordeal is nonetheless frightening.

The National Alliance of the Mentally Ill (NAMI) has done much to fight the stigma of mental illness, particularly schizophrenia. Founded by parents and consumers (the term used by people struggling with mental illness), NAMI has promoted greater understanding, better treatment, and a more compassionate view of people with mental illness. With proper treatment, these people can lead productive lives.

In addition, NAMI has successfully fought the view once held by mental health professionals and the general public that mental illness is caused by inept mothering. NAMI supports the view, as do most mental health professionals, that schizophrenia is a

biologically based brain disorder. And while the consensus among professionals is that it cannot be cured, it can be treated with a combination of medication, counseling, support groups, and rehabilitation.

A group of individuals called *psychiatric survivors* challenge the view that schizophrenia is incurable. These individuals have been diagnosed with schizophrenia but claim they no longer have it. In *Toxic Psychiatry*, Peter Breggin describes schizophrenia as a psychospiritual crisis that can be healed through self-analysis and therapy. Like many in the psychiatric survivor movement, Breggin feels that the drugs used to treat schizophrenia damage the brain rather than heal it. He asks whether it is more accurate to view people who are labeled schizophrenic as broken, defective, and disordered or as persons and souls in struggle. When we try to understand the profound psychospiritual hurt and failure in these individuals' lives rather than view them as people with a brain dysfunction, Breggin argues, we can find an infinite number of ways to help.⁶

Psychiatric survivors Daniel Fisher and Laurie Ahern, of the National Empowerment Center, believe that people who get stuck in the emotional distress of coping with loss, conflict, and trauma are eventually labeled *mentally ill*. Similarly, in his book *The Far Side of Madness*, John Weir Perry suggests that people may need to go through severe emotional distress in order to experience self-renewal.⁷ If they do not have the necessary inner resources and social, cultural, and economic supports during this deep process of reintegration of self, they often cannot maintain a social role. When this happens, they are assigned the role of mental patient and no longer seen as valid members of society. In fact, we view them as invalids. Fisher and Ahern go on to write,

With the *label of mental illness*, a whole new set of discriminations and problems must be overcome. There is a loss of rights. People can lose property, lose custody of children, lose privacy and lose due process before the law. They are basically taken out of the traditional legal system and placed in

the extra-legal psychiatric system. The major tasks then in *recovering from mental illness* are to regain social roles and identities which are recognized as valid by oneself and the people in one's community.⁸

In their article "People Can Recover from Mental Illness," Fisher and Ahern also cite studies from the United Nations World Health Organization, which show that the rate of recovery from severe mental illness is much better in Third World countries than in Western industrialized countries, which rely more on drugs for treatment.⁹

Ahern tells a story on the National Empowerment Center's website about two college-age men who return home after experiencing similar psychotic breakdowns. One is immediately hospitalized, and the other is kept at home and treated with alternative therapy strategies to help him heal from his pain. The latter man is eventually able to return to school, while the man who was hospitalized is still barely able to function.¹⁰

Other psychiatric survivors share similar stories about the process of healing from schizophrenia as an emotional and spiritual struggle. One powerful story is told by Mark Bedillion in *Psychiatric Survivor*.¹¹ Bedillion was confined for years in a state hospital for the criminally insane, during which time he was treated with mind-numbing drugs and electroshock therapy. Despite all this, he achieved a transformative healing through a combination of spiritual counseling and his acceptance of personal responsibility.

Psychiatric survivor Jim Moore, in his review of *The Necessity of Madness and Unproductivity*, by Dr. John Breeding, writes that he was inspired to become a counselor out of his own experience with mental illness and psychiatric practices. He saw many people cast into the role of the chronically disordered who lost their personal freedom and cognitive capabilities. Yet he saw that the depth of their human light could still shine. He writes, "I am very grateful that I was able to slowly find persons and resources that saw my experience of madness as having a wisdom that was understood in

the context of a spiritual, religious, or psychic transformation.”¹²
He goes on to say,

John’s book gives hope to those of us that see the great potential in embracing the whole of human experience. Madness can be seen for what it is. There is nothing to fear or suppress. It is something to be supported and integrated. . . . We are full and whole spiritual beings in a potentiated and/or happening process of dynamic evolution. Naturally, peeling off the worn aspects of the Self can be a very dynamic and non-ordinary experience. It is who we are and we need to support experiences out of the narrow and seemingly getting narrower corridor of acceptability.¹³

Ministering to Families

It is important to realize that people with mental illness have been neglected, abused, mistreated, maimed, lobotomized, shocked, and drugged throughout history. For the most part, their concerns have been dismissed, and they have been treated as dependents who are too confused to help themselves. In fact, though, many people with schizophrenia (whether they are on medication or believe they have been cured) live full lives and contribute to their own care and happiness.

As members of a faith community, it is appropriate for us to look at schizophrenia from a spiritual perspective. Much of the current literature on this topic concerns the process of healing and returning to a greater wholeness upon successfully responding to life’s losses, conflicts, and traumas. Many books have been written to help people emerge from trauma and loss with a greater appreciation for the sacredness of life and its spiritual wonders.

Using this information as a foundation, our congregations and religious education programs can provide opportunities for spiritual exploration. We can also consider literature that explores alternative treatment strategies and the civil rights of people diagnosed

with schizophrenia. Parents are less likely to receive this type of information from the mainstream mental health professionals.

As with any emotional, mental, or behavioral disorder, maintaining a positive and hopeful attitude makes a profound difference in healing. As ministers and religious educators, we can provide an atmosphere of hope for those parents and children who are coping with shame, confusion, and grief. Constant support will be critical to parents and families as they battle the mental health system and wade through an enormous amount of information and advice concerning what is best for their child.

As religious educators and ministers, we may encounter two different scenarios involving families coping with schizophrenia. In one, the parents have a child who has been diagnosed with schizophrenia, and they have taken the medical model approach to treatment. In the other, the parents are suddenly coping with a child who is hearing voices and hallucinating, and they want to know what to do. In either case, the parents may seek alternative treatments to medication, which means they will need support as they sort through all the conflicting information from doctors, mental health professionals, people with schizophrenia, parents, and psychiatric survivors.

Parents will need support, too, in dealing with their feelings about having a child with schizophrenia. They are likely to feel guilt and/or shame. They may feel that others blame them for their child's condition. Moreover, they may be grieving for the child that they feel they have lost to this disorder. Their lives have been permanently changed, which can cause anger, resentment, and confusion. Caring for their child may have totally consumed them. Our job is to listen and to offer support. We can work with parents to help them find balance in their lives and ways to take care of themselves.

With recent research showing that disturbing behavior may be due to brain chemistry, parents are no longer blamed for their child's schizophrenia. While parents are no longer cast as the "bad guys," their behavior and interaction with their child does affect his or her behavior.

Unfortunately, the treatment strategy used with children who are depressed, highly explosive, or oppositionally defiant frequently fails when applied to children with schizophrenia. Treating schizophrenia with drugs is the overwhelming approach of psychiatrists. As previously noted, NAMI supports the view that schizophrenia is a disease of the brain, in part because that explanation is preferable to the idea that the parents are to blame and in part because medication can relieve some symptoms.

Our role as religious professionals and lay leaders is to support parents on the path they have chosen to cope with their child's schizophrenia. Those who are struggling with the immense amount of information available about mental illness might benefit from participating in the NAMI workshop entitled "Journey to Hope." (Go to www.nami.org to find a local chapter.) Parents who want to explore alternative therapies might benefit from contacting a psychiatric survivors network, such as the National Empowerment Center (1-800-769-3728).

Ideas for Teaching

Involving individuals diagnosed with schizophrenia in our youth groups will be a challenge. They will most likely be on medication, and their behavior will often be different than it was before they were medicated. They may be in and out of the hospital, disrupting contact with and support from friends and family. Moreover, their peers will probably not understand their mental illness and may view their behavior as weird and disturbing. Because of this, it will be very important to talk with members of the youth group about what their friend is going through and to ask for suggestions on how to continue to include him or her in the group.

One of the most important supports a youth group can provide is a safe haven—a place where a youth will always feel accepted, even if he or she comes and goes because of periods of hospitalization. Adolescents diagnosed with schizophrenia are terribly lonely. Consider that their lives have been disrupted, and they may have lost their friends and their support network.

Our congregations can stay in relationship with these youth and help them re-establish their connections with other people. We can also offer opportunities to work through psychospiritual struggles and renew the soul. Here are some useful ideas for ministry:

- *Respond and respect genuinely.* So many times, adolescents with schizophrenia are dismissed for having unusual or crazy ideas. Their concerns and feelings are ignored when all their behavior is seen as symptomatic of mental illness. Do not dismiss what they say, no matter how bizarre it appears. Understand that much of these youth's behavior may stem from the normal struggles of adolescence, not their illness. We can respect these young people's rights and views.

- *Establish predictability and security.* For young people whose lives are in turmoil, a predictable and secure place to come provides immense support and healing.

- *Enhance self-esteem.* The self-esteem of adolescents with schizophrenia has been crushed. Any way we can nurture it will help with their healing. Robert Brooks's and Sam Goldstein's ideas about establishing "islands of competence" for children who struggle (see page 39) will be useful here.¹⁴ With the parents' help, identify a strength or an activity the adolescent loves doing. Also see if his or her "island of competence" can be incorporated into the church experience. For example, if the youth loves music, put him or her in charge of selecting the pieces to be sung or played at each youth group meeting and give plenty of praise.

- *Love and support the real adolescent, not the unusual behavior.* Many youth with schizophrenia become experts at hiding their true feelings and their true selves. Regrettably, many come to believe that they are worthless victims of their disease. Our ministry to these young people should help them see that they are unique children of the universe and that there is nothing they can do to destroy our love for them.

- *Create ways to understand others.* Schizophrenia, by its very nature, means that the adolescent has become self-involved, with little ability to relate to his or her environment or empathize with others. Finding ways to engage teens with schizophrenia in helping others can expand their understanding and lessen the focus on their own pain.
- *Include visualization, guided meditations, and prayer.* Helping teens connect with a higher or deeper power can provide hope and a sense of what is sacred and meaningful in their lives. This is critically important for adolescents diagnosed with schizophrenia.
- *Restore hope continuously.* People with schizophrenia have lost hope, in part, perhaps, due to the psychiatric community's view that this disorder is incurable. No matter how controversial it is to believe in a cure, we can provide hope by believing in these individuals' ability to heal and renew themselves. For children and youth, in particular, the adults in their lives must provide that vision of hope.

The following story, which comes from Emily Green, the former director of religious education of a midsized church, illustrates how a religious community can successfully respond to the needs of a youth with schizophrenia and provide a place of connection and spiritual search:

We have a boy in our church who is schizophrenic. His parents are long-time members of the church and are very involved in many church activities. When Alex became a teenager, he started hearing frightening voices. His parents did not want to leave him home alone because they were afraid he might harm himself. Neither did they feel comfortable having him attend one of the classes, for fear of what might happen when he started hearing voices.

We set up a mentor situation for Alex that involved four volunteer adults who knew and liked Alex. We also had

substitutes lined up. Each Sunday, Alex had the option, with his mentor, to attend any class third grade and up, to talk to the mentor, or to do some sort of activity, such as taking care of the recycling or counting the offering. We held a special teacher meeting to inform the religious education teachers about Alex's condition and how the mentor system would work. We let the teachers choose if they wanted Alex to come into their class, and everyone said yes.

This situation has worked out very well for all concerned. The mentors really enjoy their time with Alex. Every Sunday, Alex comes to me to find out what the classes are doing so he can make his choice. He chooses the activities that interest him, so his class time is always positive. He rarely stays for an entire class and often ends up talking with his mentors. I've heard that the conversations have been wonderful.

We are now in our second year of this arrangement and Alex has requested some reading materials to share and talk about with his mentors. We started with reading and talking about the Bible and have also used several UU meditation manuals for short readings to begin discussion. He often joins the high school class in their discussions of hot issues like abortion, gun control, and the death penalty.

The relationships that Alex has developed during this time have become extremely meaningful to his family. They have allowed his parents to stay involved in church life and provided a positive way for Alex to participate in our community. Every Wednesday evening, Alex greets me with a big smile before he rings the bell to announce that dinner is ready. He has found a place where he is loved and appreciated for who he is.

Motor Disabilities

Being a person with spina bifida has meant many things to me. Having spina bifida has meant that I have to work twice as hard at things that come naturally to some people, such as trying to walk, to take care of myself, and to make my own living. These things have been hard at times, but not nearly as difficult as trying to get other people to see me as “normal” and treat me as they would anyone else. . . . As a child, it was hard to go out in public and be stared at by people and pointed at and talked about by kids, but I learned to just go on as if I didn’t hear or see them, because I knew the kids didn’t know any better, and neither did the adults, if they had never been around someone with a disability. I learned to ignore all that, but it didn’t make it any easier.

—Adrian Sandler, *Living with Spina Bifida*

CHILDREN WITH VISIBLE PHYSICAL IMPAIRMENTS are confronted daily with the reactions of the people they meet. Sometimes, as Adrian Sandler points out, the reactions are not kind; at best, they are rude and uninformed. Regardless, facing these reactions is part of the daily existence of children with physical disabilities.

When we have children with physical disabilities in our churches and religious education programs, we are immediately confronted with the challenge of inclusion. Our job is to create a safe haven for these children—a place free from the stares and the constant challenge to prove themselves; a place where they are

accepted for who they are and not defined by their physical limitations; and a place that offers a healing ministry in which the children feel safe, secure, accepted, and understood.

Description

There are many types of motor disabilities and as many or more causes. *Orthopedic impairments* affect the muscles, joints, and bones and thus affect movement. Sometimes, their cause is unknown; other times, they are caused by trauma or disease before, during, or after birth. *Genetic defects* eventually lead to neuromuscular disorders, such as Duchenne muscular dystrophy. Accidents during childhood are another cause and can result in spinal cord and traumatic brain injuries.

As with any disability, the severity of a motor disability can vary widely. Also, some children have multiple disabilities that require multiple medical and rehabilitation treatments. The common element of all motor disabilities is that they impair movement, which necessitates the use of crutches, braces, or a wheelchair. A small number of children with motor disabilities also have other conditions, such as learning disabilities, seizures, mental retardation, heart conditions, attention-deficit disorder, and hearing or visual impairments. The most common types of motor disabilities are discussed in the following sections.

Cerebral Palsy. This term is used to describe a group of motor disorders that result from damage to the brain before, during, or after birth in infancy. The damage affects the child's body movement and muscle coordination; exactly how depends on what part or parts of the brain were damaged. The United Cerebral Palsy Organization writes that cerebral palsy is characterized by the inability to fully control one's motor system:

Depending on which areas of the brain have been damaged, one or more of the following may occur: muscle tightness or spasticity; involuntary movement; disturbance in gait or

mobility; difficulty in swallowing and problems with speech. In addition, the following may occur: abnormal sensation and perception; impairment of sight, hearing or speech; seizures; and/or mental retardation. Other problems that may arise are difficulties in feeding, bladder and bowel control, problems with breathing because of postural difficulties, skin disorders because of pressure sores, and learning disabilities.¹

Cerebral palsy is not caused by problems of the muscles or nerves. Moreover, the brain damage that causes cerebral palsy does not get worse, so this is not a progressive disease. Someone with cerebral palsy will always have motor difficulty, however, and secondary conditions, such as muscle spasticity, may improve, worsen, or remain the same. *Scoliosis*, or curvature of the spine, can also occur with cerebral palsy, and spinal fusion surgery may be needed. It is very common for children with cerebral palsy to have accompanying learning disabilities.

Signs of cerebral palsy usually occur before the child is eighteen months old. The parents begin to suspect that something is wrong with their infant when his or her motor skills develop abnormally or very slowly. Diagnosing cerebral palsy usually involves testing the infant's motor skills and examining the mother's and infant's medical histories. Training and therapy can help improve functioning for people with cerebral palsy. Service animals similar to seeing-eye dogs can be used successfully to provide general assistance, such as helping a child balance, pulling a wheelchair, helping a child get up from a sitting or fallen position, retrieving items that are dropped or out of reach, and carrying items for the child.

Neuromuscular Diseases or Disorders. These types of disorders have a genetic basis, are usually progressive, and affect the muscles. There are over forty types of neuromuscular disorders, but they can generally be divided into three groups: *myopathies*, or muscle diseases; *neuropathies*, or disorders involving the nervous system; and conditions in which changes in the metabolism of the internal tissues of the body result in muscle weakness.² The public is most

aware of the myopathies, or *muscular dystrophies*, due largely to the Jerry Lewis Telethon. While the medical causes and symptoms of the many neuromuscular disorders are different, their effects are the same in that the child's muscles and coordination begin to deteriorate. These disorders also have a similar impact on the family in terms of providing care. For information on other neuromuscular disorders, please refer to *Raising a Child with a Neuromuscular Disorder*, by Charlotte E. Thompson.

Muscular Dystrophy. Muscular dystrophies are characterized by abnormal wasting and weakness of the muscles. The type of dystrophy is determined by what muscle group is affected or by the distribution of the muscle weakness. The weakness is usually symmetrical, although one side of the body may feel weaker than the other. As with cerebral palsy, scoliosis can occur, which may require spinal fusion surgery. Other tissues and organs can also be affected. All dystrophies are caused by genetic defects, which means these conditions are not contagious or infectious.

Some dystrophies start in infancy or early childhood, and some start later in life. Cases of later onset can be milder. The dystrophies are generally progressive, although there can be periods of arrest. Severe forms can lead to early death, usually from muscle weakness around the heart and lungs. Because the course and severity of the disease depends on the type of dystrophy, it is important to receive a correct diagnosis.³ Treatment should focus on helping the child be as independent as possible while using whatever equipment and aides are needed.

Spina Bifida. According to the Spina Bifida Association of America, spina bifida is a type of *neural tube defect*, a serious birth defect that occurs very early in pregnancy and involves incomplete development of the brain or spinal cord or the protective coverings of these organs.⁴ (The term *spina bifida* literally means "split or divided spine.") This disorder affects mobility and bladder and bowel control in the same way as a spinal cord injury.⁵ An

estimated 20 to 30 percent of the children with spina bifida will have seizures. The extent of motor difficulty is determined by the location of the lesion on the spine. Some children begin to walk with aides but then need a wheelchair. Others can walk without braces but lurch from side to side. More than 20 percent of children born with spina bifida have a clubfoot, meaning that the muscles on one side of the foot are stronger than the muscles on the other. Children with spina bifida are also at increased risk for bone fractures, but they usually heal quickly. Another common problem is contractures, which occur when there is an unbalance of the underlying muscles and tendons at a joint, so that the joint does not have full movement. For children with spina bifida, contractures usually occur in the hip, knee, or ankle. Children with spina bifida can also experience dislocation of the hip or curvature of the spine. Many of the common orthopedic problems in children with spina bifida are best treated with surgery.

Spinal Cord Injury. Most spinal cord injuries in children are due to spina bifida. However, these injuries can also be caused by accidents from cars, boats, bicycles, skiing, and swimming, which can occur at any age. Teenagers are more likely than young children to experience spinal cord injuries due to accidents because they are more likely to take risks. The location of the injury on the spinal cord will determine the nature and severity of the impairment. In general, the higher the injury on the spinal cord, the greater the impairment. Children and youth with spinal cord injuries need therapy to learn bladder and bowel management and to learn to walk with an aide or to use a wheelchair.

Traumatic Brain Injury (TBI). Like many spinal cord injuries, traumatic brain injuries result from accidents and often lead to mobility impairments. Unlike spinal cord injuries, however, TBI can also cause serious cognitive impairments. Some common symptoms of TBI are loss of consciousness, weakness in one part of the body, and difficulty in speaking or thinking. Ongoing

neurological problems include postconcussion syndrome, headaches, seizures, hydrocephalus, and motor impairments leading to the use of braces, crutches, a walker, or a wheelchair. Serious heart and lung problems can occur as well. TBI can disrupt all the body's systems, and there can be immense variability in impairment and rehabilitation. Moreover, once a child has had a TBI, he or she will be more susceptible to accidents because of loss of coordination and impaired cognitive functioning. Like cerebral palsy, TBI is not progressive. The damage to the brain does not get worse, but the manifestations of damage can change.⁶

All children with traumatic brain injuries need rehabilitation to help restore the abilities that they have lost. But because every TBI is unique, the rehabilitation plan must be individualized to meet the needs of each child. Most of the natural recovery from TBI occurs during the first year following the injury. After that, the recovery process gradually slows down, sometimes continuing over a long period of time. Extensive hospitalizations and medical interventions are usually required. The learning and behavioral problems directly related to the brain injury are the most common, persistent, and problematic issues in working with a child with TBI.

Discussion

When parents have a child with a motor disability, barriers to mobility within the home become immediately obvious. As the child grows and needs to use braces, crutches, or a wheelchair, stairs will become an impediment. Bathrooms will need to be made accessible. Mechanical aides become necessary so the child can accomplish various tasks. Things the child always needs will have to be placed at a level he or she can easily reach. For the entire family's well-being, the home should be adapted so that the child with limited mobility can be as independent as possible. Autonomy is critical to his or her sense of self-worth. Family members will understandably want to help children who struggle physically, but it is important to encourage and facilitate their independence.

Federal law requires schools to be accessible to people with physical disabilities. Unfortunately, most other places are not accessible. For instance, friends' houses are rarely accessible, and neither are many restaurants and other public places. Your church may not be accessible. Even children who are able to walk using braces or crutches will probably have difficulty getting around unless accommodations are made.

Accessibility means more than just physical access. It also means being free from prejudices and misconceptions. It means being accepted, first and foremost, as a person who has many abilities, not as someone who has limitations and impairments. Many people, including some parents of children with disabilities, have handicapped thinking, such that they see only limitations, not possibilities. An accessible, inclusive community sees only possibilities.

Children with motor disabilities have no choice but to live with them. Some do it gracefully, and some do not. Children with motor disabilities can become depressed and/or angry about being different from other children. And since these disabilities are generally quite visible, children may have to endure the taunts of their peers and the unkindness of some adults. Most of the hurtful treatment comes from people who simply do not understand.

Children with physical disabilities do not want people to feel sorry for them. They just want to be treated like other children, with consideration for the things that they can and cannot do.

Ministering to Families

While each of the disabilities described in this chapter is distinct, with unique medical problems and interventions, many of the experiences of the children and parents are similar. The constant care and medical expense required to raise a child with motor disabilities can take its toll on the immediate and the extended family.

“Accepting a child’s disability involves the death of a dream,” says Kathleen Deyer Bolduc in *His Name Is Joel*. She goes on to say, “In all the uncertainty and confusion of grieving for the lost

dream, one truth is unavoidable. Until a parent faces the pain of loss and brokenness, he or she cannot begin the journey toward healing, wholeness, and acceptance.”⁷

Most parents’ dreams do not include the limitations imposed by a disability. They dream of success in school and sports; hikes with the family; music, dance, or art lessons; and running and playing in the back yard with friends. Suddenly, the parents of the child with motor disabilities see all those visions crumble, and they may find it difficult, if not impossible, to envision any new dreams for their child.

The parents of a child born with cerebral palsy or spina bifida may realize the loss of their dream immediately or after several months of agonizing doubt. The parents of a child with muscular dystrophy most often learn of his or her condition later, in the toddler or grade school years. Traumatic brain injury and spinal cord injury happen with terrifying suddenness, and so does the realization that the child that was, no longer is.

With all of these disabilities, the parents have to contend with the immediate crisis of hospitalization and surgery, followed by complicated secondary medical conditions, conflicting information, a sometimes lengthy period of not knowing what their child will or will not be able to do, extraordinary expenses, and explaining it all to concerned friends and family. In short, the demands are relentless, leaving little time for the parents’ own healing and recovery.

Most parents must face all these challenges while trying to care for and be available to their other children. These children might feel alone and neglected because so much of their parents’ attention is directed to the needs of their sibling. Family therapy is often needed to help everyone express his or her needs and feelings and to help the family find creative solutions to ongoing challenges.

Ministering to the families of children with motor disabilities should involve the entire faith community. Just as congregations offer support when someone is ill or has a death in the family, the congregation can support the family with a special-needs child.

Children with orthopedic and/or neurological impairments are often in and out of the hospital. These are the times when families need help caring for their other children. A network of church members can be organized to run errands, babysit, arrange transportation, provide meals, and serve as a liaison to the outside world so the parents do not constantly have to communicate information about their child to concerned others. A church support group can also provide parents some time to themselves, particularly when they are feeling most fragile and vulnerable. Finally, church members can volunteer to be mentors, aides, and caregivers for the child when the family comes to church.

It is a sad fact that some of the children with these disabilities will die. For instance, most of the muscular dystrophies result in early death. The loss of a child can be the most painful and devastating experience that parents can suffer. Even if the death is expected, there is no way to completely prepare for the loss. Parents who have spent much of their time and energy caring for their child may feel totally lost as to what to do with their lives once that child is gone.

Consider, too, that with the loss of the child, some of the parents' friends and supports may be lost as well. Many friendships and support systems develop through caring for their child, and upon his or her death, these important individuals will no longer be part of the parents' daily lives.

In this time of great loss, we can be most helpful by just listening and holding sacred the memory of the child. When the parents can look past their loss and remember and celebrate what was special about their child, healing can begin.

Ideas for Teaching

Three primary issues need to be addressed in our religious education ministry to children with mobility impairments. First, anticipate that the other children in the program will recognize that their peer has a disability, as most mobility impairments are

observable and involve the use of a wheelchair, crutches, braces, walker, or cane. Be sure to discuss each child's condition positively with the other children in the group.

Second, address architectural and other physical barriers in the church generally and in the classrooms specifically. Work with the child's parents to fully comprehend his or her special requirements for physical accommodations.

Finally, address attitudinal barriers by providing information and sensitivity training for teachers and perhaps for the other children in the program. These children should know that their peers with motor impairments have dreams, hopes, talents, and the need for friends, just like they do.

Here are other suggestions for successfully including children with motor disabilities in religious education classrooms:

- Do not assume what children with motor impairments can or cannot do. Ask them what they can do and how they want to be helped. Consult with parents about children's physical abilities.
- Avoid doing everything for these individuals. Like all children, they need opportunities to develop a sense of accomplishment and competence.
- Find each child's "island of competence," described by Robert Brooks and Sam Goldstein in *Raising Resilient Children*.⁸ (See page 39.) Depending on the circumstances, the child's self-esteem may be very fragile. Adapt activities to make sure every child can always be included in some way.
- Do not pity children with motor disabilities. Because these children's physical impairments are so visible, people tend to imagine how awful they themselves would feel with a similar condition. Even empathy is sometimes expressed in a patronizing manner. These children, like all children, need love, understanding, and encouragement. Instead of adopting the "disability paradigm," adopt the "giftedness paradigm" and see what is unique and wonderful about the child.

- While we should not continuously stare at these children, neither should we totally ignore them. Engage them in conversation; make eye contact. If they are in a wheelchair, avoid talking over their head or down at them. Also, do not lean on the wheelchair; it is part of their personal space.
- Never move a child's crutches, walker, or cane out of his or her reach.
- If a child has difficulty speaking, give him or her plenty of time to answer. In particular, do not answer for the child or even finish his or her sentences. Model patience, love, and genuine interest in what the child has to say.
- Some children with motor disabilities do not like to be touched, but in general, a kind touch on the back or the hand is a loving way to assure children that they are loved and accepted. If all the children in the group are getting hugs, be sure the child with disabilities also gets a hug. Do not let any sense of fear keep you from touching someone with a physical disability. We all benefit from human touch.
- Avoid speaking to children with motor disabilities in a too-loud or too-simple manner. Most of these children have normal hearing, so there is no need to speak loudly, and unless you know they have some cognitive impairment, do not assume they will not understand. Speak to them as you do to the other children.
- Likewise, treat children with disabilities the same as the other children if they act out or do not follow the expectations of behavior agreed to in the group.
- Adapt all activities, even physical activities, to include children with motor impairments. If you are stuck for ideas, involve the entire group in coming up with creative solutions. If you cannot find a solution, then do not do the activity. Nothing is more humiliating for a child than watching from the sidelines while everyone else gets to participate. Accommodating each special child's needs does

not mean limiting the other children's choices; rather, it helps them all learn what it means to belong to an inclusive community.

- Arrange the room so that it is accessible for a child who uses braces, crutches, a wheelchair, or a walker. Make sure that there is no clutter on the floor and that the child can move easily from one activity to the next without having to go around unnecessary obstacles.
- For sharing or discussion time, instead of sitting on the floor on pillows or rugs, provide beanbag chairs and/or couches, so that a child in a wheelchair will be at eye level with everyone else.
- If there is no elevator to the classroom, move the special-needs child's group to a room on a floor that will be accessible to him or her.
- If the child has difficulty feeding himself or herself, ask his or her parents and the child how best to provide help. Have a supply of straws available for children who have difficulty holding a cup.
- Provide an aide for a child with severe physical disabilities who needs someone to help him or her get around and participate.

Blindness and Visual Impairments

The poets have taught us how full of wonders is the night; and the night of blindness has its wonders, too. The only lightless dark is the night of ignorance and insensibility. We differ, blind and seeing, one from another, not in our sense, but in the use we make of them, in the imagination and courage with which we seek wisdom beyond our sense.

—Helen Keller, *The World I Live In*

BECAUSE MOST OF US CAN SEE, we tend to assume that having sight is preferable to being blind. But if we make this assumption when interacting with people with blindness or when ministering to children with blindness, then we will limit their opportunities for connection and learning.

I once worked with a man who was born blind, and he told me a story about being stopped on a sidewalk by someone who shook his hand and told him how brave he was. This had happened more than once. Every time, my friend would laugh and say, “People just do not understand. There is nothing brave about being blind. It is part of who I am. I have no choice but to live with it.”

We cannot arrogantly assume that to be sighted is always better. As religious professionals and lay leaders, we can appreciate the unique way in which those who are blind or visually impaired relate to the world. We can respect their difference and perhaps learn to appreciate the world of touch, smell, taste, and hearing.

Description

The terms *blindness* and *visual impairment* do not represent discreet conditions but instead describe a range of impairments, from low or partial vision to total blindness. Usually, someone is considered visually impaired when he or she has severe difficulty completing daily activities without making special adaptations for a lack of sight. Most individuals have some usable vision, and even those who are considered blind usually have some perception of light and dark. Among children with visual impairment, 50 to 60 percent also have other disabilities, such as hearing impairment, mental retardation, or cerebral palsy.¹

In general, the term *visual impairment* refers to any condition in which eyesight cannot be corrected to what is considered normal. That might include the loss of *visual acuity* (the ability to see objects and detail clearly) or the loss of the *visual field* (the total area to be seen without moving the eyes or head). Someone is considered *legally blind* if his or her visual acuity in both eyes tests at 20/200, even with corrective lenses, or if his or her visual field is less than 20 degrees. This does not mean a total absence of vision, however. *Low vision* describes someone who has a visual acuity between 20/70 and 20/200 with corrective lenses.

There are many causes of blindness and visual impairment, including heredity, premature birth (before the retinas have fully developed), tumors, and head traumas (perhaps related to traumatic brain injury). Diseases such as measles, rubella, diabetes, tuberculosis, meningitis, encephalitis, syphilis, and anoxia can also cause blindness and visual impairment.

A very few children become both deaf and blind at an early age, most often due to meningitis or scarlet fever, diseases that have been virtually eradicated. The most common cause of deafness and blindness in combination today is a genetic syndrome called *Usher syndrome*, which affects approximately half of the deaf/blind population. Unless someone with Usher syndrome becomes part of a community of people who are also deaf and blind, he or she may lead an extremely isolating and lonely life.²

The location, extent, and type of visual impairment often determine the accommodations, adaptive devices, and learning style of the child. A child who is legally blind or has low vision qualifies for special education services.

Discussion

A good deal of ignorance and prejudice underlie society's treatment of people who are blind. Many individuals are uncomfortable being around people who are blind or visually impaired. They do not know how to act, what to say, how to help, or even whether they should help.

Historically, it was believed that the only way people could think was through seeing; therefore, if you could not see, you had to be mentally defective. Even today, our society is heavily dependent on two senses—sight and hearing. When one of them is impaired, we believe it makes the person limited or defective.

In addition, many people fear becoming blind, which may explain our fear of people who are blind or visually impaired. Our language betrays our perceptions. Think about how often we use the word *blind* to connote a lack of understanding or a state of helplessness, ignorance, or confusion: *blind faith*, *blind luck*, *blind alley*, *double-blind study*, *colorblind*, *blind spot*, *the blind leading the blind*, *blinded by hatred*, *blind submission*, and *blind to people's needs*.³

In some respects, society has come a long way in how it treats and educates children who are blind or visually impaired. We know that *blind* does not mean "unintelligent." We also know that children who are blind or visually impaired grow into adults who live independent, meaningful lives. Yet prejudice persists. We tend to view people who are blind or visually impaired as either helpless or heroic.

In addition, society tends to tell blind children and adults that they cannot do certain things because they cannot see. For instance, Olympic long-distance runner Marla Runyon was once told she could not run track and especially not hurdle events, but

she became very accomplished nonetheless. She describes her experiences in the book *No Finish Line*.⁴ Similarly, Erik Weihenmayer writes in *Braille Monitor* that he was told he would never be able to climb Mount Everest, but he did.⁵ Once he had accomplished this feat, however, some people believed that it was not his own skill but other people's help that led him to the top. Ironically, when someone with blindness or visual impairment looks normal and gets around well, some people think he or she is faking blindness. Weihenmayer says people are always coming up in front of him and waving their hands in his face to determine if he can see. When he flinches from the feel of the moving air on his face, they think he can see.

People who are deaf and blind have to cope with a double dose of prejudice and misconception. The story of Helen Keller has been made famous by several movies, countless books, and her own writings. Blind and deaf from the age of two, Keller went on to graduate from Radcliffe College and become a noted lecturer, writer, social activist, and advocate for blind and deaf people. Her achievements helped dispel the notion that people who were blind or deaf and blind could not enjoy full lives.

According to Laurie Lawlor in her book *Helen Keller*, Keller did not consider herself gifted but saw blindness and deafness as parts of who she was, like character traits.⁶ From this understanding, she developed a wonderful spiritual vision of the sacredness and oneness of all life. She learned to live in harmony with herself and the world through determination and a clear sense of her own identity, and people felt graced by her presence.

Ministering to Families

Except for their vision impairment, children who are blind or visually impaired are just like other children: They vary in ability and personality; they need love and affirmation; and they like to run, play, and socialize with their friends. The primary difference between them and other children is that they learn about the world through senses other than sight, particularly through touch.

Having a child with blindness or visual impairment, however, changes the dynamics of the family. The special needs of the child may consume the parents' time and attention, perhaps to the exclusion of the other children. The parents may need to learn how to interact with a baby who cannot see or prepare the home to accommodate the special needs of such a child. The parents may also become frustrated or confused as they face the many misconceptions held by professionals, family members, friends, and strangers about children with blindness or visual impairments.

While the special needs of the child with visual impairment will require more time and attention, they should not become the sole focus of the family and its activities. The parents will need to model how the family should interact with the child with blindness or visual impairment, balancing everyone's need for love, independence, and individual attention. The other children in the family will need to learn how to cope with the negative and sometimes hurtful reactions other people may have about their sibling. Like their parents, they may become effective advocates for their brother or sister.

Children with visual impairment or blindness will encounter many obstacles in life, which may undermine their self-esteem. For instance, grade school children may be excluded from games and activities by people who assume they cannot safely participate. Similarly, a teenage youth may feel left out when he or she cannot obtain a driver's license, like everyone else.

Just like the man described earlier in the chapter, children and youth will also encounter people who think blindness is a terrible tragedy. In *Children with Visual Impairments*, Cay M. Holbrook presents this anecdote: "One horrified mother tells of an encounter at a party with an elderly gentleman who patted her five-year-old on the head and said, 'Bless his poor heart. I just want to cry when I see children like him.'"⁷

Adjusting to the realities of blindness or visual impairment is a life-long process that constantly affects the individual's self-esteem. When confronted with negativity or rejection, children may first experience shock and denial, followed by mourning

and then withdrawal. Some may even become depressed. But usually, children soon tire of feeling down and want to get on with life. These stages can occur over and over again throughout life, however.

With good emotional support, coping activities, and realistic goal setting, children with blindness and visual impairments become more comfortable coping with the negatives they confront and grow stronger and build self-esteem. Runner Marla Runyon asserts that people's doubting attitude only made her more determined to prove them wrong.

Children who are born with blindness and those who lose their sight will have vastly different experiences. Children born with this condition may become resentful or angry when they cannot do the same things in the same ways as their sighted friends, but they usually accept the fact that they have a visual impairment. Children who somehow lose their vision, however, may go through years of denial.

Erik Weihenmayer, who lost his vision as a teenager, describes his experiences in learning to accept being blind:

When I was thirteen, I became blind from a rare disease, *retinoscheses*. There were a few months of frustration when I wasn't really sure what I'd be able to do, but something interesting happened. I didn't want to accept blindness and accept myself as a blind person. I didn't want to be identified as a blind person, but I found something interesting: when I actually accepted blindness—I didn't try to transcend it or go beyond it or beat it but just accepted it—that was the greatest thing I could ever have done. I went off to a rehabilitation center where I learned how to use computers . . . and learned how to use a cane and learned Braille. I found that, when I was able to read a poem in Braille in front of my class or was able to walk down a hallway with a cane with my buddies, those things that I thought would separate me actually connected me back to the world. I started thinking, if I thought I

couldn't read, but I can and if I thought I couldn't be mobile, but I can, maybe there are other things that I can do that I didn't think I could do, if I just approached it differently, if I thought about the idea that we can get to the top; we just have to do it a different way. So my Dad suggested that I go rock climbing. He said, "There is a program for blind kids going rock climbing." I thought, "That sounds crazy," so I signed up.⁸

Similarly, the parents who are just beginning to cope with the visual impairment or blindness of a newborn child will have different needs for ministry and support than the parents of an older child, regardless of how long that child has been blind or visually impaired. New parents will be focused on the immediate care of their baby and may not have much time to grieve or come to terms with the fact that their child has a disability.

Parents whose child becomes blind or visually impaired later in life will go through the same stages of grief as the parents whose baby is born with such a condition. The difference is that the older child will already have had a life of routines and activities that now must change. The same can be said of the other family members as well. Everyone will be affected and have to learn new ways of functioning. The dynamics of the whole family will change.

In focusing on helping their child, the parents may not confront their own feelings of loss. And at least initially, some may resent that they now have to help their child do things he or she could once do independently. Other parents may overcompensate and try to do everything for their child, leaving little room for his or her acceptance and independence.

Ideas for Teaching

The children in the religious program should receive awareness training about blindness and visual impairment, regardless of whether they know the child in a context outside the church. The

teachers in the program should also receive such training, as they will probably have some of the same fears, misconceptions, and misunderstanding as the children. Keep in mind that blindness is not a common condition, and discomfort is fueled by unfamiliarity.

If they are agreeable, involve both the parents and the child in planning the sensitivity training. Some children will prefer not to be present when the training occurs, and this decision should be respected. Others will feel comfortable talking about their blindness or visual impairment and want to help their peers understand them and their likes and dislikes. Make sure the children involved in the training have a chance to ask all the questions they have, as they will be genuinely curious.

Some of the following teaching ideas are adapted from *All God's Children*, by Gene Newman and Joni Eareckson Tada:⁹

- Be aware how to adapt each activity for the child with visual impairment or blindness.
- Remember that these children learn primarily through touch and hearing. Use concrete examples and incorporate or refer to as many of the other senses as possible.
- Be sure the child has an opportunity to *feel* what is going on. For example, create a chalice and flame out of felt that can be symbolically lit during prayer or meditation. Let the child feel the felt pieces and explain what you and the other students are doing so he or she will always know what is happening.
- Make sure the child is aware of who is in the room. The gathering activity is a good time for everyone to say his or her name.
- A gentle touch on the child's elbow is the best way to get his or her attention.
- Ask the child whether he or she wants assistance in walking—say, to the chapel or the lunchroom. If he or she wants assistance, do not grab his or her arm but instead offer your arm. The child

may want to walk a half step behind you in order to tell from the motion of your body when there are steps, turns, and so on. Also talk with the child's parents to determine how much assistance he or she needs getting from one activity to another.

- Orient the child to the classroom, and try to maintain consistency in how it is arranged. Always inform the child if there are new objects in the room or if existing objects have been rearranged.

- A child who has developed competency with a cane or uses a guide dog will probably want to become familiar with the entire church environment. The other children should learn about how these aides work, perhaps as part of the awareness training.

- At snack time, always explain and show the child where the juice cup and food are placed. Be consistent every time with the placement.

- Most religious education does not require children to read, so providing braille reading materials will not usually be an issue. However, if the child wants to read about a particular subject, you can record the information on tape or have it typed on a braille typewriter. The child's parents will be the best resource on providing these materials.

- Both teachers and children need to avoid being too helpful and constantly doing things for the special-needs child without asking first. With each new activity, ask the child if he or she wants assistance. Be aware of those things the child can do independently, and let him or her do them without first offering to provide help.

- Create an environment in which *all* children learn from each other, appreciate each other's gifts, and know that, despite appearances, they are more alike than different.

Deafness and Hardness of Hearing

Deafness is about communication, not sound.

—Paul W. Ogden, *The Silent Garden*

IN ORDER TO MINISTER TO DEAF AND hard-of-hearing children, it is important to understand the issues related to deafness. Some members of what is referred to as the *Deaf-World* do not consider themselves to have an impairment but rather a mode of communication other than speech. To them, deafness is about communication. Other people who are deaf or hard of hearing do not see themselves as part of the Deaf-World and want to function only within the hearing community. There is continuing conflict between these two communities, and how deaf and hard-of-hearing children are raised and educated depends on which community their parents belong to.

Because members of the Deaf-World consider themselves a linguistic and cultural minority, they will probably not be attracted to a Unitarian Universalist church, unless a Deaf program is a primary ministry of that church. (Similarly, we wouldn't expect someone who speaks only Spanish to attend a church that uses only English.) However, our congregations do include deaf and hard-of-hearing adults and children who do not identify primarily with the Deaf-World community.

Description

Deaf and hard-of-hearing people are very diverse in terms of the cause and degree of their hearing loss, the age of onset of their hearing loss, their educational background, their communication methods, and their feelings about their hearing loss. Despite these individual differences, the terms *deaf* and *hard of hearing* are generally preferred by the community of people with hearing loss. And as explained in *Deaf in America*, by Carol Padden and Tom Humphries, the term *deaf* should be lowercase in some instances and capitalized in others:

Following a convention proposed by James Woodward (1972), we use the lowercase *deaf* when referring to the audiological condition of not hearing, and the uppercase *Deaf* when referring to a particular group of deaf people who share a language—American Sign Language (ASL)—and a culture.¹

Padden and Humphires also provide this description of the Deaf-World:

The members of this group reside in the United States and Canada, have inherited their sign language, use it as a primary means of communication among themselves, and hold a set of beliefs about themselves and their connection to the larger society. We distinguish them from, for example, those who find themselves losing their hearing because of illness, trauma, or age; although these people share the condition of not hearing, they do not have access to the knowledge, beliefs, and practices that make up the culture of Deaf people. . . . This knowledge of Deaf people is not simply a camaraderie with others who have a similar physical condition; [it is] historically created and actively transmitted across generations.²

How people label themselves usually reflects either their identity with the Deaf community or how their hearing loss affects

their ability to communicate.³ For instance, the term *hard of hearing* is sometimes used to describe people with mild to moderate hearing loss who can use their hearing for communication purposes. This term can also refer to deaf persons who do not have or do not want to have a cultural affiliation with the Deaf-World.

Discussion

Throughout most of history, deaf people have been met with neglect, ignorance, and contempt. Deafness was seen as a disgrace, and children who were born deaf were thought to be defective. Teaching them to speak was considered of the utmost importance because the use of manual gestures was seen as a lower form of communication.

Because they could not hear or communicate, deaf children were thought to be incapable of thinking and reading. Many were considered mentally retarded. Thus, the term *deaf and dumb* conveyed the prevailing impression that deaf people were incapable of reasoning and learning.

Understanding the philosophy of the Deaf-World is important for interacting with Deaf people. Most of the information that follows is from *A Journey into the Deaf-World*, by Harlan Lane, Robert Hoffmeister, and Ben Bahan.⁴ These authors represent the diversity of people belonging to the Deaf-World: Lane is a specialist in the psychology of language and a professor and researcher of Deaf history and language, Hoffmeister is a professor of Deaf studies and the son of deaf parents, and Bahan is a Deaf scholar in ASL linguistics and a storyteller.

An estimated one million people are part of the Deaf-World, a minority group that possesses a unique language (ASL) and culture. The larger and more heterogeneous population of deaf and hard-of-hearing people that exists outside the Deaf-World is estimated to be about twenty million in the United States. This population communicates primarily through spoken language.⁵

Members of the Deaf-World are generally born into it, possess a sense of Deaf culture and history, use ASL, and are deaf.

However, people who are hard of hearing and speak well enough to be understood but choose to use ASL and identify with Deaf culture can also be members. The hearing children of deaf adults (called *codas*) can also be members of the Deaf-World. Because of their facility with ASL and participation in the Deaf-World, many *codas* become interpreters and serve as bridges between the Deaf and hearing worlds. The hearing parents of deaf children who are fluent in ASL can also become members of the Deaf-World.

The range of deaf people's ability to use ASL varies. Some are fluent and some are not; some are better at signed English than at ASL; and some are just naturally better at signing. However, they all recognize ASL as a symbol of their identity and culture.

Deaf culture is primarily passed down through the network of residential schools where Deaf-World members acquire their shared language and culture. As explained by Lane et al. in *A Journal into the Deaf-World*,

The importance of place for Deaf people, and the primary role of the residential school as this place, are reflected in several facts about Deaf culture, Deaf introductions, as we have said, require stating one's school. The *Deaf World* favors voluntary separation for Deaf children in residential schools and is bitterly opposed to mainstreaming most Deaf children in local hearing schools. Deaf people have mounted aggressive campaigns to block the closing of residential schools where this has been proposed, for example, by advocates for children with disabilities. Deaf ties formed at school are commonly lifelong.⁶

Deaf culture is also nurtured by Deaf clubs, which exist in most major cities for acculturation and socializing. Together, residential schools and Deaf clubs have helped to end the intense isolation experienced by many deaf people.

Because ASL is not a written language, the heritage of the Deaf-World has been passed down through storytelling. Poetry, legends, stories, drama, and humor have all been relayed face to face—in recent years, through a resurgence of Deaf arts. There is

power in the rhythmic images of Deaf poetry and grace and beauty in the movement of Deaf drama. Deaf sculptors and other artists display their creativity with visual themes of the Deaf-World. Arden Neisser describes the visual strengths of deaf people in *The Other Side of Silence*:

Before oralism defined deafness as failure to speak, failure to hear, failure to create literature and music, the educated deaf person was associated with positive talents and heightened visual sensitivity. Deaf people are, in fact, very visual. It may be less a matter of compensatory talent (a popular theory) than a practiced skill. . . . The deaf are interested in many things, including poetry, but seem especially involved with almost every activity that can be described as visual and/or spatial.⁷

The Deaf-World's identity as a linguistic and cultural minority stands in sharp contrast to the hearing world's view of deaf people as being seriously disabled or handicapped. In the Deaf culture, the hearing world's prejudice, not the condition of deafness, is seen as the handicap. The Deaf agenda also differs from the agenda of most other disability rights groups, whose primary focus is the acceptance and integration of people with disabilities into the classroom, workforce, and community. As described by Lane et al.,

School integration is anathema to the Deaf-World. Because most Deaf children have hearing parents, they can only acquire full language and socialization in specialized schools, in particular the prized network of residential schools. Whereas advocates of people with disabilities recoil in horror at segregated institutions, many Deaf alumni of residential schools return to their Deaf alma maters repeatedly over the years, contribute to their support, send their Deaf children to them, and vigorously protest the efforts of well-meaning but misguided members of the disability rights movement to close them down. These disability advocates fail to take

account of language and culture, and therefore of the difference between imposed and elective separateness. Where people with disabilities cherish independence, culturally Deaf people cherish interdependence. People with disabilities may gather for political action; Deaf people traditionally gather primarily for socializing. Indeed, Deaf people marry Deaf people ninety percent of the time in the U.S.⁸

The Deaf-World does support the disability rights movement because both groups are struggling for control of their own destiny. However, the Deaf-World does not want to be subsumed under the category of *people with disabilities*.

Ministering to Families

Before a child is diagnosed as deaf or hard of hearing, the parents usually sense that something is wrong. Ignorance about deafness and the discounting of parents' concerns can lead to late diagnosis. Diagnosis can also be delayed when the child has some residual hearing and responds to loud sounds, such as thunder or pots banging. Regardless, when the parents are concerned, they should seek professional testing.

Once a diagnosis has been made, the parents are likely to react with shock and denial followed by anger, guilt, depression, anxiety, and fear, whether the child is born deaf or loses his or her hearing later in life. Hearing parents may find it painful when they recognize the difference between themselves and their deaf child. In contrast, most deaf parents who give birth to a deaf child are sad that their child will have to face the challenges of living in a hearing world but also joyful because the child will be part of their world.

After the parents accept their feelings about their child's deafness, they can begin to cope with the overwhelming amount of information that is available and make the decisions that are best for their child and their family. They must realize the importance of

their role in preparing their child to exist in a hearing world. Paul Ogden, a professor of Deaf studies who is also deaf, writes,

By its very nature, deafness limits access to sound and speech. But in the hearing world, sound and speech are only means to ends; they are communication routes to other people. By blocking access to these connectors, deafness has profound impact on your child's social development, interfering with the relationships that otherwise would form naturally and grow in complexity as the child matures. It is in this area—the fostering of healthy relationships—that you will function most importantly as teacher, informing your child about the ways people interact in our culture; in other words, the where, whats, whys, when, and how of communication.⁹

Everyone agrees that communication is important for children, and communication is much more than the exchange of words. It is about sharing and being in relationship with others. Choosing the best form of communication to use with their deaf or hard-of-hearing child is a critical decision for parents. Ideally, the form they select will provide an easy flow of information among all family members, both hearing and otherwise. They should consider the challenges of learning a new language themselves. (Learning ASL is similar to learning a foreign language, such as French or Russian, with additional visual and physical challenges.) Making this decision about communication, however, places parents in the middle of a conflict between two opposing approaches: the oralists and the manualists.

The *oralists* advocate for teaching deaf and hard-of-hearing children solely through spoken language using techniques such as speech, speech reading (or lipreading), and the amplification of residual hearing with hearing aids and other technological devices, such as cochlear implants. Purists of the oralist method do not allow the use of any sign language or gestures.

The *manualists* advocate teaching deaf and hard-of-hearing children with sign language. Some also argue in favor of combining sign language with other oral forms of communication,

although sign language is taught first. Given that each approach has its zealots, hearing parents can easily become overwhelmed trying to sort out what is best for their child.

Children who lose their hearing after acquiring speech will have greater options for communication than children who are born deaf or become deaf as infants. The parents' decision will also be related to the level of residual hearing their child has. Parents of children with mild to moderate hearing loss are often drawn to the oralist approach to communication. However, children who are profoundly deaf will likely have extreme difficulty learning to lipread, and only a small number will develop speech that is intelligible to anyone outside their family.

An issue that has both refocused and re-energized the debate between the oralists and the manualists is the use of the *cochlear implant*: an electronic device that is implanted in the ear and converts sounds to electric impulses. The implant does not restore regular sounds but provides beeps, buzzes, and whistles that can then be encoded with meaning.¹⁰

The use of implants and other technology is advocated by those who support the oralist approach and by most in the medical community. However, advocates of the manualist approach, including organizations of deaf people such as the National Association of the Deaf (NAD) and the World Federation of the Deaf, question the benefits of implants and vigorously protest their use. Not only do they oppose subjecting children to the surgery involved, but they also object to the implication that deafness is a disability and needs to be fixed. Regardless of the controversy, the use of cochlear implants is becoming more and more popular with hearing parents, who want to give their children any benefit they can provide. Thus, some people feel it is irresponsible to use cochlear implants and some feel it is irresponsible not to. The issue has refocused and re-energized the debate between the oralists and the manualists.

American Sign Language (ASL) is a manual, gestural, and facial mode of communication and has its own syntax and vocabulary. ASL is the fourth most common language in the United States.

Manually coded English consists of signs that represent English words and are arranged according to English grammar and syntax. As such, it is not a separate language. There are basically three forms: signed exact English (SEE), signed English (SE), and English-based signing, sometimes referred to as pidgin sign English (PSE).

The obvious advantage of using manually coded English is that it can be used simultaneously with spoken English. Thus, most hearing parents who choose manualism select manually coded English to learn to communicate with their child. Beyond that, they will usually choose between two education philosophies called *simultaneous communication (SimCom)* and *total communication*.

SimCom employs the simultaneous use of speech and signing, which involves SEE, SE, or PSE. According to proponents of this approach, "Providing both the oral and signing options simultaneously allows the child to learn language in a way best suited to his or her needs while developing communication skills to function in the hearing world."¹¹

Total communication promotes the use of all possible methods of communication, including both the oralist and manualist approaches, and seems to be most effective in teaching deaf and hard-of-hearing children. Even so, critics voice concern that children who are bombarded with all types of communication may fail to master any.

Parents who choose to teach their children ASL generally use the *bilingual/bicultural approach*, in which children learn ASL as their primary language and English as their second language. With this approach, a deaf or hard-of-hearing child can gain access to the Deaf community, with its customs, history and values, and thus develop a feeling of belonging. Yet he or she can also gain access to and participate in the hearing world.

Hearing parents must learn to create an environment that meets their child's needs. In doing so, they can learn from deaf parents. According to Lane et al., deaf parents will bring their new deaf baby home to an environment that is set up to provide visual cues and conducive to using vision as the main means of commu-

nication. For instance, their home will be wired so that the doorbell and telephone will flash lights, instead of ring, and it will have a teletypewriter (TTY) system, so they can communicate over the telephone. Daria Medwind and Denise Chapman Weston have many suggestions for people learning to parent deaf children in their book *Kid-Friendly Parenting with Deaf and Hard of Hearing Children*.¹²

As ministers and religious educators, we need to realize that the parents who come to our churches with a deaf or hard-of-hearing child will already have spent much time and effort deciding on the best way to raise and communicate with their child. Moreover, they may be exhausted from balancing a home and a job, parenting other children, trying and learning new methods of communication, and advocating for their child.

Our most important task is to support and accept the family, no matter what decisions they have made, because if church is another place where they have to struggle for acceptance, they will most likely leave. In addition to support and acceptance, we can offer these parents some time off to take care of themselves.

Ideas for Teaching

It is important that religious educators create an environment in which the deaf or hard-of-hearing child feels welcome and accepted for who he or she is. These children's attention to the visual provides them with a different view of the world than that of hearing people. This visual awareness is a strength that we can incorporate into the religious education program.

Unless your church has developed a special ministry for deaf people, the deaf or hard-of-hearing children who come to your religious education program will most likely have hearing parents. Discuss with them how they communicate with their child, and use that approach in the classroom.

If the deaf or hard-of-hearing child is using sign language for communication, then it will be necessary to hire a sign language interpreter. You may find an advanced sign language student who

is willing to interpret for young children, but for older children, it is important to hire a skilled, certified interpreter. Most states have certification procedures; if yours does not, consult the national Registry of Interpreters for the Deaf (RID) for assistance in locating a qualified interpreter.

Some congregations balk at the expense of hiring an interpreter. Clearly, making this decision will depend on the church's commitment to welcoming all children. Awareness training for the entire congregation may be helpful in encouraging this commitment.

Technology is continually evolving and producing new assistive devices to help people hear. Be sure to find out from the child's parents what type of hearing aid he or she is using, if any. Also find out how much sound the child can actually hear. Some assistive devices include a microphone for the teacher/speaker to wear that transmits his or her voice directly into the hearing aid, so the individual does not receive all the confusing background noise. A church committed to ministering to all children may consider purchasing such devices a worthwhile expense.

Once a communication approach has been identified, teachers and others in the religious education program will need to practice communicating. Again, consult with the parents. No matter what approach you use, assume that the deaf or hard-of-hearing child will need visual cues in order to follow what is being taught. Also consider that the amount of hearing loss will affect how much a child can understand and how well he or she can converse with others. Moreover, deaf and hard-of-hearing children who use the oralist approach often lag behind hearing children in developing language and therefore may become confused in the religious education program.

Where and how the deaf or hard-of-hearing child is being educated is another significant piece of information for your planning, as it will probably determine his or her level of socialization with peers. Children who are mainstreamed into public school classrooms may feel isolated and have few friends, or they may

function well in a hearing setting. Deaf children who attend a school for the deaf will most likely have Deaf friends.

The attitudes of the children and teachers will, of course, be important in creating an environment in which the deaf or hard-of-hearing child feels welcome and accepted. Many of the children and teachers may never have met someone with deafness or a hearing impairment, and so some sensitivity training will be helpful. The parents and the child may be willing to talk about what it means to be deaf and how the child would like to be treated.

In particular, it is important to teach the children in your religious education program that deaf and hard-of-hearing children are just as smart as hearing kids and they have dreams and goals, strengths and weaknesses, wants and dislikes, and individual personalities—just like all children do. As I. King Jordan, past president of Gallaudet University, told a group of Gallaudet students, “You can do anything except hear.”

The following list of teaching tips is recommended for including children who are deaf or hard of hearing in our religious education programs:

- Deaf and hard-of-hearing children learn primarily through visual means, so be sure to provide them with many colorful and engaging visual cues about the lesson: pictures, diagrams, calendars, gestures, and body movements.
- Use gestures consistently.
- Do not just read stories. Act them out using the children as actors.
- Keep the order of activities consistent from session to session.
- Be sure the deaf or hard-of-hearing child sits close to you, so he or she can receive the maximum sound and read your lips, as needed. Do not cover your mouth with your hands while speaking, and avoid mumbling and speaking quickly. Also make eye contact when speaking to the child.

- Slow the pace of the other children's talking and foster respect when anyone is speaking. You can encourage these practices by using the Native American *talking stick* idea. Designate a special object for this purpose and pass it from child to child while sitting in a circle. When a child holds the special object, it is his or her turn to speak and everyone else should listen. (Be sure children know it is acceptable to pass the stick if they do not want to speak.) This technique gives children who are deaf or hard of hearing the chance to be part of the conversation.

- Flash the lights in the room to signal a time for children to be quiet.

- If the child has an interpreter, talk to the child, not the interpreter. The interpreter will not be offended.

- Do not allow the other children to interrupt when talking to a deaf or hard-of-hearing child. Make sure they understand this and remind them of it, as needed.

- Do not correct a deaf or hard-of-hearing child's English, unless he or she asks for help. Children who use the oralist approach are constantly being corrected. It will be a nice break for them if they do not have to worry about it in church.

- Do not pretend that you understand what a child is saying if you do not. If a child can read and write, always have a pencil and paper available for him or her to use when you have difficulty understanding.

- Try some sign language and encourage the other children to sign as well. Do not worry that you might make some mistakes; the deaf or hard-of-hearing child will be delighted that you are trying.

- Gently touch the child in order to get his or her attention.

- Encourage children who are deaf or hard of hearing to participate in all activities, and make the adaptations necessary to allow them to do so.

Hidden Disabilities (Chronic Illnesses)

THE TERM *HIDDEN DISABILITIES* REFERS TO conditions that involve chronic illnesses that affect day-to-day life but are not immediately noticeable to others. In many cases, we may never know someone has such a disability unless we get to know him or her better. (Of course, severe forms of these diseases can cause more noticeable difficulties.)

Children and youth with hidden disabilities may have physical limitations, tire more easily than other children, and need to take medication at certain times of the day. We need to be aware of the children with chronic illnesses who come to our churches. In particular, we need to know what special accommodations they need and what to do in the case of an emergency.

Description

The most common of the chronic illnesses that affect children and youth are asthma, diabetes, epilepsy, heart conditions, juvenile arthritis, and lupus.

Asthma. Asthma is a chronic lung disease involving two primary factors: *constriction*, the tightening of the muscles surrounding the airways, and *inflammation*, the swelling and irritation of the

airways.¹ Together, constriction and inflammation cause breathing problems. Symptoms are wheezing, coughing, tightness in the chest, and shortness of breath. Usually, these symptoms are triggered by things in the environment that irritate the lungs, such as allergic elements, infections or viruses, strong odors or fumes, and particles in the air.

People who have asthma need to manage it every day. If left untreated, it can cause long-term loss of lung function. Children are often treated with two kinds of asthma medication: an inhaler and a controller medicine.

Diabetes. Diabetes is a chronic disease in which the body does not produce or properly use *insulin*, a hormone needed to convert sugars, starches, and other food into the energy required for living.² Although there is no known cause of diabetes, environmental and genetic factors contribute to its onset. Lack of exercise and obesity, in particular, have been identified as significant factors in causing diabetes.

Diabetes is a silent killer. Often, people become aware that they have diabetes only after they have developed life-threatening complications, such as heart disease, stroke, high blood pressure, vision loss or blindness, amputation, nervous system disease, dental disease, pregnancy, and kidney disease.

There are two major types of diabetes that affect children. *Type I diabetes* is an autoimmune disease in which the body does not produce any insulin. In children, the symptoms of Type I can mimic the flu. Warning signs include frequent urination, unusual thirst, extreme hunger, unusual weight loss, extreme fatigue, and irritability. *Type II diabetes*, which is more common than Type I, is a metabolic disorder resulting from the body's inability to make enough insulin or to use it properly. Once seen mainly in adults, Type II diabetes is increasingly diagnosed in children and adolescents. Warning signs include those of Type I as well as frequent infections, blurred vision, cuts and bruises that are slow to heal, tingling or numbness in the hands or feet, and recurring skin,

gum, or bladder infections. However, people with Type II diabetes often have no symptoms.

Managing diabetes involves diet, exercise, and often weight loss. Monitoring blood glucose levels is critical. Children with Type I diabetes need to take insulin injections. Children with Type II diabetes may be able to control their disease with diet and exercise. If that strategy does not work, the doctor may prescribe diabetes pills or insulin if the pills are ineffective.

Epilepsy. Epilepsy is a fairly common neurological condition in which the normal electrical signals in the brain are disrupted by overactive electrical discharges of energy.³ (The word *epilepsy* means “to hold or seize” in Greek.) This disruption causes a temporary communication problem between nerve cells, which may affect a person’s consciousness, movements, and sensations. When these physical changes occur in the body, the individual is having a *seizure*.

Anyone can experience a seizure as the result of extreme conditions, such as severe dehydration and high body temperature. A person is considered to have epilepsy, however, when the seizures occur repeatedly for no apparent external reason or because of an internal problem that cannot be corrected. The conditions in the brain that produce seizure *episodes* may be present from birth or may develop later in life due to injury, infection, structural abnormalities in the brain, exposure to toxic agents, or other factors that are not well understood.

Seizures are not painful and they affect people in different ways, depending on the type of seizure and the person’s specific biological makeup. There are two main types of seizures: generalized seizures and partial seizures.

Generalized seizures involve electrical disturbances that occur simultaneously all over the brain. Consciousness may be affected in some way, such that the person may not respond to any stimuli; he or she may appear to be daydreaming or staring off into space. The person may also pass out, his or her muscles may stiffen, or he

or she may make jerking motions and suddenly go limp and fall over. Generalized seizures may be triggered by flashing or bright lights, a lack of sleep, stress or overstimulation, fever, and certain medications.

Partial seizures start in one area of the brain and sometimes move to other parts of the brain. There are two types of partial seizures: simple and complex.

During a *simple partial seizure*, the individual does not lose consciousness but remains awake and aware. Sometimes, the individual can talk normally to others during this type of seizure; other times, he or she is aware of what is happening but cannot talk. Either way, the individual will usually remember later exactly what happened during the seizure. Simple partial seizures can affect movements, emotions, sensations, and feelings in unusual ways. For instance, the individual may have uncontrolled movement in any part of the body, or he or she may have sudden feelings of fear, anger, or even joy. Simple partial seizures can also produce sensations in touch, hearing, taste, and smell, such as sensations on the skin; unusual hissing, buzzing, or ringing sounds; voices that are not really there; experiencing unpleasant tastes and strange smells; and, perhaps most upsetting, seeing things in distorted ways. Simple partial seizures do not require any special response from others, except to recognize what is happening and to be supportive.

A *complex partial seizure* affects a larger area of the brain and can affect consciousness. During this type of seizure, the person cannot act normally and is not in control of his or her movements, speech, or actions. The person will not know what he or she is doing and will not remember what happened during the seizure. People experiencing this kind of seizure may appear to be conscious because they are on their feet with their eyes open, but they will not be able to move and will be in a trance-like state. The person may be able to speak, but his or her words will be unintelligible. Complex partial seizures can affect any area of the brain, but they often affect one of the two temporal lobes. Therefore, the condition is sometimes called *temporal lobe epilepsy* or *psychomotor epilepsy*.

When someone is having a complex partial seizure, it is important to do the following:

- Reassure others by explaining that the unusual behavior has been brought on by a seizure and will end in a few minutes.
- Remove anything that might injure the person having the seizure.
- Do not restrain the person because doing so may produce an unconscious aggressive response.
- Guide the person away from anything that might be dangerous, like a busy street.
- If the person seems agitated or belligerent, stay back from him or her until the episode has ended.
- Be reassuring and helpful as the person's awareness returns because he or she may be confused, depressed, irritated, agitated, belligerent, or drowsy after the seizure is over.
- Time the duration of the seizure. If it lasts longer than a minute or two, get medical help.

Although partial seizures affect people in different ways, these characteristics are common:

- These seizures do not last long, only a minute or two, although the person who had the seizure may be confused afterward and need a lot of time to recover.
- Except in rare cases, partial seizures end naturally. The brain seems to have its own way of ending seizures safely.
- These seizures cannot be stopped, so the most effective response is to protect the person from harm and let the seizure run its course.
- Partial seizures are not dangerous to others because the person experiencing the seizure is too confused and unorganized to threaten anyone.

Heart Conditions. Two types of heart disease can occur in children: Congenital heart disease or defect is present at birth, and acquired heart disease develops during childhood.

Acquired heart disease is rare in children, but it can result from damage due to an infection such as Kawasaki disease or rheumatic fever. Kawasaki disease is relatively common in the United States and is a major cause of heart disease in children. It is more frequent among children with an Asian American background but can occur in any racial or ethnic group. One in five children who develop this disease will experience damage to the heart. Rheumatic fever is an inflammatory disease that can attack anyone but usually occurs in children five to fifteen years old. If a rheumatic heart disease develops, it will last for life.

A *congenital heart disease or defect* occurs before birth when the heart or vessels near the heart do not form properly. Most problems with the heart develop soon after conception, often before the mother is aware that she is pregnant. Thus, there is nothing the mother could have done to prevent the defect. In fact, in most cases, it is not known why the defect occurred. Children with congenital heart problems can usually lead normal lives, although their activity may be limited. Routine medical care is important for these children, who will get through most childhood illnesses as safely as other children. Children with congenital heart defects usually survive into adulthood.⁴

Juvenile Arthritis. The term *arthritis*, which means “joint inflammation,” is a general term that refers to more than one hundred rheumatic diseases.⁵ These diseases affect the joints and can cause pain, swelling, and stiffness to other supporting parts of the body, such as the muscles, tendons, ligaments, and bones. Some rheumatic diseases can also affect other parts of the body, including internal organs.

Children can develop almost all the types of arthritis that affect adults, but they most commonly develop *juvenile rheumatoid arthritis (JRA)*. JRA usually starts before age sixteen and is characterized by joint inflammation and stiffness for more than six weeks. The signs and symptoms of JRA vary from child to child and even from day to day in the same child. It can be a mild

condition that causes few problems, or it can be very persistent, causing joint and tissue damage. In severe cases, JRA can produce serious complications.

Lupus. Lupus is a commonly occurring chronic autoimmune disease in which the body's immune system loses its ability to discriminate between foreign substances (such as viruses and bacteria) and its own cells. As a result, the body makes antibodies directed against itself.

Lupus can affect any part of the body, but people usually experience symptoms in a few organs. These symptoms can range from mild to life threatening and often mimic those of other less serious illnesses. At times, lupus can be in remission. The most common symptoms of lupus are achy joints, frequent fevers of more than 100 degrees Fahrenheit, arthritis, prolonged or extreme fatigue, anemia, kidney dysfunction, pain in the chest upon deep breathing, skin rashes (particularly a butterfly-shaped rash across the cheeks and nose), sun or light sensitivity, hair loss, abnormal blood clotting, Raynaud's phenomenon (the fingers turn white or blue in the cold), seizures, and mouth and nose ulcers.

Children are generally not diagnosed with lupus until the disease is well developed. This means that they have often been ill for a long time and are more likely than adults to have significant internal organ involvement. Therefore, aggressive therapy is usually required soon after a child is diagnosed. The course of lupus is unpredictable, so it is difficult to know the outcome for an individual child. However, many children do very well.⁶

Discussion

According to the National Center for Chronic Disease Prevention and Health Promotion, chronic illnesses such as heart disease, stroke, cancer, and diabetes are among the most prevalent, costly, and preventable of all health problems.⁷ Each year, they account for 70 percent of all deaths in the United States and more than

75 percent of the \$1.4 trillion in medical costs. These numbers could be reduced substantially if more Americans would commit to good nutrition, physical activity, and avoiding tobacco. Eliminating the exposure to toxic substances in the home and environment would also help.

As ministers and educators in Unitarian Universalist congregations, we can help with the prevention of chronic diseases in any number of ways. For example, we can disseminate information on the beneficial use of environmentally safe cleaning and gardening products and make sure our own facilities are environmentally safe and toxin free. In addition, we can convey to our children the importance of healthy eating and physical exercise as well as the need to take care of our environment. And we can offer programs for all ages on how to enjoy physical, emotional, and spiritual health.

Ministering to Families

The parents of children with chronic illnesses are often stressed financially and emotionally. The medical costs of treating these children can be astronomically high, and coping with a chronic illness day in and day out can take a serious emotional toll.

Some parents and children will become engrossed in a constant struggle for health, and some will accept and find joy in living. Their outlook and degree of acceptance will change with the course of the illness—from times of remission to times of flare-up. The parents may need extra emotional support at those times when their child is struggling the most. When he or she is in the hospital, for instance, find ways to help the parents and family, such as delivering meals, cleaning house, caring for siblings, and providing transportation.

Ideas for Teaching

In general, children with chronic illnesses will not require major accommodations or special teaching strategies to participate in religious education programming. (For children who may have a

chronic illness and a learning disability or mobility issue, refer to the appropriate chapters in this book.) Nonetheless, it is important for religious educators and teachers to know who these children are, to be aware of any restrictions on their participation, and to know what to do in the case of a medical emergency. Be sure to get this information from parents at registration and follow up with them as needed.

Joanne Giannino, a former director of religious education at First Parish Church in Bridgewater, Massachusetts, shares her experience in church as the mother of a chronically ill child:

My son has diabetes. He must take insulin every day so that his body can absorb nutrients. A side effect of taking insulin is that he has episodes of low blood sugar, where he may lose consciousness or worse. I share this information with his religious education group leaders, post warning signs on the wall of his room, and have food and other supplies he may need available, including a glucagon shot.

In a casual way, Andrew lets others know about his illness. However, we as his parents have educated the congregation about his needs through sharing suggestions for snack (low sugar is best) and asking for pledges each year for the walk for a cure. We now put directions about Andrew in front of the group leader's curriculum that say: "Andrew is in your class. He has diabetes. If you notice XYZ, please come and get either his father or me. We will be in ABC . . ."

This procedure paid off recently, when the teaching team recognized that Andrew was low and unresponsive. They found me immediately, and I was able to get to Andrew early enough to avoid invasive treatment. I am so grateful for my church family and their diligence.

We also have a new child in our group with peanut allergies. His mom has an epi-pen with her at all times. We will let the teachers know about this the same way we have informed them about Andrew. Communicate, communicate, communicate.

Children with chronic illnesses will also benefit from the support and understanding of their peers. Sharing information about a child's chronic illness will not only help that child feel more secure and welcome but also provide a positive growth experience for all the children in the program.

Chronic illnesses often forces children to lead highly structured and restricted lives—always watching what they do or what they eat. Being able to just hang out with friends and relax may be one of the best ways they can renew their spirit. Our faith communities can be places where all children are accepted for who they are.

Conclusion

FAR TOO OFTEN, the institutions created to teach and care for our children deny them their inherent worth and dignity, their full humanity. And while we have made significant progress in the treatment of children with disabilities, many practices still exist that limit their full participation in society and that affect how we treat all children. Children with physical or cognitive limitations are still excluded and misunderstood. Energetic children are often labeled and medicated instead of helped to develop the spiritual and emotional skills they need to navigate life's stormy seas. The emphasis on standardized testing in schools encourages teachers to "teach to the test." Rote learning threatens to take the place of creative thinking, leaving many children bored and uninspired. Emphasis on the outcome of one standardized test also means that more children will be labeled and placed into special education. The different learning styles and needs of children are too often ignored.

This book is organized by the diagnostic labels assigned to various physical limitations and disorders in an effort to explain the struggles these children face and to suggest ways to minister to them with understanding and creativity. I know that in a chaotic world, there is a need to categorize in an effort to find clarity and a way to heal. Finding the correct diagnosis to troubling behavior can bring relief and understanding to years of pain and confusion. The Education for All Handicapped Children Act was groundbreaking legislation that finally made education available for chil-

dren who had been excluded from classrooms and left on the margins of society. Labeling is an unfortunate necessity that allows these children to receive the special resources they deserve.

Yet have we gone too far? Labeling many facets of behavior as disorders or disabilities means that the range of what is considered normal is shrinking. Would Albert Einstein or Thomas Edison be considered normal under today's standard? If Einstein were a child today, he might well be diagnosed with dyslexia and Asperger's syndrome. Edison might be labeled as someone with attention-deficit disorder. Both would probably do poorly in our schools today, which emphasize teaching to a standardized test. In fact, Einstein dropped out of school because of his difficulty with memorization and tests. Are we labeling imaginative and creative children as disabled and dysfunctional? Are we nurturing the creativity of all children?

Labels, with their associated behaviors, can become self-fulfilling prophecies. Imagine that you had to walk around all day with a sign on your chest that listed all your faults and deficits. Imagine how people would interact with you, how you would feel, and how you would act. Now imagine what it would be like if all people ever saw were your gifts and strengths. Imagine how you would feel and how people would interact with you. Children who have been labeled with a disability walk around as if they have huge signs on their chests that list all their problems and deficits. And we wonder why some of these children are angry, anxious, and depressed! Labels can become self-fulfilling prophecies.

I believe children with special needs can inspire us to create a more inclusive world in which differences are seen as gifts. We can challenge educational and medical practices that are not working for our children and adopt what Judith Snow calls the *giftedness paradigm* instead of the *disability paradigm* that exists today. Each of us is different in a myriad of ways. In the disability paradigm, society decides what differences are normal and what differences are disabilities. In the giftedness paradigm, every person is seen as unique and therefore all differences are seen as normal.

We can adopt the giftedness paradigm in our faith communi-

ties, nurturing the innate spirituality of children, recognizing differences as opportunities for meaningful interaction, weaving all children into the fabric of our church communities, embracing social justice issues related to special needs, and offering a sanctuary in which children are safe and free to explore who they are. We can support a struggling family with the embrace of a caring congregation through support circles and spiritual exploration. We can see all children as perfect in God's eyes.

Acknowledgments

Many people made this book possible: funders, advisors, friends, and family. My sincere thanks go to the Fund for Unitarian Universalism of the UU Funding Program for providing the majority of the money for the writing of this book. I am deeply indebted to Hillary Goodridge, the Program Director, for her enthusiasm, unfailing sense of humor, constant emotional support, and complete understanding of what I was trying to accomplish. I am also grateful to the Unitarian Sunday School Society for contributing generously and enthusiastically. The UU Veatch Program at Shelter Rock generously supported the editing phase and provided funding for denominational training, for which I am also truly grateful.

There have been many changes of staff at the UUA since this project began. Through it all, I have had enduring patience and support, guidance, and understanding from Rev. Pat Hoertdoerfer. This book would not have been possible without her leadership, advocacy, and sincere belief in the need for such a manual. I am also appreciative of Jacqui James's early support and advice. During the final stages, Judith Frediani's guidance and expertise were critical in ushering the book to publication. She was an unswerving advocate during a critical time. And finally, thanks to Rev. Deborah Greenstein, who entered my life during the editing process and lent her support and expertise.

Special thanks to my church, the Winchester Unitarian Society in Massachusetts, which acted as my fiscal agent and all that im-

plies, from writing checks to keeping track of the money. And to Rev. Ralph Roberts, MRE at my church and a member of my Advisory Committee, heartfelt thanks for being a friend and a colleague who is always willing to listen, brainstorm, and try new ideas. His total commitment to children with special needs continues to be awe inspiring. To the other members of the Advisory Committee—Pat Ellenwood, DRE at the UU Society of Wellesley Hills, Massachusetts; Claire Rosenbaum, member of the First Unitarian Church in Providence, Rhode Island, Family Support Coordinator for the Paul V. Sherlock Center on Disabilities at Rhode Island College, and mother of a young adult with developmental disabilities; and Helen Bishop, a member of the First UU Church of San Diego, California, and Director of The Mountain Learning Center for Leadership in North Carolina—thank you for sticking with me for the two-plus years it took to finish this book, for your willingness to read lots of information, and for your always helpful and much appreciated advice and suggestions about resources. The book was greatly strengthened by your review and input. Thank you, thank you.

Many friends cheered me on the way, gave me ideas when I got stuck, and always believed that I would finish. My dearest and oldest friend, Rev. Jeanette Stokes, provided constant love and support and recognized my abilities before I did. Pam Budner listened endlessly with patience to all my ideas. Carolyn Jensen stoked my spiritual fire and provided spiritual insight when I was mired in confusion.

Finally, but most importantly, I thank my family for their love and patience. I thank my husband Rick for giving me space when I needed it and for offering his steadfast, unswerving love and faith that I could actually write this book. My lovely, intelligent, and compassionate daughter Sarah is inspiring as a model for unconditional love and total acceptance of all children. My son Tyler is who he is—kind, sensitive, and quirky. Just by being, he was a catalyst for a major life change. If asked, he is slightly puzzled by all of this but very pleased. So thank you, Tyler, for teaching me what it means to be different, unique, and special. Thank you for leading me on this incredible journey of spiritual discovery and healing. I am truly blessed.

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Resources

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Center for an Accessible Society: www.accessiblesociety.org. Funded by the National Institute on Disability and Rehabilitation Research. Focuses on research and public education concerning disability and independent living issues.

Greenstein, Doreen. *Backyards and Butterflies: Ways to Include Children with Disabilities in Outdoor Activities*. Ithaca, NY: New York State Rural Health and Safety Council, 1993. This excellent manual by a Unitarian Universalist author for children and parents provides colorful pictures and easy-to-read instructions on projects that families of children with disabilities can do outdoors.

Stratton, Peter A., and Michael J. Crosbe, eds. *A Basic Guide for Fair Housing Accessibility: Everything Architects and Builders Need to Know about the Fair Housing Act Accessibility Guidelines*. New York: John Wiley and Sons, 2001.

Terry, Evan, ed. *Pocket Guide to the ADA: American with Disabilities Act Accessibility Guidelines for Building and Facilities*. Rev. ed. New York: John Wiley and Sons, 1997.

United States Access Board: www.access-board.gov. An independent federal agency committed to accessible design. Provides information on laws, technical assistance, and training.

Spiritual Accessibility

Bolduc, Kathleen Deyer. *His Name Is Joel: Searching for God in a Son's Disability*. Louisville, KY: Bridge Resources, 1999. A mother's passionate portrayal of her faith journey concerning her child with severe disabilities.

- Bolduc, Kathleen Deyer. *A Place Called Acceptance: Ministry with Families of Children with Disabilities*. Louisville, KY: Bridge Associates, 2001. Information on how churches can be welcoming places for children with disabilities
- Eisland, Nancy L., and Don E. Saliers, eds. *Human Disability and the Service of God: Reassessing Religious Practice*. Nashville, TN: Abingdon, 1998. A Christian perspective on the theological and spiritual call for churches to minister to people with disabilities
- National Organization on Disability. *That All May Worship: An Interfaith Welcome to People with Disabilities*. Washington, DC: Author, 1997. Basic information on welcoming people with disabilities into churches.
- Newman, Gene, and Joni Eareckson Tada. *All God's Children: Ministry with Disabled Persons*. Grand Rapids, MI: Zondervan, 1993. Simple steps for welcoming people with disabilities into churches.
- Senelick, Richard C., and Karla Cougherty. *Beyond Please and Thank You: Disability Sensitivity Handbook for Families, Co-Workers and Friends*. Cincinnati: Thomson Learning, 2001. Good for sensitivity training. Includes a questionnaire for assessing disability awareness.
- Webb-Mitchell, Brett. *Dancing with Disabilities: Opening the Church to All God's Children*. New York: United Church, 1997. Discusses why people with disabilities are often not welcomed in churches.
- Webb-Mitchell, Brett. *God Plays Piano, Too: The Spiritual Lives of Disabled Children*. New York: Crossroad/Herder and Herder, 1993. Children with emotional and mental challenges share their life stories, worlds, and spiritual perspectives.
- Webb-Mitchell, Brett. *Unexpected Guests at God's Banquet: Welcoming People with Disabilities into the Church*. New York: Crossroad/Herder and Herder, 1994. A Christian perspective on why the church is called to minister to people with disabilities.

Children's Spirituality and Religious Education

- Armstrong, Thomas. *The Radiant Child*. Wheaton, IL: Theosophical, 1985. How to recognize and foster children's natural spiritual development.
- Child Spirit Institute: www.childspirit.net. An organization dedicated to understanding and nurturing the spirituality of children and adults.
- Myers, Barbara Kimes, and William R. Myers. *Engaging in Transcendence: The Church's Ministry and Covenant with Young Children*. Cleveland: Pilgrim, 1992. Transforming information on how we minister to children.
- Natural Child Project: www.naturalchild.org. Provides resources for treating all children with dignity, compassion, and understanding.
- Nieuwejaar, Jeanne Harrison. *The Gift of Faith: Tending the Spiritual Lives of Children*. 2nd ed. Boston: Skinner House, 1999. A Unitarian Universalist author and minister writes about why it is important for children to be part of a faith community.

Pearce, Joseph Chilton. *The Magical Child: Rediscovering Nature's Plan for Our Children*. New York: Plume, 1992. Guidelines for understanding the spiritual nature of children.

Spirituality for Kids: www.spiritualityforkids.com. Excellent curriculum for teaching children to expressing their own spirituality.

Tribes: www.tribes.com. Advice on how to transform environments to help children learn and relate to each other.

Books for Children and Youth

Garth, Maureen. *Starbright: Meditations for Children*. San Francisco: Harper, 1991. Wonderful meditations that engage the imagination.

Lite, Lori. *A Boy and a Bear: The Children's Relaxation Book*. Plantation, FL: Specialty, 1996. A young boy and polar bear learn relaxing breathing techniques while climbing a snow-covered mountain.

Walsch, Neale Donald. *The Little Soul and the Sun: A Children's Parable*. Charlottesville, VA: Hampton Roads, 1998. A story for young children. Adapted from *Conversations with God*.

Different Learning Styles

Armstrong, Thomas. *In Their Own Way: Discovering and Encouraging Your Child's Multiple Intelligences*. New York: Tarcher/Putnam, 2000. Good information on how children learn.

Armstrong, Thomas. *Seven Kinds of Smart: Identifying and Developing Your Multiple Intelligences*. Rev. ed. New York: Plume, 1999. Good, easy-to-understand information on multiple intelligences theory, including the two most recently identified.

Armstrong, Thomas: www.ThomasArmstrong.com. Focuses on multiple intelligences and attention-deficit disorder.

Gardner, Howard. *The Disciplined Mind: Beyond Facts and Standardized Test, The K-12 Education That Every Child Deserves*. New York: Penguin, 2000. An assessment of the typical American school system and excellent ideas for improvement.

Gardner, Howard. *Multiple Intelligences: The Theory in Practice*. New York: Basic, 1993. A good and readable overview of multiple intelligences theory and how it is used.

Lazear, David. *Eight Ways of Knowing*. 3rd ed. Arlington Heights, IL: Skylight Professional Development, 1998. Another easy-to-understand book on the multiple intelligences.

Markova, Dawna. *How Your Child Is Smart*. Berkeley, CA: Conari, 1992. A discussion of the different ways children learn that is not based on multiple intelligences theory.

MI Immersion: www.surfaquarium.com/mi_overview.htm. Information from several sources about Howard Gardner's theory of multiple intelligences.

Project SUMIT: www.pzweb.harvard.edu/SUMIT. Schools using multiple intelligences theory.

Project Zero: www.pzweb.harvard.edu. Provides ways to enhance learning, thinking and creativity in the arts, humanities, and sciences; based on the multiple intelligences theory of Howard Gardner.

Family and Parenting

Byronchild: www.byronchild.com. A magazine dedicated to conscious parenting and conscious living.

Chopra, Deepak. *The Seven Spiritual Laws for Parents*. New York: Crown, 1997. Chopra's basic spiritual philosophy as it pertains to parenting.

Doe, Mimi. *Ten Principles for Spiritual Parenting: Nurturing Your Child's Soul*. New York: Harper Perennial, 1998. One of the best and most well known books on spiritual parenting.

Edelman, Marian Wright. *The Measure of Our Success: A Letter to My Children and Yours*. Boston: Beacon, 1992. A message for teaching and creating a better world for our children.

Exceptional Parent: www.eparent.com. A magazine for parents and families of children with disabilities.

Fuchs-Kreimer, Nancy. *Parenting as a Spiritual Journey: Deepening Ordinary and Extraordinary Events into Sacred Occasions*. Woodstock, VT: Jewish Lights, 2002. How to find the spiritual in everyday occasions.

Gill, Barbara. *Changed by a Child: Companion Notes for Parents of a Child with Disability*. New York: Doubleday, 1997. Offers wonderful, healing insights on what it means to parent a child with a disability.

Kabat-Zinn, Myla, and Jon Kabat-Zinn. *Everyday Blessings: The Inner Work of Mindful Parenting*. New York: Hyperion, 1997. Excellent advice and ideas on parenting from a Buddhist perspective.

Klein, Stanley D., and Kim Schive. *You Will Dream New Dreams: Inspiring Personal Stories by Parents of Children with Disabilities*. New York: Kensington, 2001. Inspiring essays by parents about what it is like to parent a child with disabilities.

Klein, Stanley D., and Maxwell J. Schleifer. *It Isn't Fair! Siblings of Children with Disabilities*. South Hadley, MA: Bergin and Garvey, 1993. An exploration of sibling relationships when one child has a disability.

McHugh, Mary. *Special Siblings: Growing Up with Someone with a Disability*. New York: Hyperion, 1999. Good practical advice from the perspective of a sibling about how to handle the emotions and struggles of having a brother or sister with disabilities.

PACER (Parent Advocacy Coalition for Educational Rights): www.pacer.org. Provides information, resources, training, and assistance for parents of children with disabilities.

- Parents Leadership Institute: www.parentleaders.org. Provides resources for parents to connect with family members to solve problems.
- Safer, Jeanne. *The Normal One: Life with a Difficult or Damaged Sibling*. New York: Bantam Dell, 2003. Especially for siblings of children with mental illness.
- Snow, Kathie. *Disability Is Natural*. Woodland Park, CO: Braveheart, 2001. Common-sense techniques for raising children with disabilities. Recognizes that disability is a natural part of the human experience.
- Spangler, David. *Parent as Mystic, Mystic as Parent*. New York: Riverhead, 1998. Inspiring ideas on what it means to parent from a spiritual place.
- Spiritual Parenting: www.spiritualparenting.com. The website of Mimi Doe, a well-known author and lecturer on spiritual parenting.

Inclusive Communities

- Asante, Shafik. *When Spider Webs Unite: Challenging Articles and Essays on Community, Diversity and Inclusion*. Toronto, Canada: Inclusion, 1997. Inclusion from the perspective of an African American.
- Community Works! www.community-works.net. Dedicated to working toward communities in which each individual is cherished.
- Connect for Kids: www.connectforkids.org. Project by the Benton Foundation to make communities better places for families and children.
- Family Village: www.familyvillage.wisc.edu. Promotes the integration of people with disabilities; provides many references to welcoming religious communities.
- Inclusion Press: www.inclusion.com. Dedicated to creating inclusive communities for everyone. Provides information about Judith Snow's work and ideas.
- Pearpoint, Jack, and Judith Snow. *From Behind the Piano: The Building of Judith Snow's Unique Circle of Friends, and What's Really Worth Doing and How to Do It: A Book for People Who Love Someone Labeled Disabled (Possibly Yourself)*. Toronto, Canada: Inclusion, 1998. A truly inspirational book on inclusive communities.
- Philia: www.philia.ca. An organization dedicated to creating caring communities that include all citizens, including those with disabilities.
- Planned Lifetime Advocacy Network: www.plan.ca. Working toward safeguarding the future of people with disabilities.
- TASH: www.tash.org. An international association of people with disabilities advocating for equity, opportunity, and inclusion.

General Spirituality and Education

- Dyer, Wayne W. *There's A Spiritual Solution to Every Problem*. New York: HarperCollins, 2001. A wonderful look at overcoming life's problems from a place of spirit.

- HeartMath Institute: www.heartmath.org. Explores and researches the relationship between the heart and the brain. Provides training strategies for thinking with the heart, which will be useful in helping adults and children cope with stress.
- Kaufman, Barry Neil. *Happiness Is a Choice*. New York: Ballantine, 1991. Suggests ways to change beliefs and make choices to be happy. Associated with the Option Institute.
- Moffett, James. *The Universal Schoolhouse: Spiritual Awakening through Education*. San Francisco: Jossey-Bass, 1994. One of the best books on alternative visioning for educating children.
- Option Institute, International Learning and Training Center: www.option.org. Provides excellent training on ways to choose to be happy. Connected to the Son-Rise program for children within the autism spectrum.
- Pearce, Joseph Chilton. *The Biology of Transcendence: A Blueprint of the Human Spirit*. Rochester, VT: Park Street, 2002. Fascinating information on the biological seeds of violence and ways to transcend this phenomenon by nurturing ourselves and our children.
- Pearmain, Elisa Davy. *Doorways to the Soul*. Cleveland: Pilgrim, 1998. Stories for strengthening individual spirituality.

Disabilities

General Information

- Batshaw, Mark L. *Children with Disabilities*. 5th ed. Baltimore, MD: Paul H. Brookes, 2002. A general resource book.
- Boyles, Nancy S., and Darlene Contadino. *The Learning Differences Sourcebook*. Chicago: Lowell House, 1998. Provides good, basic information.
- Brooks, Robert, and Sam Goldstein. *Raising Resilient Children: Fostering Strength, Hope, and Optimism in Your Child*. Chicago: Contemporary, 2001. A terrific book. Describes “islands of competence” and “charismatic adults.”
- Brooks, Robert. *The Self-Esteem Teacher*. Circle Pines, MN: American Guidance Service, 1991. Brooks’s first book describing “islands of competence.”
- Brooks, Robert: www.drrobertbrooks.com. Advice on nurturing resilience, self-esteem, motivation, and family relationships.
- Council for Exceptional Children: www.cec.sped.org. Information for improving educational outcomes for students who have disabilities or are gifted.
- Federation for Children with Special Needs: www.fcsn.org. Provides comprehensive information for parents of children with special needs.

- Greenspan, Stanley I., and Serena Weider. *The Child with Special Needs: Encouraging Intellectual and Emotional Growth*. Reading, MA: Perseus, 1998. A good explanation of treating children with special needs by how they function, rather than using a deficit approach.
- IDEA Practices: www.ideapractices.org/index.htm. Information about the Individuals with Disabilities Education Act (IDEA).
- March of Dimes: www.modimes.org. This organization works to prevent birth defects.
- National Dissemination Center for Children with Disabilities: www.nichcy.org. A central resource of information about the Individuals with Disabilities Education Act (IDEA), the No Child Left Behind Act, and effective educational practices.
- National Easter Seals: www.easterseals.com. Offers services and support to people with disabilities and their families. Provides links to local Easter Seals organizations.
- Nekola, Julie. *Helping Kids with Special Needs*. Wayzata, MN: Nekola, 2001. Extensive information and resources on children's emotional and neurological disorders.
- Special Child: www.specialchild.com. An online publication and bulletin board for parents of children with special needs. An excellent source of general information.
- Sumar, Sonia. *Yoga for the Special Child: A Therapeutic Approach for Infants and Children with Down Syndrome, Cerebral Palsy, and Learning Disabilities*. Evanston, IL: Special Yoga, 1998. Information and techniques on the positive effects of yoga for children with special needs.

Books for Children and Youth

- Brown, Tricia. *Someone Special Just Like You*. New York: Owllet, 1995. Using photographs, children with disabilities talk about the many things they like to do, just like other children. For preschoolers.
- Moran, Maggie. *The Magic in Me*. Wilmington, MA: New Voices, 2002. Talks about how all children have magic within them. For young children.
- Rogers, Fred. *Extraordinary Friends (Let's Talk about It)*. New York: Puffin, 2000. Using photographs, Mr. Rogers talks about children who are special. For children ages four to eight.
- Smith, Sally L. *Different Is Not Bad, Different Is the World: A Book about Disabilities*. Longmont, CO: Sopris West, 1994. A good book about the interconnecting web for young children.

Mood, Anxiety, and Behavior Disorders

- Al Sofa Organization: www.alsofa.org. A bilingual website for mental health information.

- Alexander, Debra Whiting. *Children Changed by Trauma*. Oakland, CA: New Harbinger, 1999. An excellent, practical guide for working with children who have experienced crises or who are depressed.
- Alternative Health News Online: www.altmedicine.com. A wonderful resource for basic information on alternative health care.
- American Academy of Child and Adolescent Psychiatry: www.aacap.org. Information on the treatment of developmental, behavioral, and mental disorders.
- American Psychological Association: www.APA.org. A scientific and professional organization. Provides good articles and publications.
- Breeding, John: www.wildestcolts.com. A different look at what it means to have mental illness.
- Breggin, Peter R. *Reclaiming Our Children*. Reading, MA: Perseus, 2001. Addresses treating and respecting children without the use of drugs.
- Breggin, Peter R. *Toxic Psychiatry: Why Therapy, Empathy, and Love Must Replace the Drugs, Electroshock, and Biochemical Theories of the "New Psychiatry."* New York: St. Martin's, 1991. A fascinating book on healing without drugs.
- Burns, David D. *Feeling Good: The New Mood Therapy*. New York: Wholecare, 1999. An explanation of cognitive therapy, which is widely used by therapists.
- Fight for Kids: www.fightforkids.com. Provides information about labeling children as *mentally ill* and medicating them with psychiatric drugs.
- Greene, Ross W. *The Explosive Child*. New York: Quill, 2001. One of the best books available on how to parent explosive, inflexible children.
- Greenspan, Stanley I. *The Challenging Child: Understanding, Raising, and Enjoying the Five "Difficult" Types of Children*. Reading, MA: Perseus, 1996. A hopeful book that approaches the whole child, rather than using the deficit model approach.
- Hallowell, Edward. *When You Worry about the Child You Love*. New York: Simon & Schuster, 1996. An excellent resource for understanding and parenting children with difficulties.
- Koplewicz, Harold. *It's Nobody's Fault: New Hope and Help for Difficult Children and Their Parents*. New York: Times, 1997. Emphasizes that parents cannot be blamed for their children's mental illnesses.
- People Who: www.peoplewho.org. Intended for people who experience mood swings, hear voices, and see visions.
- PsychologyNet: www.psychologynet.org. Gives the diagnostic criteria described in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)*.
- Uplift Program: www.upliftprogram.com. Offers resources for creating optimism, overcoming depression, and building healthy relationships.
- Valenstein, Elliot S. *Blaming the Brain: The Truth about Drugs and Mental Health*. New York: Free, 1998. Posits that we have gone from one extreme

of blaming parents for all children's problems and behavior to the other extreme of blaming the brain.

Wind Horse Associates: www.windhorseassociates.org. A therapeutic program that integrates mind, body, and soul for people with mental illness.

Learning Disabilities

Canadian Dyslexia Association: www.dyslexiaassociation.ca. Provides information and resources.

Citro, Teresa Allissa, ed. *The Experts Speak*. Weston, MA: Learning Disabilities of Massachusetts (LDAM), 1998. A good overview of learning disabilities from well-known experts in the field. (LDAM has changed its name to Learning Disabilities Worldwide.)

Davis, Ronald D. *The Gift of Dyslexia*. New York: Perigee, 1997. A different method of correcting dyslexia and allowing children's innate gifts to emerge.

Dyslexia Parents Resource: www.dyslexia-parent.com. A resource for parents. Includes an online magazine.

Dyspraxia Foundation (in England): www.emmbrook.demon.co.uk/dysprax/madrev.htm. There is no comparable site in the United States.

Ennis's Gift [video]. A wonderful video that shows the positive side of having dyslexia through the experiences of adults and children with dyslexia. Hello Friend/Ennis William Cosby Foundation. To order: www.hellofriend.com.

Everybody Has a Song [video]. Henry Winkler, Narrator. Everybody's Song. To order: 310-446-1420.

Guyer, Barbara P. *The Pretenders: Gifted People Who Have Difficulty Learning*. Homewood, IL: High Tide, 1997. Fascinating stories of young people dealing with learning difficulties.

How Difficult Can This Be? The F.A.T. City Workshop [video]. Richard D. Lavoie. Describes what children with learning disabilities struggle with at school. To order: www.LDOnline.com.

LDOnline: www.ldonline.org. One of the most comprehensive and informative websites on learning disabilities.

LDPride: www.ldpride.net. A site by and for young adults with learning disabilities.

Learning Disability Association of America: www.ldanatl.org. Provides comprehensive information, resources, and support.

Levine, Mel. *A Mind at a Time*. New York: Simon & Schuster, 2002. Insightful information on teaching children with learning disabilities.

Levinson, Harold N. *The Upside Down Kids: Helping Dyslexic Children Understand Themselves and Their Disorder*. New York: M. Evans, 1991. Describes how children with learning disabilities can appear normal but perform and learn differently.

Look What You've Done: Stories of Hope and Resilience [video]. Robert Brooks.

Looks at learning disabilities and self-esteem. To order: 800-343-5540. National Center for Learning Disabilities: www.nclld.org. Offers comprehensive advocacy, information, and resources.

Recording for the Blind and Dyslexic: www.rfbd.org. A national educational library for people with print-related disabilities.

Schwab Foundation for Learning: www.schwablearning.org. One of the most comprehensive sites for parents. Includes a bulletin board, newsletters, resources, and other information.

Shaywitz, Sally. *Overcoming Dyslexia: A New and Complete Science-Based Program for Reading Problems at Any Level*. New York: Knopf, 2003. The latest research and information on dyslexia.

Silver, Larry B. *The Misunderstood Child*. 2nd ed. New York: McGraw-Hill, 1992. The first book to read on learning disabilities. A classic in the field.

Smith, Sally L. *Succeeding against the Odds*. New York: Tarcher/Putnam, 1991. Wonderful information on children who learn successfully from teaching that builds on their strengths.

Smith, Sally L. *The Power of the Arts: Creative Strategies for Teaching Exceptional Learners*. Baltimore, MD: Paul H. Brookes, 2001. Information on how the arts are used in a school for children with learning disabilities.

Sternberg, Robert J., and Elena L. Grigorenko. *Our Labeled Children: What Every Parent and Teacher Needs to Know about Learning Disabilities*. Reading, MA: Perseus, 1999. Information on how society decides what children to label as having a learning disability.

Vail, Priscilla L. *About Dyslexia: Unraveling the Myth*. Cambridge, MA: Modern Learning, 1990. Good, basic, and hopeful information.

West, Thomas G. *In the Mind's Eye*. Buffalo, NY: Prometheus, 1991. An inspiring look at talented people with dyslexia. Suggests that having dyslexia aids in their brilliance.

Co-Occurring with Attention-Deficit Disorder (ADD)

Note: Many of the websites about learning disabilities also cover ADD, and many of the websites about ADD also cover learning disabilities.

Carroll, Lee, and Jan Tober. *The Indigo Children*. Carlsbad, CA: Hay House, 1999. A different spiritual perspective on children with ADD and learning disabilities and the role they play in our lives.

Crawford, Veronica, and Larry B. Silver. *Embracing the Monster: Overcoming the Challenges of Hidden Disabilities*. Baltimore, MD: Paul H. Brookes, 2001. A mother talks about bipolar disorder, learning disabilities, ADD, and sensory integration problems.

Kranowitz, Carol Stock. *The Out-Of-Sync Child: Recognizing and Coping with Sensory Integration Dysfunction*. New York: Perigee, 1998. Explains the sensory integration dysfunction so often associated with autism, ADD, learning disabilities, and the like.

- Lavoie, Richard D. *When the Chips Are Down, Learning Disabilities and Discipline* [program guide and video]. Washington, DC: WETA/Learning Disabilities Project, 1996. Excellent practical information on working with students who have ADD and learning disabilities.
- LCP Solution: www.lcpsolution.com. Promotes nutrition and vitamins for people with learning disabilities and ADD.
- Osman, Betty B. *No One to Play With: Social Problems of LD and ADD Children*. Norato, CA: Academic Therapy, 1995. Information on the social aspects of having ADD and learning disabilities.
- Stordy, Jacqueline B. *The LCP Solution: The Remarkable Nutritional Treatment for ADHD, Dyslexia, and Dyspraxia*. New York: Ballantine, 2000. A nutritional treatment based on using omega-3 fatty acids.
- Taymans, Juliana M., and Lynda L. West, with Madeline Sullivan. *Unlocking Potential: College and Other Choices for People with LD and AD/HD*. Bethesda, MD: Woodbine House, 2000. Good reference information for children with learning disabilities and ADD who want to pursue a post-secondary education.
- Virtue, Doreen, and Jan Tober. *The Care and Feeding of Indigo Children*. Carlsbad, CA: Hay House, 2001. A good companion book to Carroll and Tober's *Indigo Children*. Provides additional information.
- When the Chips Are Down* [video]. Richard D. Lavoie. An inspiring video with practical ideas on using positive discipline for youths with ADD and learning disabilities. To order: www.LDOnline.com.

Books for Children and Youth

- Abeel, Samantha. *Reach for the Moon*. Duluth, MN: Pfeifer-Hamilton, 1994. Poems written by a fifteen-year-old girl with learning disabilities.
- Dahl, Roald. *The Vicar of Nibbleswicke*. New York: Puffin, 1994. A hilarious look at problems with words.
- Fenner, Carol. *Yolanda's Genius*. New York: Alladin Paperbacks, 1997. An African American girl tries to help her bother who does not talk much or read well but plays the harmonica beautifully; a Newbery honor book.
- Fisher, Gary, and Rhoda Cummings. *The Survival Guide for Kids with LD: Learning Differences*. Minneapolis: Free Spirit, 1990. A guide for children with learning disabilities. Discusses the different types of disorders, programs and school, coping with negative feelings, and making friends. Includes a section for parents and teachers.
- Fisher, Gary, and Rhoda Cummings. *The Survival Guide for Teenagers with LD*. Minneapolis: Free Spirit, 1993. A similar guide for teenagers with learning disabilities.
- Hoffman, Alice. *Fireflies*. New York: Disney, 1997. A boy is ridiculed for his clumsiness until he solves the mystery of the missing fireflies.

- Janover, Caroline. *How Many Days Until Tomorrow?* Bethesda, MD: Woodbine House, 2000. An adventure story about Josh, a twelve-year-old who has dyslexia, set during the summer on a remote island of the coast of Maine. For grades 3 through 6.
- Polacco, Patricia. *Thank You, Mr. Falker.* New York: Philomel, 1998. The heart-warming story of how one person made a difference in the life of a child with learning disabilities.
- Root, Ann, and Linda Gladden. *Charlie's Challenge.* Austin, TX: Printmaster, 1995. Charlie is a little boy who faces a challenge: He must discover why he can design an award-winning castle yet have difficulty with reading and spelling.

Attention-Deficit Disorder (ADD)

- A.D.D. Warehouse: www.addwarehouse.com: An excellent source of books, videos, training programs, games, professional texts, and assessment products.
- ADDvance: www.addvance.com. A resource for women and girls with ADD.
- Armstrong, Thomas. *The Myth of the ADD Child: Fifty Ways to Improve Your Child's Behavior and Attention Span without Drugs, Labels, or Coercion.* New York: Plume, 1997. An excellent, practical resource that presents children with ADD in a positive light.
- Block, Mary Ann. *No More ADHD: Ten Steps to Help Improve Your Child's Attention and Behavior without Drugs.* Hurst, TX: Block, 2001. Advice on how proper nutrition can lessen or eliminate hyperactive behavior.
- Block, Mary Ann: www.blockcenter.com. Offers a nondrug approach to treating attention-deficit hyperactivity disorder (ADHD).
- Born to Explore: www.borntoexplore.org A positive and interesting site. Provides information in tune with Hartmann and Freed's ideas.
- Breeding, John. *The Wildest Colts Make the Best Horses.* Austin, TX: Bright, 1996. A positive look at having ADD.
- Breggin, Peter R. *Talking Back to Ritalin: What Doctors Aren't Telling You About Stimulants for Children.* Monroe, ME: Common Courage, 1998. Breggin was one of the first psychiatrists to question the use of Ritalin.
- Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD): www.chadd.org. Information on ADD. Local CHADD chapters are available around the country and will likely provide information to help plan programs for children with ADD.
- Debroitner, Rita Kirsch, and Avery Hart. *Moving Beyond ADD/ADHD: An Effective Holistic Mind-Body Approach.* Chicago: Contemporary, 1997. Suggestions for taking a holistic approach to working and parenting.
- Freed, Jeffrey. *Right-Brained Children in a Left-Brained World.* New York: Simon & Schuster, 1998. One of the best books on changes in our culture that affect how best to educate different learners.

- Hallowell, Edward M., and John J. Ratey. *Answers to Distraction*. New York: Bantam, 1996. A good follow-up to these authors' first book, *Driven to Distraction*.
- Hallowell, Edward M., and John J. Ratey. *Driven to Distraction: Recognizing and Coping with Attention Deficit Disorder from Childhood Through Adulthood*. New York: Touchstone, 1995. A classic, must-be-read book on ADD.
- Hartmann, Thom. *Attention Deficit Disorder: A Different Perception*. Grass Valley, CA: Underwood, 1997. An excellent book for those who want a more positive and compassionate way to view children with ADD.
- Hartmann, Thom. *Healing ADD: Simple Exercises That Will Change Your Daily Life*. Grass Valley, CA: Underwood, 1998. Spiritual exercises for coping with ADD.
- Hartmann, Thom. *The Edison Gene: ADHD and the Gift of the Hunter Child*. Rochester, VT: Park Street, 2003. The latest research on ADD and how it supports Hartmann's hunter/farmer theory.
- Hartmann, Thom: www.ThomasHartmann.com. Hartmann is a well-known author and proponent of alternative visioning for children and adults with ADD.
- Nadeau, Kathleen G., Ellen Litman, and Patricia D. Quinn. *Understanding Girls with AD/HD*. Silver Spring, MD: Advantage, 2000. An informative read for parents of girls with ADD.
- Palladino, Lucy Jo. *Edison Trait: Saving the Spirit of Your Nonconforming Child*. New York: Random House, 1997. Describes a wonderful approach to parenting children with ADD.
- Reichenberg-Ullman, Judyth, and Robert Ullman. *Ritalin-Free Kids: Safe and Effective Homeopathic Medicine for ADD and Other Behavioral and Learning Problems*. Rocklin, CA: Prima, 2000. For those who want to follow a homeopathic method of treatment.

Books for Children and Youth

- Alster, Jason Mark. *Being in Control*. n.p.: Rainbow Cloud, 2001. A self-help book for children with attention problems; includes relaxation and yoga techniques, games, and social and learning skills.
- Caffrey, Jaye Andras. *First Star I See*. Fairport, NY: Verbal Images, 1997. A humorous novel for girls with ADD to help them learn to appreciate their imagination.
- Corman, Clifford L., and Esther Trevino. *Eukee the Jumpy, Jumpy Elephant*. Plantation, FL: Specialty, 1996. Eukee is hyperactive and inattentive but succeeds with help from his friends, family, and doctor.
- Gantos, Jack. *Joey Pigza Swallowed the Key*. New York: Harper Trophy, 2000. Describes from Joey's point of view what it is like to have ADD. Both a

humorous and serious story for children ten and older.

- Gantos, Jack. *Joey Pigza Loses Control*. New York: Harper Trophy, 2002. Joey is coping better with his ADD, until he spends the summer with his divorced father. This Newbery honor book is for children ten and older.
- Gehret, Jeanne M. A. *Eagle Eyes: A Child's Guide to Paying Attention*. Fairport, NY: Verbal Images, 1996. Tells about a young boy with ADD who gains acceptance and finds a hidden blessing.
- Janover, Caroline. *Zipper: The Kid with ADHD*. Bethesda, MD: Woodbine House, 1997. An eleven-year-old struggles with life but learns to cope with ADHD and find real friends.
- Smith, Mark. *Pay Attention, Slosh*. Morton Grove, IL: Albert Whitman, 1997. A boy's life improves as he learns to cope with ADHD.
- Watterson, Bill. *The Essential Calvin and Hobbes*. Kansas City, MO: Andrews & McMeel, 1988. Calvin is a wonderful example of a highly creative, right-brained boy with ADD that all adults and children can love and laugh with.
- Zimmet, Debbie. *Eddie Enough!* Bethesda, MD: Woodbine House, 2001. Third-grader Eddie Minetti is a human whirlwind who thinks, moves, and speaks quickly and often gets into trouble. For grades K–4.

Autism Spectrum

Autism

- Autism Research Institute: www.autism.com/ari. Focuses on natural approaches to treating autism.
- Autism Resources: www.autism-resources.com. An excellent site for links to and resources for all areas of autism.
- Autism Society of America: www.autism-society.org. An excellent site for general information and resources.
- Autism Treatment Center of America, Son-Rise Program: www.son-rise.org. Describes the Son-Rise program, which is based on a child-centered approach to treating autism.
- Autism-PDD Resources Network: www.autism-pdd.net. Information on the key issues associated with autism spectrum disorders.
- Davis, Bill. *Breaking Autism's Barriers: A Father's Story*. Philadelphia: Jessica Kingsley, 2001. A story of hope and parental commitment.
- Doug Flutie, Jr., Foundation for Autism: www.dougflutie.org. Provides financial aid for disadvantaged families with autistic children.
- Grandin, Temple. *Emergence: Labeled Autistic*. New York: Warner, 1996. Written from the perspective of someone who is autistic.
- Grandin, Temple. *Thinking in Pictures and Other Reports from My Life with Autism*. New York: Vintage, 1995. A wonderful follow-up book on what

it is like to live with autism.

- Harris, Sandra L. *Siblings of Children with Autism: A Guide for Families*. Bethesda, MD: Woodbine House, 1994. A straightforward, instructional resource.
- Hart, Charles A. *A Parent's Guide to Autism*. New York: Pocket, 1993. An excellent overview of the autism spectrum from a parent's perspective.
- I Want My Little Boy Back* [video]. Option Institute, n.d. A BBC documentary of one family's journey through the Son-Rise Program. To order: www.option.org.
- John Maxwell Biasco Foundation for Children with Autism: www.maxie.org. A good resource for books, videos, articles, and the like.
- Kaufman, Barry Neil. *A Miracle to Believe In*. New York: Random House, 1981. Another inspiring story of overcoming autism using the Kaufmans' child-centered method.
- Kaufman, Barry Neil. *Son Rise: The Miracle Continues*. Tiburon, CA: H. S. Kramer, 1994. A powerful, inspiring story about the Kaufmans' method for helping their son overcome autism.
- Lewis, Lisa. *Special Diets for Special Kids*. Arlington, TX: Future Horizons, 1998. Good information on nutrition.
- Miracle of Love, A* [video]. Option Institute, n.d. An inspiring movie made about the Kaufmans' experience with their autistic son, which started the treatment method for the Son-Rise Program. To order: www.option.org.
- Park, Clara Claiborne. *Exiting Nirvana: A Daughter's Life with Autism*. Boston: Little, Brown, 2001. An excellent follow-up book on how her daughter is doing as an adult with autism.
- Park, Clara Claiborne. *The Siege: A Family's Journey into the World of an Autistic Child*. Boston: Little, Brown, 2001. A parent's moving story of living with a child with autism.
- Seroussi, Karyn. *Unraveling the Mystery of Autism and Pervasive Developmental Disorder: A Mother's Story of Research and Recovery*. New York: Simon & Schuster, 2000. A story of recovering from autism with proper diet and nutrition.
- Shore, Stephen. *Beyond the Wall: Personal Experiences with Autism and Asperger's Syndrome*. 2nd ed. Shawnee Mission, KS: Autism Aspergers, 2003. The fascinating autobiography of a man with Asperger's syndrome.
- Stehli, Annabel. *A Sound of a Miracle: A Child's Triumph over Autism*. Westport, CT: Georgiana Organization, 1995. A story of overcoming autism with alternative approaches.
- Stehli, Annabel. *Dancing in the Rain: Stories of Exceptional Progress by Parents of Children with Special Needs*. Westport, CT: Georgiana Organization,

1995. Inspiring stories of alternative approaches to treating autism.

Williams, Donna. *Nobody Nowhere: The Extraordinary Autobiography of an Autistic*. Philadelphia: Jessica Kingsley, 1994. The gripping autobiography of an abused child with autism.

Williams, Donna. *Somebody Somewhere, Breaking Free from the World of Autism*. Philadelphia: Jessica Kingsley, 1995. The continued story of Williams's emergence from autism.

Asperger's Syndrome and Nonverbal Learning Disability (NLD)

Asperger Syndrome Coalition of the U.S.: www.asperger.org. A good site for information about Asperger's syndrome and NLD.

Attwood, Tony. *Asperger's Syndrome: A Guide for Parents and Professionals*. Philadelphia: Jessica Kingsley, 1998. A source of basic information by the foremost expert on Asperger's syndrome.

Attwood, Tony: www.tonyattwood.com. The website of the leading expert on Asperger's syndrome.

Fling, Echo R. *Eating an Artichoke: A Mother's Perspective on Asperger Syndrome*. Philadelphia: Jessica Kingsley, 2000. Asperger's syndrome from a mother's perspective.

Green, Deborah. *Growing Up with NLD*. 2nd ed. Albuquerque, NM: Silicon Heights Computers, 2002. A good first-person account of what it is like to have NLD.

Myles, Brenda Smith, and Jack Southwick. *Asperger Syndrome and Difficult Moments: Practical Solutions for Tantrums, Rage, and Meltdowns*. Shawnee Mission, KS: Autism Asperger, 2001. Provides good practical information.

NLDontheWeb: www.NLDontheweb.org. An excellent resource for information about NLD.

Non Verbal Learning Disability Association: www.NLDA.org. Dedicated to research, education, and advocacy.

O.A.S.I.S. Online Asperger's Syndrome Information and Support: www.udel.edu/bkirby/asperger. A wonderful place to look for resources on Asperger's syndrome as well as autism. Also mentions NLD.

Thompson, Sue. *The Source for Non Verbal Learning Disorders*. East Moline, IL: Lingui Systems, 1997. Thompson is the foremost expert on NLD.

Thompson, Sue: www.NLDLine.com. Provides the most current information on NLD. Includes general information, a chat room, and more.

Wiley, Liane Holliday. *Pretending to Be Normal, Living with Asperger's Syndrome*. Philadelphia: Jessica Kingsley, 1999. Insight into what it is like to live with Asperger's syndrome.

Books for Children and Youth

Bleach, Fiona. *Everybody Is Different: A Book for Young People Who Have Brothers or Sisters with Autism*. Shawnee Mission, KS: Autism Asperger,

2002. For children ages four to eight.

- Edward, B. *My Brother Sammy*. Brookfield, CT: Millbrook Press Trade, 1999. Tired of hearing about his “special” older brother, a boy discovers that he is special, too.
- Lears, Laurie. *Ian’s Walk: A Story about Autism*. Morton Grove, IL: Albert Whitman, 1998. Julie tells about walking through town with her brother Ian, who is autistic. For children ages four to eight.
- Sullivan, Connor, and Danielle Sullivan. *I Love My Brother! A Preschooler’s View of Living with a Brother Who Has Autism*. West Plains, MO: Phat Art 4, 2001. The true story of a young boy’s love for his brother who has autism.
- Thompson, May. *Andy and His Yellow Frisbee*. Bethesda, MD: Woodbine House, 1996. A sister gently and kindly provides insight about her autistic brother. For children ages four to eight.
- Werlin, Nancy. *Are You Alone on Purpose?* New York: Houghton Mifflin, 1994. A girl whose twin brother has autism and a boy whose mother has died initially dislike each other but then find that they have much in common. For children ages nine to twelve.

Mental Retardation/Developmental Delays

- American Association on Mental Retardation: www.aamr.org. The oldest advocacy organization for people with mental retardation.
- Arc, The: www.thearc.org. A national organization for and about people with mental retardation.
- Beck, Martha. *Expecting Adam: A True Story of Birth, Rebirth, and Everyday Magic*. New York: Berkley, 2000. An inspirational story about what it is like to give birth to and parent a child with Down syndrome.
- Berubé, Michael. *Life as We Know It: A Father, a Family, and an Exceptional Child*. New York: Vintage, 1998. A father’s thoughtful exploration of parenting a child with Down syndrome.
- Burke, Chris, and Jo Beth McDaniel. *A Special Kind of Hero: Chris Burke’s Own Story*. New York: Doubleday, 1991. Chris Burke tells his story of having Down syndrome.
- FRAXA Research Foundation: www.FRAXA.org. Provides information on fragile X syndrome
- Kingsley, Jason, and Mitchell Levitz. *Count Us In: Growing Up with Down Syndrome*. New York: Harcourt Brace, 1994. Another excellent book on life with Down syndrome, as told by two boys.
- Lovett, Herbert. *Learning to Listen: Positive Approaches and People with Difficult Behavior*. Baltimore, MD: Paul Brookes, 1996. A compassionate look at people with mental retardation and what they have to offer society.
- Michael, Dorris. *Broken Cord*. New York: HarperCollins, 1990. A parent’s story about his child with fetal alcohol syndrome.
- National Association for Down Syndrome: www.nads.org. Provides critical

counseling and support services.

National Down Syndrome Society: www.ndss.org. Offers comprehensive resources and information.

National Fragile X Foundation: www.nfxf.org. Provides advocacy, information, and resources.

National Organization on Fetal Alcohol Syndrome: www.nofas.org. An advocacy organization that provides information and resources.

National PKU News: www.pkunews.org. News and information about phenylketonia.

Oaks Group: www.oaksgroup.org. Advocates for children with developmental disabilities.

Prader-Willi Syndrome Association: www.pwsausa.org. Information and support for families and people with Prader-Willi syndrome.

Selikowitz, Mark. *Down Syndrome: The Facts*. 2nd ed. New York: Oxford University, 1997. Provides good basic information.

Smith, Romayne. *Children with Mental Retardation: A Parent's Guide*. Bethesda, MD: Woodbine House, 1993. Very readable, basic information.

Streissguth, Ann Pykowicz. *Fetal Alcohol Syndrome: A Guide for Families and Communities*. Baltimore, MD: Paul Brookes, 1997. Provides basic information.

Trainer, Helen. *Differences in Common: Straight Talk on Mental Retardation, Down Syndrome and Your Life*. Bethesda, MD: Woodbine House, 1991. A wonderful book for parents on day-to-day life with a child with mental retardation.

Weber, Jayne Dixon. *Children with Fragile X Syndrome: A Parent's Guide*. Bethesda, MD: Woodbine House, 2000. Provides good basic information.

Books for Children and Youth

Carter, Alden R. *Big Brother Dustin*. Morton Grove, IL: Albert Whitman, 1997. A picture book about a child with Down syndrome becoming a big brother. For children ages four to eight.

Christopher, Matt. *Long Shot for Paul*. New York: Little, Brown, 1990. A boy wants his brother, who is developmentally disabled, to become a good basketball player and to make friends. For children ages nine to twelve.

Dodds, Bill. *My Sister Annie*. Honesdale, PA: Caroline House-Boys Mills Press, 1993. A boy entering middle school, who wants to join a club, play baseball, and slow dance, has a sister with Down syndrome. For children ages nine to twelve.

Flemming, Virginia. *Be Good to Eddie Lee*. Glenview, IL: Scott, Foresman, 1997. A girl learns to value her neighbor, Eddie, who has Down syndrome, when he guards ducks from another boy who wants to torment

them. For children ages four to eight.

- McNey, Martha, and Leslie Fish. *Leslie's Story: A Book about a Girl with Mental Retardation*. Minneapolis, MN: Lerner, 1996. An eight-year-old girl with rheumatoid arthritis and brain damage tells the true story of her life. For children ages four to eight.
- O'Shaughnessy, Ellen. *Somebody Called Me a Retard Today . . . and My Heart Felt Sad*. New York: Walker, 1992. A girl is saddened by teasing, even though she knows her own worth. For children ages four to eight.
- Penske, Robert. *Show Me No Mercy: A Compelling Story of Remarkable Courage*. Nashville, TN: Abingdon, 1984. Paralyzed in an accident that kills his wife and daughter, Andy, a bus driver, struggles to overcome his handicap and to keep his teenage son with Down syndrome from being institutionalized. For teens.
- Rabe, Berenice. *Where's Chimpy?* Morton Grove, IL: Albert Whitman, 1991. A picture book about a girl with Down syndrome who looks for her toy at bedtime and then helps Daddy find his glasses. For preschool children.
- Rubin, Susan Goldman. *Emily Good as Gold*. San Diego, CA: Browndeer, 1993. A thirteen-year-old girl with developmental disabilities faces adolescence and learns she can make good social choices. For children ages nine to twelve.
- Rubin, Susan Goldman. *Emily in Love*. San Diego, CA: Browndeer, 1997. In this sequel to *Emily Good as Gold*, Emily goes to high school, marking the first time she has attended a regular school. Does she have the nerve to tell Hunt, the boy she likes, about her disability? For children ages nine to twelve.
- Shyer, Marlene Panta. *Welcome Home, Jellybean*. New York: Aladdin, 1988. A boy's sister with developmental disabilities comes home from a residential placement. For children ages nine to twelve.
- Tashjian, Janet. *True Confessions*. New York: Scholastic, 1999. A twelve-year-old girl wants a career in television and to help her developmentally disabled twin brother. For children ages nine to twelve.
- Testa, Maria. *Thumbs Up Rico!* Morton Grove, IL: A. Whitman, 1994. In three short stories, Rico, a boy with Down syndrome, makes friends and learns how to be a good brother. For children ages four to eight.
- Wilson, Nancy Hope. *The Reason for Janey*. New York: Avon Books, 1994. A developmentally disabled adult moves in with the family of a girl whose parents have recently divorced. For young adults.
- Wood, June Rae. *The Man Who Loved Clowns*. New York: Hyperion, 1995. A girl likes her uncle with Down syndrome but is ashamed of him. For children ages nine to twelve.

Mood Disorders

- Carlson, Trudy. *The Life of a Bipolar Child: What Every Parent and Professional Needs to Know*. Duluth, MN: Benline, 2000. Excellent practical information from a mother of a child with bipolar disorder.
- Child and Adolescent Bipolar Foundation: www.cabf.org or www.bpkids.org. Information, support, and advocacy on early intervention and treatment.
- Cytryn, Leon, and Donald McKnew. *Growing Up Sad: Childhood Depression and Its Treatment*. New York: W. W. Norton, 1998. Good basic and compassionate information.
- Depression and Bipolar Support Alliance: www.dbsalliance.org. Information and support to improve the lives of people with mood disorders.
- Duke, Patty. *A Brilliant Madness: Living with Manic-Depressive Illness*. New York: Bantam, 1993. Duke's story of denial and then learning to live with bipolar disorder.
- Families for Depression Awareness: www.familyaware.org. Information for families living with depression or bipolar disorder.
- Fassler, David G., and Lynne S. Dumas. *Help Me I'm Sad: Recognizing, Treating, and Preventing Childhood and Adolescent Depression*. New York: Penguin USA, 1998. A good resource book.
- Glenmullen, Joseph. *Prozac Backlash: Overcoming the Dangers of Prozac, Zoloft, Paxil, and Other Antidepressants with Safe, Effective Alternatives*. New York: Touchstone, 2000. The dangers of medication and an alternative look at treating mood disorders.
- Harbor of Refuge Organization: www.harbor-of-refuge.org. A peer-to-peer support for people with bipolar disorder and those that care about them.
- Ingersoll, Barbara, and Sam Goldstein. *Lonely, Sad and Angry: A Parent's Guide to Depression in Children and Adolescents*. Plantation, FL: Specialty, 2001. Good up-to-date information.
- Jamison, Kay Redfield. *An Unquiet Mind*. New York: Random House, 1997. Jamison's compelling autobiography of living with bipolar disorder.
- Koplewicz, Harold S. *More Than Moody: Recognizing and Treating Adolescent Depression*. New York: Perigee, 2003. Helpful information for parents.
- Lynn, George T. *Survival Strategies for Parenting Children with Bipolar Disorder*. Philadelphia: Jessica Kingsley, 2000. Helpful information for parents.
- Mental Health Sanctuary: www.mhsanctuary.com. A mental health website that provides information on finding a therapist.
- National Foundation for Depressive Illness: www.depression.org. Provides public education, information, and referrals.

- Papolos, Demitri, and Janice Papolos. *The Bipolar Child: The Definitive and Reassuring Guide to Childhood's Most Misunderstood Disorder*. New York: Broadway, 2002. Comprehensive information by the foremost experts on bipolar disorder.
- Pendulum Resources: www.pendulum.org. Information and resources for people with bipolar disorder by people with bipolar disorder.
- Robertson, Joel, with Tom Monte. *Natural Prozac: Learning to Release Your Body's Own Anti-Depressants*. New York: HarperCollins, 1998. An alternative and natural approach to healing depression.
- Simon, Lizi. *Detour: My Bipolar Road Trip*. New York: Washington Square, 2003. A fascinating story of living with bipolar disorder.
- Steel, Danielle. *His Bright Light: The Story of Nick Traina*. New York: Delacorte, 2000. Chronicles the day-to-day struggles and immense difficulties of living with and trying to treat someone with bipolar disorder.
- Stolle, Andrew L. *The Omega-3 Connection*. New York: Simon & Schuster, 2001. The connection between essential fatty acids and depression and bipolar disorder.
- Waltz, Mitzi. *Bipolar Disorders: A Guide to Helping Children and Adolescents*. Sebastopol, CA: Patient-Centered Guides, 2000. Practical and readable information.
- Wilder, Paul A. *Overcoming Depression and Manic Depression (Bipolar Disorder): A Whole Person Approach*. Rutherford, NJ: Wellness Communications, 2001. An excellent book on treating depression and bipolar disorder without medication by someone who has healed himself.

Eating Disorders

- Anderson, Arnold. *Males with Eating Disorders*. New York: Brunner-Routledge, 1990. Provides information just for boys, which is difficult to find.
- Anorexia Nervosa and Related Eating Disorders, Inc.: www.anred.com. Provides information, resources, and self-help tips.
- Eating Disorder Referral and Information Center: www.EDreferral.com. Provides information and treatment resources.
- Hornbacher, Marya. *Wasted: A Memoir of Anorexia and Bulimia*. New York: HarperCollins, 1999. Autobiography of a young woman living with anorexia and coming to terms with her disorder.
- Natenshon, Abigail. *When Your Child Has an Eating Disorder: A Step by Step Workbook for Parents and Other Caregivers*. San Francisco: Jossey-Bass, 1999. Good basic information.
- National Association of Anorexia Nervosa and Associated Disorders (ANAD): www.anad.org. Provides information, resources, and hotline counseling.

Overeaters Anonymous: www.overeatersanonymous.org. Based on the twelve-step method. Provides information and help finding meetings.

Pipher, Mary. *Reviving Ophelia*. New York: Ballantine, 1994. Wonderful information about growing up female in American culture by a Unitarian Universalist author.

Suicide

American Foundation for Suicide Prevention: www.afsp.org. Provides information, resources, and education.

ANSWER (Adolescents Never Suicide When Everyone Responds): www.teenanswer.org. Information on prevention.

Bolton, Iris. *My Son . . . My Son . . . : A Guide to Healing after Death, Loss, or Suicide*. Rev. ed. Atlanta, GA: Bolton, 1983. The powerful story of Bolton's journey of healing after the loss of her son to suicide.

Carlson, Trudy. *Suicide Survivors' Handbook*. Duluth, MN: Benline, 2000. Helpful coping and survival strategies for parents.

Collins, Judy. *Sanity and Grace: A Journey of Suicide, Survival, and Strength*. Los Angeles: J. P. Tarcher, 2003. Collins's story of healing after her son's suicide.

Jamison, Kay Redfield. *Night Falls Fast: Understanding Suicide*. New York: Vintage, 2000. A perspective from someone with bipolar disorder who has contemplated suicide.

National Organization of People of Color Against Suicide: www.nopcas.com. Information and resources.

Suicide Awareness Voices of Education: www.save.org. An organization dedicated to educating the public about suicide prevention.

Suicide Prevention Action Network USA (SPANUSA): www.spanusa.org. SPAN's goal is to save lives through prevention by providing information and advocacy.

Books for Children and Youth

Anglada, Troy. *Brandon and the Bipolar Bear*. Looks at the symptoms, fears, and treatment of bipolar disorder from a young boy's perspective. For children ages four to ten. To order: www.bipolar-childrenbigstep.com.

Garland, E. Jane. *Depression Is the Pits, but I'm Getting Better: A Guide for Adolescents*. Washington, DC: Magination, 1998. A user-friendly guide for teenagers who are experiencing any level of depression.

Grieve, Bradley Trevor. *The Blue Day Book*. Kansas City, MO: Andrews McMeel, 2001. A picture book that helps kids keep things in perspective.

Hall, Liza F. *Perk!: The Story of a Teenager with Bulimia*. Carlsbad, CA: Gurze Designs & Books, 1997. For young adults.

Homes, Margaret M., and Sasha J. Mudlaff. *A Terrible Thing Happened: A Story for Children Who Have Witnessed Violence or Trauma*. Washington,

- DC: Magination, 2000. A story about a child who sees a “terrible thing” and how it affects his life. For children ages four to eight.
- Sanders, Mark D., and Tia Sillers. *I Hope You Dance*. Nashville, TN: Rutledge Hill, 2000. Based on the song “I Hope You Dance,” by Lee Ann Womack, this book helps young people learn to live their lives with hope, wonder, and love.
- Sommers, Michael A. *Everything You Need to Know about Bipolar Disorder and Manic Depressive Illness*. New York: Rosen, 2000. A book for adolescents ages thirteen to eighteen.

Anxiety Disorders

- Angelou, Maya. *I Know Why the Caged Bird Sings*. New York: Bantam, 1983. Angelou describes how selective mutism and sexual abuse affected her childhood.
- Anxiety Disorders Association of America: www.adaa.org. Provides information, resources, advocacy, and support groups.
- Anxiety Panic Internet Resource: www.algy.com/anxiety. The web’s oldest site of resources and services for people with anxiety disorders. Created and sustained by its users.
- Bloomfield, Harold H. *Healing Anxiety Naturally*. n.p.: Perennial, 1999. Looks at alternative treatments for anxiety disorders, such as herbs, meditation, and music.
- Chansky, Tamar E. *Freeing Your Child from Obsessive-Compulsive Disorder*. Three Rivers, MI: Three Rivers, 2001. Good practical information.
- Dacey, John S., and Lisa B. Fiore. *Your Anxious Child: How Parents and Teachers Can Relieve Anxiety in Children*. San Francisco: Jossey-Bass, 2000. One of the most useful and positive books for helping a child with an anxiety disorder. Dacey is a Unitarian Universalist author.
- Dayhoff, Signe A. *Diagonally-Parked in a Parallel Universe: Working through Social Anxiety*. Placitas, NM: Effectiveness-Plus, 2000. Good information for anyone who has a high level of anxiety in social situations.
- Gravitz, Herbert L. *Obsessive Compulsive Disorder: New Help for the Family*. Santa Barbara, CA: Healing Visions, 1998. Hopeful information for families.
- Hallowell, Edward M. *Worry, Hope and Help for a Common Condition*. New York: Ballantine, 1998. Practical as well as hopeful information.
- Manassis, Katharina. *Keys to Parenting Your Anxious Child*. Hauppauge, NY: Barrons Educational Series, 1996. Good practical information.
- National Center for Post Traumatic Stress Disorder: www.ncptsd.org. A program of the U.S. Department of Veterans Affairs that provides information on PTSD in children.
- Obsessive Compulsive Foundation: www.ocfoundation.org. Provides advocacy, education, and support.

Rapoport, Judith. *The Boy Who Couldn't Stop Washing: The Experience and Treatment of Obsessive Compulsive Disorder*. New York: New American Library, 1997. The classic story that shed light on obsessive-compulsive disorder.

Wilensky, Amy. *Passing for Normal: A Memoir of Compulsion*. New York: Broadway, 2000. A young woman's story of growing up with obsessive-compulsive disorder and Tourette's syndrome.

Tourette's Syndrome

Hilkevich, John S. *Don't Think About Monkeys: Extraordinary Stories Written by People with Tourette's Syndrome*. Duarte, CA: Hope, 1992. Provides insight into what it is like to live with Tourette's syndrome.

Tourette Syndrome Association: www.tsa-usa.org. Information, resources, and advocacy.

Tourette's Syndrome Online: www.tourette-syndrome.com. An excellent online community devoted to children and adults with Tourette's syndrome.

Waltz, Mitzi. *Tourette's Syndrome: Finding Answers and Getting Help*. North Sebastopol, CA: O'Reilly & Associates, 2001. Well-researched, basic information for parents.

Books for Children and Youth

Buehrens, Adam. *Adam and the Magic Marble*. Duarte, CA: Hope, 1991. Three children with disabilities, including one with Tourette's, find a magic marble that helps them deal with bullies.

Buehrens, Adam. *Hi, I'm Adam: A Child's Book about Tourette Syndrome*. Duarte, CA: Hope, 1990. A child talks about what it is like to have Tourette's syndrome.

Colas, Emily. *Just Checking: Scenes from the Life of an Obsessive-Compulsive*. New York: Washington Square, 1999. For adolescents as well as adults.

Foster, Constance H. *Polly's Magic Games: A Child's View of Obsessive-Compulsive Disorder*. 1994. Available online: www.booksonthe.net. For children ages four to eight.

Hesser, Terry Spencer. *Kissing Doorknobs*. New York: Bantam, 1998. A young girl's story about having obsessive-compulsive disorder. For young adults.

Moritz, E. Katia, and Jennifer Jablonsky. *Blink, Blink, Clap, Clap: Why Do We Do Things We Can't Stop? An OCD Storybook*. Plainview, NY: Childsworld/Childsplay, 2001. For young children.

Schaefer, Charles, and Judith Friedman. *Cat's Got Your Tongue? A Story for Children Afraid to Speak*. Washington, DC: Magination, 1992. For young children.

- Snyder, Zilpha Keatley. *Fool's Gold*. New York: Delacorte, 1993. A fast-paced adventure book about a boy and his friendships and coming to terms with his claustrophobia. For young adults.
- Summers, Marc, and Eric Hollander. *Everything In Its Place: My Trials and Triumphs with Obsessive Compulsive Disorder*. Los Angeles: J. P. Tarcher, 2000. For adolescents and young adults.

Disruptive Behavior Disorders

- Barkley, Russell A., and Christine M. Benton. *Your Defiant Child: Eight Steps To Better Behavior*. New York: Guilford, 1998. Excellent compassionate and helpful information.
- Barkley, Russell A., Arthur L. Robin, and Gwenyth H. Edwards. *Defiant Teens*. New York: Guilford, 1999. A thoughtful and compassionate look at why youths are defiant.
- Brendtro, Larry K., Martin Brokenleg, and Steve Van Bockern. *Reclaiming Youth at Risk: Our Hope for the Future*. Bloomington, IL: National Educational Service, 1998. An inspiring approach to healing our troubled and alienated youth from a Native American perspective.
- Bustamante, Eduardo M. *Treating the Disruptive Adolescent: Finding the Real Self Behind Oppositional Defiant Disorders*. Northvale, NJ: Jason Aronson, 2000. A compassionate approach to working with children with ODD.
- Chandler, Jim: www.klis.com/chandler/HOME.htm. Describes several psychological disorders.
- Eddy, J. Mark. *Aggressive and Defiant Behavior: The Latest Assessment and Treatment Strategies for the Conduct Disorders*. Eau Claire, WI: Compact Clinicals, 2001. Very technical but one of few resources available on conduct disorders.
- Taylor, John F. *From Defiance to Cooperation: Real Solutions for Transforming the Angry, Defiant, Discouraged Child*. Roseville, CA: Prima, 2001. Provides specific, sensible, and easy-to-implement suggestions for working with and living with a child with ODD.
- Teens with Problems: www.teenswithproblems.com. A resource for problems that are particularly associated with adolescents.
- Tobin, L. *What Do You Do with a Child Like This?* Duluth, MN: Whole Person Associates, 1991. Provides insight into the world of troubled children, with guidelines on how to relate to and teach them.
- Willman, Robert, and Judyth Reichenberg-Willman. *Drug-Free Kids: Homeopathic Medicine for Defiant, Aggressive, and Violent Children*. Roseville, CA: Prima, 1999. Information for those looking for alternative approaches.

Books for Children and Youth

Sparkes, Beatrice, ed. *Go Ask Alice*. New York: Pocket, 1998. The powerful real-life diary of a teenager who struggles with addiction to drugs.

Schizophrenia

Bedeillion, Mark. *Psychiatric Survivor: From Misdiagnosed Patient to Hospital Director*. Baden, PA: Rainbow's End, 1999. One person's compelling story of recovering from schizophrenia.

Breeding, John. *The Necessity of Madness and Unproductivity: Psychiatric Oppression or Human Transformation*. Available online: www.wildestcolts.com. A social commentary on mental illness in the United States.

Breggin, Peter R., and David Cohen. *Your Drug May Be Your Problem*. Reading, MA: Perseus, 2000. Information on the harmful side effects of medication.

Breggin, Peter: www.breggin.com. Information on Breggin's books and articles, along with other information on healing from schizophrenia.

Edelman, Eva. *Natural Healing for Schizophrenia and Other Common Mental Disorders*. Eugene, OR: Borage, 2001. For those who want information on alternative, natural approaches.

Glasser, William, and Peter R. Breggin. *Counseling with Choice Theory*. New York: Quill, 2001. An explanation of choice therapy in treating people with mental illness.

Hoffer, Abram. *Orthomolecular Treatment for Schizophrenia: Megavitamin Supplements and Nutritional Strategies for Healing and Recovery*. New York: McGraw-Hill, 1999. Excellent information on a treatment approach with proven success.

Mad Nation: www.madnation.cc. People working together for social justice and human rights in mental health.

MentalWellness.com: www.mentalwellness.com. Lifestyle types and counseling service for people with schizophrenia.

Mindfreedom: www.mindfreedom.org. Provides information about and for psychiatric survivors, including interesting and moving stories from an oral history project.

National Alliance for the Mentally Ill: www.nami.org. A nonprofit, grassroots organization of people with severe mental illnesses and their families and friends. Offers support and advocacy.

National Empowerment Center: www.power2u.org. Practical information to help people recover. One of the best sites representing the psychiatric survivor point of view.

Perry, John Weir. *Trials of the Visionary Mind: Spiritual Emergency and the Renewal Process*. Albany, NY: State University of New York, 1998. Discussion of schizophrenia from a spiritual perspective.

- Remschmidt, Helmut, ed. *Schizophrenia in Children and Adolescents*. Cambridge, England: Cambridge University, 2001. Highly technical information but one of the few books addressing schizophrenia in children.
- Schizophrenia-Help Resource Center: www.schizophrenia-help.com. Information on schizophrenia.
- Schizophrenia Society of Canada: www.schizophrenia.ca. Promotes public awareness and education and offers family support, advocacy, and initiatives and programs to fund research.
- Steele, Ken, and Claire Berman. *The Day the Voices Stopped*. New York: Basic, 2001. The personal story of a man with schizophrenia.
- Torrey, E. Fuller. *Surviving Schizophrenia: A Manual for Families, Consumers, and Providers*. 4th ed. New York: Quill, 2001. A well-known expert discusses treating schizophrenia. Supported by the National Association on Mental Illness.
- Treatment Advocacy Center: www.psycglaws.org. Information on Dr. E. Fuller Torrey's views, books, and articles plus other information.
- Walker, Sydney, III. *A Dose of Sanity: Mind, Medicine, and Misdiagnosis*. New York: John Wiley & Sons, 1998. How people are sometimes misdiagnosed as having schizophrenia when it is another physical problem.
- Whitaker, Robert. *Mad in America: Bad Science, Bad Medicine, and the Enduring Mistreatment of the Mentally Ill*. Reading, MA: Perseus, 2002. A detailed look at the science and social beliefs behind the treatment of people with schizophrenia.
- www.schizophrenia.com. Hosts chat groups and provides information and resources.

Books for Children and Youth

- Hanson, Regina. *The Face at the Window*. New York: Clarion, 1997. With her parents' help, a young girl in Jamaica gets over her fear of an elderly neighbor with mental illness. For children ages six to eight.
- Johnson, Angela. *Humming Whispers*. New York: Scholastic, 1996. A fourteen-year-old girl copes with her sister's schizophrenia and gets help from her family and community. For adolescents.

Motor Disabilities

Sports

- American Academy for Cerebral Palsy: www.aacpdm.org. Research and education, along with an online library and multimedia resources.
- Canadian Wheelchair Sports Association: www.cwsa.ca. Information on wheelchair sports in Canada.
- Cerebral Institute of Discovery: www.cerebral.org. A comprehensive collection of resources about neurological topics.

Cerebral Palsy

- Cerebral Palsy Association: www.ucp.org. A comprehensive informational site as well as the leading advocacy organization for people with cerebral palsy.
- Dormans, John P. *Caring for Children with Cerebral Palsy: A Team-Based Approach*. Baltimore, MD: Paul H. Brookes, 1998. The definitive guide to the interdisciplinary care of children with cerebral palsy.
- Geralis, Elaine, ed. *Children with Cerebral Palsy: A Parents' Guide*. Bethesda, MD: Woodbine House, 1998. Comprehensive information on the treatment and care of a child with cerebral palsy.
- Kennedy, Marie A. *My Perfect Son Has Cerebral Palsy: A Mother's Guide of Helpful Hints*. n.p.: First Books Library, 2001. Good practical advice offered in a hopeful yet candid way.
- Kramer, Laura Shapiro. *Uncommon Voyage: Parenting a Special Needs Child*. Berkeley, CA: North Atlantic, 2001. A mother's story of hope and struggle in caring for her son with cerebral palsy.
- National Disability Sports Alliance: www.ndsonline.org. The coordination of competitive sports for individuals with cerebral palsy, traumatic brain injury, and stroke.
- Wheelchair Sports USA: www.wsusa.org. Dedicated to the guidance and growth of wheelchair sports.

Neuromuscular Disease

- Children with Duchenne: www.findacure.com. An organization dedicated to finding a cure for children with Duchenne muscular dystrophy.
- Emery, Alan E. *Muscular Dystrophy: The Facts*. 2nd ed. New York: Oxford University, 2000. Describes all the muscular dystrophies with minimal technical jargon.
- Muscular Dystrophy Association: www.mdausa.org. A voluntary health agency that provides medical and community services as well as professional and public health education.
- Muscular Dystrophy Family Foundation: www.mdff.org. Provides adaptive equipment and emotional support to individuals and families affected by neuromuscular diseases.
- Neuroland: www.neuroland.com. Information about neuromuscular disease.
- Siegel, Irwin M. *Muscular Dystrophy in Children: A Guide for Families*. Gardena, CA: SCB Distributors, 1999. Good practical information.
- Stepank, Mattie J. T. *Heartsongs*. New York: Hyperion, 2002. Mattie is a boy with muscular dystrophy who writes wonderful spiritual poems about life.
- Thompson, Charlotte E. *Raising a Child with a Neuromuscular Disorder*. New York: Oxford University, 1999. An excellent book for parents. Provides thorough information on resources, advocacy, treatment, education, and so on.

Spina Bifida

- Children with Spina Bifida: www.waisman.wisc.edu/~rowley/sb-kids/index.html. A resource page for parents.
- Driscoll, Jean, with Janet and Geoff Bengé. *Determined to Win*. New York: Waterbrook, 2000. Driscoll, an Olympic wheelchair winner, tells her story.
- Lutkenhoff, Marlene, ed. *Children with Spina Bifida: A Parents' Guide*. Bethesda, MD: Woodbine House, 1999. Good practical information.
- Sandler, Adrian. *Living with Spina Bifida: A Guide for Families and Professionals*. Raleigh, NC: University of North Carolina, 1997. Highly useful and thorough information.
- S-B Teens: http://_sb_teens.homestead.com. An online support group for teens with spina bifida.
- Spina Bifida Association of America: www.sbaa.org. Comprehensive information and resources on spina bifida.

Spinal Cord Injury

- American Paraplegia Society: www.apssci.org. Focused on improving the quality of medical care for people with spinal cord injury.
- American Spinal Injury Association (ASIA): www.asia-spinalinjury.org. This organization facilitates research and fosters communication concerning spinal cord injury.
- Christopher and Dana Reeve Paralysis Resource Center: www.paralysis.org. A program of the Christopher Reeve Paralysis Foundation. An excellent source of comprehensive resources and information on spinal cord injury.
- National Spinal Cord Injury Association (NSCIA): www.spinalcord.org. One of the oldest organizations concerned with spinal cord injury.
- Palmer, Sara, Kay Harris Kriegsman, and Jeffrey B. Palmer. *Spinal Cord Injury, A Guide for Living*. Baltimore, MD: Johns Hopkins University, 2000. Provides a complete guide toward recovery.
- Reeve, Christopher. *Nothing Is Impossible: Reflections on a New Life*. New York: Random House, 2002. Reeve, an actor and a Unitarian Universalist author, provides more in-depth and inspiring reflection about his life.
- Reeve, Christopher. *Still Me*. New York: Ballantine, 1999. Reeve, an actor and Unitarian Universalist author, describes what his life has meant since his paralyzing accident.
- Senelick, Richard C., and Karla Dougherty. *The Spinal Cord Injury Handbook*. Birmingham, AL: HealthSouth, 1998. Practical and helpful information.
- Williams, Margie. *Journey to Well: Learning to Live after Spinal Cord Injury*. Newcastle, CA: Altarfire, 1997. Having suffered a severe spinal cord injury at age fifty-three, Williams describes her experiences and provides practical applications for wellness.

Traumatic Brain Injury

- American Brain Tumor Association: www.abta.org/whoweare/index.html. Information and resources on brain injuries from brain tumors.
- Brain Injury Association: www.biausa.org. Comprehensive information and resources on brain injury.
- Brain Injury Society: www.bisociety.org. A site for brain-injured individuals and their families.
- Head Injury Hotline: www.headinjury.com. A place to get information, join discussion groups, and build advocacy and self-care skills.
- Hylands (in Canada): www.hyghlands.com. Provides consulting to schools and the like about children with brain injury.
- Lloyd, Donald J., Shannon L. Kehoe, and Susan E. Lloyd. *Smile and Jump High! The True Story of Overcoming a Traumatic Brain Injury*. n.p.: Starlight, 2001. A compelling story of triumph over brain injury.
- Schoenbrodt, Lisa, ed. *Children with Traumatic Brain Injury: A Parents' Guide*. Bethesda, MD: Woodbine House, 2001. Comprehensive information for parents.
- Senelick, Richard C., and Karla Dougherty. *Living with Brain Injury: A Guide for Families*. 2nd ed. Birmingham, AL: HealthSouth, 2001. Up-to-date information on treating and living with brain injury.
- Winslade, William J. *Confronting Traumatic Brain Injury: Devastation, Hope, and Healing*. New Haven, CT: Yale University, 1999. Compelling facts and arguments for the prevention of traumatic brain injury.

Books for Children and Youth

- Burnett, Gail Lemley, Stephen D. Rioux, Brenda Wong, and John Cooper-smith Gold. *Muscular Dystrophy (Health Watch)*. Rev. ed. Berkeley Heights, NJ: Enslow, 2000. Each chapter discusses someone with muscular dystrophy, providing facts and pictures. For teens.
- Carlson, Nancy L. *Arnie and the New Kid*. New York: Puffin, 1992. Arnie teases Phillip, who is in a wheelchair, but the two soon become friends. For children ages four to eight.
- Farrell, Mame. *Marrying Malcolm Murgatroyd*. New York: Farrar, Strauss & Giroux, 1995. Hannah befriends weird Malcolm because he is supportive of her younger brother, Ian, who recently started using a wheelchair because he has muscular dystrophy. For children ages nine to twelve.
- Fassler, Joan. *Howie Helps Himself*. Morton Grove, IL: Albert Whitman, 1987. A boy uses a wheelchair and learns that doing things for himself is great. For children ages four to eight.
- Foland, Constance M. *A Song for Jeffrey*. Middleton, WI: Pleasant Company, 1999. Dodie, who is having a hard year because her parents have separated, becomes friends with a boy with muscular dystrophy and learns a lesson in living. For children ages nine to twelve.

- Gilman, Laura Anne. *Coping with Cerebral Palsy*. New York: Rosen, 2001. A book for adolescents with cerebral palsy.
- Helfman, Elizabeth. *On Being Sarah*. Morton Grove, IL: Albert Whitman, 1992. Twelve-year-old Sarah, who has cerebral palsy, cannot walk or talk but uses technology to help make friends in a new school. For children ages nine to twelve.
- Holcomb, Nan. *Patrick and Emma Lou*. Hollidaysburg, PA: Jason and Nordic, 1989. Two kids with spina bifida know they are not alone when they meet in physical therapy. For children ages four to eight.
- Lutkenhoff, Marlene, and Sonya G. Oppenheimer, eds. *SPINabilities: A Young Person's Guide to Spina Bifida*. Bethesda, MD: Woodbine House, 1997. For children ages nine and up.
- Nixon, Shelley. *From Where I Sit: Making My Way with Cerebral Palsy*. New York: Scholastic, 1999. For adolescents.
- Osofsky, Audrey. *My Buddy*. New York: Henry Holt, 1992. The story of a young boy with muscular dystrophy who teams up with a service dog and wins a wheelchair.
- Panzarino, Connie. *Follow Your Dreams*. Bethesda, MD: National Spinal Cord Injury Association, 1995. Two pre-teenagers in wheelchairs prepare for a race and befriend a girl in the hospital with spinal cord injury. For adolescents.
- Panzarino, Connie. *Rebecca Finds a New Way: How Kids Learn, Play, and Live with Spinal Cord Injuries and Illnesses*. Bethesda, MD: National Spinal Cord Injury Association, 1994. For adolescents.
- Rabe, Berniece. *Margaret's Moves*. New York: E. P. Dutton, 1987. Nine-year-old Margaret, who has spina bifida and uses a wheelchair, longs for a new, lightweight "sports model" so she can speed around as fast as her athletic brother.
- Senisi, Ellen B. *All Kinds of Friends, Even Green*. Bethesda, MD: Woodbine House, 2001. Seven-year-old Moses, who has spina bifida and uses a wheelchair, decides that his neighbor's disabled iguana is like him because they can both get where they want to be in different ways than everyone else around them.
- Winston, Pat. *Earl the EMU: God Has a Purpose for Those Who Are Different*. n.p.: Light Way, 2000. Jason cannot run and play as well as other children, but with his animal friends, he learns that God has a purpose for everyone. For children ages four to eight.

Blindness and Visual Impairment

- American Council for the Blind: www.acb.org. A membership organization.
- American Foundation for the Blind: www.afb.org/afb. This organization fulfills Helen Keller's vision by helping people with blindness and visual impairments live independent lives.

- AZ to Deafblindness: www.deafblind.com. Information put together by a person in England who is deaf and blind.
- Blind Sailing International: www.blindsailing.org. Helps people who are blind or have visual impairments learn to sail.
- Canadian National Institute for the Blind: www.cnib.ca. Information and resources for people in Canada.
- Center for the Partially Sighted: www.low-vision.org. Information and resources for people who have partial or low vision.
- Gershe, Leonard. *Butterflies Are Free*. New York: Random House, 1995. The story of a young man with blindness learning to live independently from his mother with the help of a free-spirited young woman.
- Herrmann, Dorothy. *Helen Keller: A Life*. New York: Knopf, 1998. A good biography of Helen Keller.
- Holbrook, Cay M., ed. *Children with Visual Impairments: A Parents' Guide*. Bethesda, MD: Woodbine House, 2001. Excellent practical and comprehensive information.
- Keller, Helen. *The Story of My Life*. New York: Bantam, 1991. A powerful story because it is in Keller's own words.
- Kleege, Georgina. *Sight Unseen*. New Haven, CT: Yale University, 1999. A compelling look at blindness from a person who is blind.
- National Association for the Visually Handicapped: www.navh.org. Information and resources.
- National Federation of the Blind: www.nfb.org. The largest and oldest membership organization of blind persons. Provides public education, information, and referral services.
- National Information Clearinghouse on Children Who Are Deaf-Blind: www.tr.wou.edu/dblink. Comprehensive information and resources.
- Recording for the Blind and Dyslexic: www.rfbid.org. The nation's educational library for people with print-related disabilities.
- Runyon, Marla, with Sally Jenkins. *No Finish Line: My Life As I See It*. New York: Putnam, 2001. The story of Marla Runyon, an Olympic long-distance runner who is blind.
- Weihenmayer, Erik. *Touch the Top of the World: A Blind Man's Journey to Climb Farther Than the Eye Can See*. Auburn, CA: Audio Partners, 2002. Weihenmayer, who is blind, tells the compelling story of how he climbed Mount Everest.

Books for Children and Youth

- Adler, David A. *A Picture Book of Louis Braille*. New York: Holiday House, 1997. A biography of Louis Braille. For children ages four to eight.
- Adler, David A. *A Picture Book of Helen Keller*. Glenview, IL: Scott, Foresman, 1992. For children ages four to eight.

- Alexander, Sally Hobert. *Do You Remember the Color Blue? And Other Questions Kids Ask about Blindness*. New York: Viking Children's, 2000. A good book for allaying children's fears and misunderstandings about what it is like to be blind.
- Condra, Estelle, and Linda Crockett-Blassingame. *See the Ocean*. Nashville, TN: Ideals Childrens Books, 1994. When the fog rolls in, a girl with blindness wins the family competition to be the first to see the ocean on the way to the beach. For children ages four to eight.
- Dorris, Michael. *Sees Behind Trees*. New York: Hyperion, 1999. A sixteenth-century Native American boy finds that he does not need to see to earn an adult name and that there is more to adulthood than rites of passage. For children ages nine to twelve.
- Lawlor, Laurie. *Helen Keller: Rebellious Spirit*. New York: Holiday House, 2001. A biography of Helen Keller. For children ages nine to twelve.
- Martin, Bill, Jr., and John Archambault. *Knots on a Counting Rope*. New York: Henry Holt, 1997. A blind Native American boy gains confidence with the help of his grandfather; a *Reading Rainbow* book for preschool children.
- Moon, Nicola. *Lucy's Picture*. New York: Puffin, 1997. While the other children paint, a girl makes a collage so her grandfather, who is blind, can appreciate her art when he visits her school. For children ages four to eight.
- O'Neill, Linda. *Being Blind*. Windermere, FL: Rourke, 2001. Explains what it is like to be blind and how blind people use braille, guide dogs, canes, and other aids to live independently. For children ages four to eight.

Deafness and Hardness of Hearing

- Adams, John W. *You and Your Deaf Child: A Self-Help Guide for Parents of Deaf and Hard of Hearing Children*. 2nd ed. Washington, DC: Gallaudet University, 1997. Practical and helpful information.
- Alexander Graham Bell Association for the Deaf and Hard of Hearing: www.agbell.org. Information on the auditory approach.
- American Society for Deaf Children: www.deafchildren.org. Helps parents communicate with their deaf children in communities through the use of sign language.
- ASL Access: www.aslaccess.org. Resources on American sign language.
- DeafMall: www.deafmall.net/deaflix/schools.html. A listing of schools for the deaf.
- Deaf Linx: www.deafmall.net/deaflix. Information on links concerning people who are deaf.
- Handspeak: www.handspeak.com. An online dictionary of sign language.

- KidsWorld Deaf Net (KWDN): <http://clerccenter2.gallaudet.edu/kidsworlddeafnet/index.html>. A national communication network of parents and professionals involved in the education of deaf and hard-of-hearing children.
- Lane, Harlan, Robert Hoffmeister, and Ben Bahan. *A Journey into the Deaf-World*. San Diego, CA: Dawn Sign, 1996. Excellent information on understanding the Deaf-World.
- Lane, Harlan. *The Mask of Benevolence: Disabling the Deaf Community*. San Diego, CA: Dawn Sign, 2000. A thought -provoking look at growing up deaf and how society treats deaf people.
- Laurent Clerc National Deaf Education Center at Gallaudet University: <http://clerccenter2.gallaudet.edu>. A comprehensive list of resources and information.
- Marschark, Marc. *Raising and Educating a Deaf Child: A Comprehensive Guide to the Choices, Controversies, and Decisions Faced by Parents and Educators*. New York: Oxford University, 1998. Useful and comprehensive information.
- National Association of the Deaf: www.nad.org. Offers advocacy and information.
- National Institute on Deafness and Other Communication: www.NIDCD.nih.gov/nidcd. Disorders (NIDOCDD). Provides information, resources, and the latest research.
- Neisser, Arden. *The Other Side of Silence: Sign Language and the Deaf Community in America*. Washington, DC: Gallaudet University, 1990. One of the first books to describe the Deaf community.
- Ogden, Paul W. *The Silent Garden: Raising Your Deaf Child*. Rev. ed. Washington, DC: Gallaudet University, 1996. Excellent useful information for parents from someone who is deaf.
- Padden, Carol, and Tom Humphries. *Deaf in America, Voices from a Culture*. Cambridge, MA: Harvard University, 1990. Descriptions of what it is like to be part of the Deaf-World.
- Registry of Interpreters for the Deaf: www.rid.org. The largest association of interpreters for people who are deaf and hard of hearing.
- Schwartz, Sue, ed. *Choices in Deafness: A Parent's Guide to Communication Options*. Bethesda, MD: Woodbine House, 1996. Helpful, easy-to-understand information.

Books for Children and Youth

- Aseltine, Lorraine, Evelyn Mueller, and Nancy Tait. *I'm Deaf and It's Okay*. Morton Grove, IL: Albert Whitman, 1987. A young deaf boy gets help from a deaf teenager to understand about growing up in a world without sound. For children ages four to eight.
- Bahan, Ben, and Joe Dannis. *My ABC Signs of Animal Friends*. San Diego, CA: Dawn Sign, 1995. For children up to age five.

- Baker, Pamela J. *My First Book of Sign*. Washington, DC: Gallaudet University, 1986. Gives signs for one-hundred fifty of the words used most frequently by young children.
- Booth, Barbara D. *Mandy*. New York: Lothrop, Lee, and Shepard, 1991. Mandy, a young deaf girl, is delightfully presented in this lively picture book. For children ages four to eight.
- Bowen, Andy Russell. *A World of Knowing: A Story About Thomas Hopkins Gallaudet*. Minneapolis, MN: Carolrhoda, 1995. For children ages four to eight.
- Butts, Nancy. *Cheshire Moon*. New York: Front Street, 1996. A deaf girl loses her friend, who was also deaf, in a boating accident, forcing her to choose between living in the past and living in the real but difficult hearing world. For children ages nine to twelve.
- Gillen, Patricia Bellan. *My Signing Book of Numbers*. Washington, DC: Kendall Green, 1987. Children learn the signs for numbers 0 through 20 and 30 through 100.
- Hafer, Jan, and Robert Wilson. *Come Sign With Us: Sign Language Activities for Children*. Washington, DC: Gallaudet University, 1996. This illustrated activities manual contains more than three hundred line drawings of people signing familiar words, phrases, and sentences using ASL in English word order. Available in Spanish and English and on video.
- Heelan, Jamee Riggio. *Can You Hear A Rainbow? A Story of a Deaf Boy Named Chris*. Atlanta, GA: Peachtree, 2002. For children ages four to eight.
- Lakin, Patricia. *Dad and Me in the Morning*. Morton Grove, IL: Concept, 1994. The beautifully illustrated story of a boy and his father on the beach. For children ages four to eight.
- Lee, Jeanne M. *Silent Lotus*. New York: Farrar, Straus, 1994. Vivid watercolor drawings bring to life the thousand-year-old tradition of Cambodian court ballet and the quiet triumph of a young deaf dancer. *A Reading Rainbow* book.
- Litchfield, Ada Bassett. *A Button in Her Ear*. Morton Grove, IL: Albert Whitman, 1987. Angie finds out that she needs to wear a hearing aid. For children ages four to eight.
- Lowell, Gloria Roth. *Elana's Ears, or How I Became the Best Big Sister in the World*. Washington, DC: American Psychological Association, 2000. A strong story about a helping pet for a deaf girl. For children ages four to eight.
- Millman, Isaac. *Moses Goes to School* and *Moses Goes to a Concert*. New York: Frances Foster, 2000. These stories about Moses illustrate what it is like to be deaf. For children ages four to eight.
- Peterson, Jeanne Whitehouse. *I Have A Sister—My Sister Is Deaf*. New York: Harper Trophy, 1984. A young deaf child is affectionately described by her older sister, providing an empathetic, positive look at the relationship between siblings. For children ages four to eight.

Rankin, Laura. *The Handmade Alphabet*. New York: Puffin, 1996. Celebrates the beauty of the manual alphabet.

Hidden Disabilities (Chronic Illnesses)

American Trauma Society: www.amtrauma.org. Advocacy for injury care and prevention within communities.

KidsHealth: www.kidshealth.org. A good website for information about children's health.

National Center for Chronic Disease Prevention and Health Promotion: www.cdc.gov/nccphp/index.htm. Provides comprehensive information and resources.

Asthma

American Lung Association: www.lungusa.org. The nation's oldest voluntary health organization focusing on lung disease research.

Bock, Steven J., Kenneth Bock, and Nancy Paulis Bruning. *Natural Relief for Your Child's Asthma: A Guide to Controlling Symptoms and Reducing Your Child's Dependence on Drugs*. New York: HarperCollins, 1999. Comprehensive information on a practical holistic approach.

Canadian Lung Association: www.lung.ca. Advocacy and information about lung disease in Canada.

Firshein, Richard N. *Your Asthma Free Child: The Revolutionary Seven-Step Breath of Life Program*. New York: Penguin Putnam, 2002. A successful program of integrative medicine that combines traditional medicine with alternative approaches.

ibreathe.com: www.gsk.ibreathe.com. Good information and resources about asthma for both kids and parents.

Plaut, Thomas F. *Children with Asthma: A Manual for Parents*. Amherst, MA: Pedipress, 1998. Useful and practical information.

Snuffles and Sneezes: www.allergyasthma.com. Allergy and asthma care and prevention for the family.

Diabetes

American Diabetes Association: www.diabetes.org. Comprehensive information on diabetes.

Betschart, Jean. *Diabetes Care for Babies, Toddlers and Preschoolers: A Reassuring Guide*. New York: John Wiley & Sons, 2001. Helpful information for parents.

Brackenridge, Betty Page, and Richard R. Rubin. *Sweet Kids: How to Balance Diabetes Control and Good Nutrition with Family Peace*. New York: McGraw-Hill, 1996. Useful ideas and tips for parents.

- Brand-Miller, Jennie, Kaye Foster-Powell, Thomas Wolever, and Heather Gilbertson. *The Glucose Revolution: Pocket Guide to Children with Type 1 Diabetes*. n.p.: Marlowe, 2001. Useful and practical suggestions for choosing the right foods.
- Children with Diabetes: www.childrenwithdiabetes.com. An online community for kids, families, and adults with diabetes.
- Diabetes Mall: www.diabetesnet.com. Comprehensive information about controlling and living with diabetes.
- Loy, Virginia Nasmyth. *Real Life Parenting of Kids with Diabetes*. New York: McGraw-Hill, 2001. Useful ideas for parents on how to handle the basic day-to-day needs of a child with diabetes.
- McAuliffe, Alicia. *Growing Up with Diabetes: What Children Want Their Parents to Know*. New York: John Wiley & Sons, 1998. Written by a twenty-one-year-old with diabetes, this book describes the social and emotional issues of diabetes from a child's perspective.
- Wysocki, Tim. *The Ten Keys to Helping Your Child Grow Up with Diabetes*. New York: McGraw-Hill, 1997. Addresses the psychological, emotional, and social issues of raising a child with diabetes.

Epilepsy

- Aicardi, Jean, Alexis Arzimanoglou, and Renzo Guerrini. *Epilepsy in Children*. 3rd ed. Philadelphia: Lippincott, 2002. Comprehensive information on diagnosis and treatment.
- American Epilepsy Society: www.aesnet.org. Comprehensive information and resources.
- Blackburn, Lynn Bennett. *Growing Up with Epilepsy: A Practical Guide for Parents*. New York: Demos Medical, 2003. A quick reference guide on treatment as well as social, psychological, and behavioral concerns.
- Epilepsy Canada: www.epilepsy.ca. Information and resources in Canada.
- Epilepsy Foundation of America: www.efa.org. Comprehensive information, education, and advocacy services.
- Freeman, John Mark, Jennifer B. Freeman, and Millicent T. Kelly. *The Ketogenic Diet: A Treatment for Epilepsy*. 3rd ed. New York: Demos Medical, 2000. Good information on the Ketogenic diet.
- Marshall, Fiona. *Your Child: Epilepsy*. New York: HarperCollins, 1999. Basic, easy-to-read yet comprehensive information on both traditional and nontraditional treatments.
- Murphy, Patricia A., and Russell L. Blaylock. *Treating Epilepsy Naturally: A Guide to Alternative and Adjunct Therapies*. New York: McGraw-Hill, 2001. Written by a person with epilepsy, this comprehensive guide provides alternative treatments that can both replace and complement traditional therapies. Also recommends how to find a health practitioner.

Schachter, Steven C., Georgia D. Montouris, and John M. Pellock. *The Brainstorm Family: Epilepsy on Our Terms: Stories by Children with Seizures and Their Parents*. Philadelphia: Lippincott, 1996. Personal accounts of what it is like to have epilepsy.

Heart Conditions

American Heart Association: www.americanheart.org/children. Provides information and resources.

Children's Heart Foundation: www.childrensheart.com. Funds promising research.

Children's Heart Institute: www.childrenheartinstitute.org. An excellent site for information and services for parents.

Keene, Nancy, and Rachel Prentice. *Your Child in the Hospital: A Practical Guide for Parents*. 2nd ed. Sebastopol, CA: O'Reilly & Associates, 1999. Practical information and wisdom from "veteran" parents on helping make a child's hospital stay easier.

Kids with Heart, National Association of Children's Heart Disorders: www.kidswithheart.org. Provides support, education, and resources for families.

Kramer, Gerri Fried, and Sheri Maurer. *The Parent's Guide to Children's Congenital Heart Defects: What They Are, How to Treat Them, How to Cope with Them*. Three Rivers, MI: Three Rivers, 2001. Medical and emotional issues are discussed in a reassuring way for parents.

Pediatric Heart Research Foundation: www.pediatricheart.org. Provides research, information, and resources.

Wild, Cheryl J., and Michael J. Neary. *Heart Defects in Children: What Every Parent Should Know*. Minneapolis, MN: Cronimed, 1998. Good and easy-to-understand information on heart defects.

Juvenile Arthritis

Arthritis Foundation, American Juvenile Arthritis Organization (AJAO): www.arthritis.org. Comprehensive information and resources.

Fall, Guy. *Everything You Need to Know About Juvenile Arthritis*. New York: Rosen, 2002. Useful and current information.

G.R.A.C.E. (Give Rheumatoid Arthritis Children Encouragement): www.fyldecoast.co.uk/grace. Helpful information for parents.

Tucker, Lori B. *Your Child with Arthritis: A Family Guide for Caregiving*. Baltimore, MD: Johns Hopkins University, 2000. Provides comprehensive information for understanding and effectively dealing with the issues facing children with arthritis.

Lupus

Digeronimo, Theresa, Stephen Paget, and Sara J. Henry. *New Hope for People with Lupus: Your Friendly, Authoritive Guide to the Latest in Traditional and Complementary Solutions*. Roseville, CA: Prima, 2002. An excellent resource for information about lupus.

Healthwell: www.healthwell.com. Information on the treatment of lupus with vitamins and herbs.

Lupus Beacon: www.galaxymall.com/commerce/lupus. A newsletter.

Lupus Foundation of America: www.lupus.org. Support, awareness, and information for families.

Moore, Sharon. *Lupus: Alternative Therapies That Work*. Rochester, VT: Inner Traditions International, 2000. Written by someone with lupus, this is an excellent source of information about alternative therapies.

Road Back Foundation: www.roadback.org. Information on rheumatic treatments and research.

Wallace, Daniel J. *The Lupus Book: A Guide for Patients and Their Families*. Rev. ed. New York: Oxford University, 2000. Provides all the information women need to understand the disease as well as its diagnosis and treatment.

Books for Children and Youth

Betschart, Jean, and Susan Thom. *In Control: A Guide for Teens with Diabetes*. New York: John Wiley & Sons, 2001. Straightforward, readable information for teenagers.

Carter, Alden R. *I'm Tougher Than Diabetes*. Morton Grove, IL: Albert Whitman, 2001. A beautifully illustrated book about how Natalie, who is nine years old, manages her diabetes using a diabetes kit named Philomena. For children ages eight to fourteen.

Gosselin, Kim. *Taking Asthma to Camp: A Fictional Story About Asthma Camp*. Plainview, NY: JayJo, 1998. A child going to camp discovers that children with asthma are no different than other children.

Gosselin, Kim. *Taking Asthma to School*. Plainview, NY: JayJo, 1994. A young boy talks about taking care of his asthma. For children ages four to eight.

Gosselin, Kim. *Taking Diabetes to School*. Plainview, NY: Jay Jo, 1994. A boy in grade school describes having and managing diabetes. For children ages four to eight.

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