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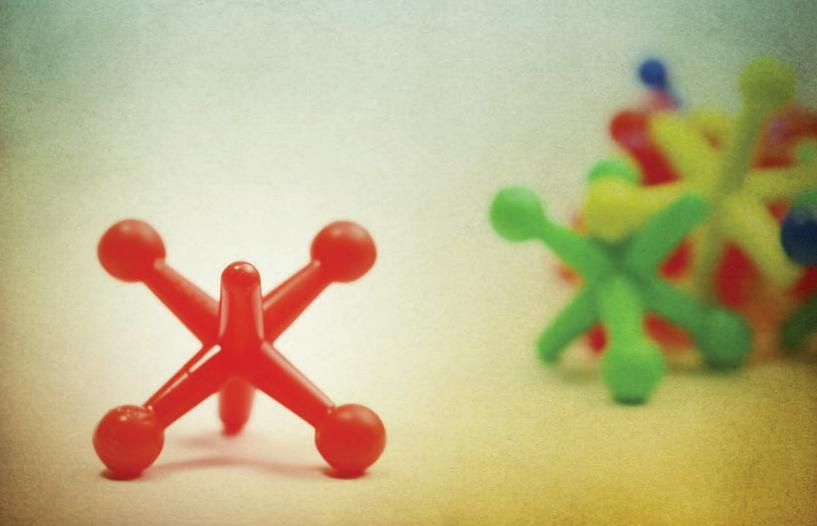
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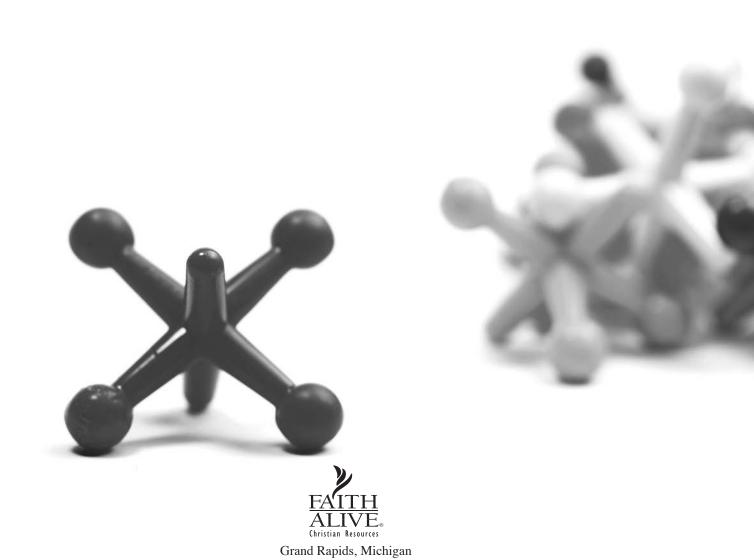
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## BARBARA J. NEWMAN

# helping kids include kids with disabilities



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### Dedicated with love to my dear family:

- my husband Barry Newman,
- and our sons John and James Newman.



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#### **Foreword**

ow is your son enjoying Sunday school?" I asked the parents at the end of our parent-teacher conference. A heavy sigh prefaced their answer. When their son with autism was three, the parents explained, he attended children's worship for the first time. After class, a weary worker returned their son and said, "Please don't bring him back to this class. We can't handle him." For the next four years, one parent attended church and one parent stayed home with their son. Too old to qualify for the nursery but unable to sit through a service, their young son, they felt, had no place in their congregation.

A young adolescent with a mild intellectual disability could hardly wait to start his first year of boys' club at church. Although he was unable to read, he saw each of his older brothers making Pinewood Derby cars, and he longed for the day when he would be able to participate. The great day finally arrived. But after the first night of boys' club, the leader called the boy's parents and asked them not to send him again. He was unable to read the materials, and the leaders didn't know how to handle that.

A congregation had been praying for several months. A little girl was having uncontrollable seizures, and the doctors had run out of medications to prescribe. The girl's church family cried out to God, asking that these frequent attacks in her brain would stop. And God answered those prayers. The seizures stopped, but the girl faced years of therapy and special education to help her grow and learn. Unaware of the extent of her brain injury, and not sharing in the painstaking routines of daily therapy, the church family happily celebrated God's answer to prayer.

At the same time, the girl's parents grew resentful and angry that God would allow their daughter to face such challenges. Now, more than ever, they needed support and care from their church family.

Fortunately, each of these three stories had a happy ending. In each case, the child's parents and their school contacted the church. Each pastor they contacted was truly sorry the incidents in question had happened, and each was eager to better understand the child's gifts and needs. The boy with autism was assigned a special helper so that his parents could worship together. The child in boys' club had a rotating buddy each week who read and wrote with him before they both enjoyed the craft. With the parents' permission, the pastor of the little girl with seizures updated the congregation so they would better understand her needs and her family could continue to receive appropriate support.

I believe that church—a place where children with disabilities and their families desperately need to experience belonging and inclusion—can sometimes be a place of misunderstanding and perceived rejection. But that can change. After twenty-seven years of working with CLC Network (Christian Learning Center) and serving as the church services division director, as well as a special education coordinator for an inclusive education program at Zeeland Christian School in Michigan, I'm convinced that God can use what we have learned in the classroom setting and in church settings to help congregations better enfold children and adults with disabilities.

This book explains some of the methods we use to help carve out a place of belonging for students with disabilities at Zeeland Christian School, as well as in a variety of church settings. As part of CLC Network, we welcome children of parents who want a Christian education for their family. Whatever their children's unique gifts and needs are, we attempt to provide programs and people to meet them in our school. It's my hope and prayer that the ideas in this book will also better equip churches to welcome children with disabilities and give them a place of respect and honor in their congregation.

#### A Word about Labels

Children with disabilities usually have been given some type of label that describes a medical condition or an educational need. This label can help teachers and other caregivers better understand that child's gifts and meet that child's needs. As you read about various kinds of descriptors and designations in this book, please remember these five things about labels:

- See the person, not the label. A child may have a great sense of humor and be a good runner and have an intellectual disability. It's easy to look at an individual with a disability and see "Down syndrome Ryan" or "spina bifida Blake," but that is certainly not in line with what God teaches in his Word. That person is "Ryan, who is made in God's image to fill a specific purpose in God's kingdom, who has been given gifts to offer others in the body of Christ, who also happens to have Down syndrome." We should always see a disability in the context of God's amazing design for that person and in the context of Christ's body, the church. Kathie Snow has done some excellent work in this area. You can find her brief but very helpful article on people-first language at disabilityisnatural.com/ images/PDF/pfl-sh09.pdf.
- Never attempt to attach a label yourself. You may read about autism spectrum disorder, for example, and notice that a child in your group has many of those characteristics. For you to apply the material in this book in your Sunday school class without a proper diagnosis and permission from the child's parents could potentially be very hurtful to that child and to his or her family.

- Labels change. This book uses labels and terms that are considered preferred usage at the time of printing. But those labels and terms change often. Please also be aware that states differ in the labels and terms they use for educational purposes to describe children who have disabilities, and these terms can change over time too. For example, a child who is called "cognitively impaired" by a school system in one state or province might be called "developmentally delayed" in another. Keep this in mind as you adapt this material for use in your own state or province.
- Start with the child. When planning for a child with a disability in a church setting, never begin by understanding the child's medical or educational label. Always begin by getting to know that child. The plans and ideas you develop need to wrap around that child's unique gift areas and need areas. While it's helpful to know some general information about areas of disability, the most important way to begin is by getting to know Maria or Blake or Tamika.
- There's more to learn. Keep in mind that this book offers only an overview of various kinds of disabilities. There is much more material available about each highlighted area. If you want to learn more, start by checking into some of the resources listed at the back of this book.

#### Dedication and Acknowledgments

I dedicate this book to my family. I want to give special thanks to my husband, Barry, who sharpens me in my walk with God and who has spent many years being my partner in ministry. I thank God for you and the ways you continue to influence my life. Thanks also to my children, John and James, who continue to teach me about each person being a unique creation of God and who also delight in accepting, welcoming, understanding, and befriending persons with disabilities. I see God's heart in both of you.

I would also like to thank the following people for their encouragement and for helping me to better understand this information and put it into a book:

All of the students at Zeeland Christian School, who have allowed me to learn with and from them.

Doug Bouman, psychologist for CLC Network in Grand Rapids, Michigan, who taught me to think in greens and pinks.

Leslie Drahos, Carol Gray, and the consultants from Ottawa Area Intermediate School District, who have taught me so much about children with autism spectrum disorder.

Dr. Thomas B. Hoeksema, William VanDyk, Richard "Bear" Berends, and Jan DeJonge, who have been so influential in my life as a special educator.

Dr. Andrew Bandstra, professor emeritus of New Testament and Theology at Calvin Theological Seminary, who also happens to be my father and who has helped and supported me in these endeavors.

My dear mother, Mae Ruth Bandstra, who passed away five years ago. Her actions and words about kindness, acceptance, and love continue to influence my actions and words on a daily basis.

My colleagues at Zeeland Christian School, from whom I learn daily.

May God use this material to build up and strengthen the church. To God be the glory.

#### **CHApte R 1**

# Information: The Key to Understanding Children with Disabilities

ach day in my classroom, there are times when a colleague speaks to me and I do not respond. A person makes a comment, and I do not even turn around and listen. When that happens, the person might interpret my failure to respond as rudeness. "Why won't she answer my question? How rude." On the other hand, she might think that I'm signifying disapproval. "I wonder if she doesn't agree with what I said. Is that why she's ignoring me?"

So you can imagine what a difference it made to my colleagues (and me!) when I shared an important piece of information: as a result of a complication with my pregnancy, I experienced the early onset of hearing loss. Although one of my ears functions within the typical range, the other ear has moderate hearing loss. For that reason, I do not always hear the words or sounds that others hear. People need to get my attention visually if I do not respond. I would much rather give out this information to the people in my life than deal with the consequences of being misinterpreted or misunderstood.

Sharing that piece of information allowed my friends and colleagues to correctly assess my actions. It's as though the information gave them a special pair of glasses that enabled them to interpret my actions correctly.

# Wearing the Right Glasses Helps Us See Better

Jesus was a master at planting information at critical times. For example, one day the teachers of the law had in their custody a woman caught in adultery. They were about to stone her to death as required by the law of Moses. But the woman was spared because Jesus gave a different pair of glasses to those who were holding the stones: "Let any one of you who is without sin be the first to throw a stone at her" (John 8:7). Jesus' words allowed the people to take a new look at the situation.

We can all benefit from wearing glasses that allow us to see better. Here's an example. Perhaps you've sat in church behind a family with a particularly squirmy child. Maybe you've found yourself thinking, "Why can't those people control that kid? A bit of discipline would go a long way. Parents are way too permissive these days." If you'd been wearing the glasses that let you recognize that this "undisciplined" child has a condition called attention deficit/hyperactivity disorder (AD/HD), you wouldn't make the same judgment. Understanding the neurological basis of a child's actions allows us to see more clearly and respond with compassion, not judgment.

I have found that accurate information is one of the most powerful tools in creating a successful program for including children with disabilities in school and church. I believe that leaders, children, and parents of peers need to be given the right glasses in order to practice greater acceptance and understanding.

#### **Understanding God's Design**

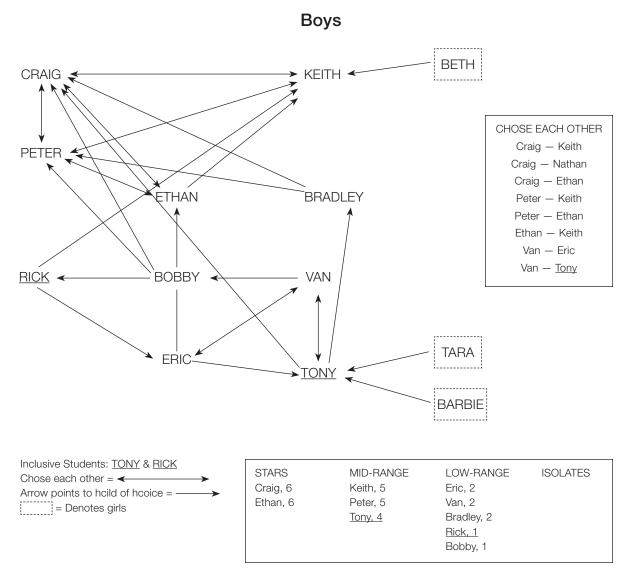
The most critical information people must have relates to understanding God's heart for children and God's design for the body of believers. God has uniquely crafted each person, and each has an important place in the body of Christ. We are called to

accept each person as a full member of the body. As we recognize God's heart for the kind of community where "The eye cannot say to the hand, 'I don't need you!' And the head cannot say to the feet, 'I don't need you!' On the contrary, those parts of the body that seem to be weaker are indispensable" (1 Cor. 12:21-22), we gain a vision for including persons with disabilities that far exceeds any educational practice or legal ruling. Christians embrace the principle of acceptance embodied in inclusive community as a part of doing God's will. This information about God's will needs to be woven into all of our preparation and communication.

#### tony and Rick

But we need to know more than God's design for the body of believers. We need to understand more about how God designed us and the other people in our lives. A study we did at school using sociograms (diagrams that show the structure of interpersonal relationships in groups) helped us understand the impact information can have on kids' acceptance of their peers with disabilities.

Here's how it worked. Tony, a first-grader, was diagnosed with autism. He was supported with an individualized curriculum, an alternate environment when needed, and a circle of friends. To encourage



-Used by permission of Karen Zoetewey, Zeeland Christian School

the children in Tony's class to form friendships with him, I talked about Tony's gifts and explained autism to the children. I told them what to expect from Tony. We held ongoing "circle" meetings to discuss what was going well and to identify problem areas. All of this information helped to equip Tony's classmates with a pair of glasses for understanding his behavior. The lenses were changed throughout the year as needed.

As you can see in the sociogram on page 12, Tony was in the mid-range list of children chosen by others when asked "Who do you want to work with?" Despite his occasionally aggressive actions, delayed speaking skills, and differences in social skills, the other kids chose him several times.

During the course of the school year, Rick, another child from that same class, was diagnosed with a very rare disorder called Landau-Kleffner syndrome. Because the diagnostic process took so long, Rick was not given an official place in the special education program. As a result, his classmates did not have the same opportunity to understand his actions. As you can see from the diagram, Rick was chosen by only one person, putting him in the low-range category.

Between first and second grade, Rick was placed in a special education support group that included individualized curriculum, an alternate environment when needed, and a circle of friends. A second sociogram from the next year showed that Rick's acceptance level soared in the second grade. That year he was chosen many times by others, despite continued behavioral concerns from grade 1. Rick was now a "star." Although other factors may have been involved, it seems clear that Rick benefited from his peers' knowledge of his gifts and needs and from what they had learned about Landau-Kleffner syndrome. That information allowed them to understand Rick and be his friends.

#### **Families Need Glasses too**

At Zeeland Christian School, not only do we give information to the classmates of kids with disabilities, we also send information home to all families in the class (after we receive written permission from the parents of the child). This information gives the families of all the kids in the class the glasses they need to support classroom friendship and understand the special situations that can develop.

Knowing that those families had the right kind of glasses helped us deal with an incident involving Tony, the first-grader with autism we mentioned earlier. Biting was sometimes a problem with Tony. In explaining autism to the kids in Tony's class, I said that each one of us has a set of keys designed by God to unlock certain sections of our brain. We have a key for moving and talking and making friends. Many of our keys look alike, but some of our keys are different. Tony already had his reading key, but some of the other children did not. For Tony, however, his understanding of how to play on the playground was a key he did not yet have. I wondered with them if Tony might get his playground key this year and if they might get a reading key.

The next day at recess, Tony bit his friend Ryan. Ryan calmly walked to find his teacher, with his aggressor in tow. Without tears, Ryan explained to his teacher that they needed to find Tony's key for not biting.

Because the bite had broken Ryan's skin, our principal asked me to phone his parents. Based on the letter I had sent home about Tony, autism, and God's desire for us to live in community with those who have autism, his parents were very understanding about the incident. A potentially very difficult situation was avoided based on the "glasses" that we had given the whole school community at the beginning of the year.

The same need for information applies to teachers, church group leaders, and volunteers. We expect them to have the skills to intervene with integrity in a variety of situations. Each one of these frontline workers needs to be equipped with accurate information about the child's individual strengths and needs, as well as information about his or her area of disability.

# Helping Kids Understand themselves

Often the most overlooked of all those who participate in caring for children with disabilities are the children themselves. In addition to giving information to parents, teachers, and peers, we need to make sure that we give children with disabilities the information they need to understand why they think and act the way they do. This enables them to advocate for themselves and allows them to know their own boundaries, challenges, and strengths.

In the next chapter, "The Mind That's Mine," you'll find strategies to accurately and positively help kids understand how God creates each one of us with unique strengths and challenges. God "knit me together in my mother's womb" (Ps. 139:13) and I am "fearfully and wonderfully made" (Ps. 139:14). I believe we honor our Creator as we marvel at the new pattern God created for each precious person.

#### How Can this Book Help?

This book is designed to help your church or school become a welcoming place for people with disabilities. To help you find the information you need, I have prepared materials on six specific areas of disability that are common in church settings. For each of these areas you'll find a basic fact sheet for the leader or volunteer, a lesson plan you can adapt for preschool through grade 6, and a sample letter to families you can send home with the child's classmates.

You'll also find two separate sections that deal specifically with school-age diagnoses as well as severe and multiple disabilities. Be aware that dual diagnosis is often a reality: a child with Down syndrome may also have autism; a child with autism may also have a seizure disorder.

For help with tailoring any lesson plan to the abilities of the children in your class, see the Activity Substitution Guide on page 73.

The book also includes a lesson plan suitable for promoting acceptance with middle school and high school students. All of this information is preceded by the chapter called "The Mind That's Mine," which will help you explain to each child a bit more about the way his or her own brain works. Be sure to read chapter 3, "Guidelines for Churches," before going on to read the section on the specific type of disability you are dealing with.

It's my hope that the information in this book will allow many children to experience a greater sense of belonging at church. I will have succeeded if these pages equip you with glasses that help you see a child with a disability less as a spectacle than as an integral part of your group setting and of the body of Christ.

# An Important Note about Sharing Information

Sharing information on disabilities in general and about particular people with disabilities is vital to helping others understand and support them. But I can't stress enough that you must always obtain permission from the person and his or her parents or guardians before you do so. Your primary concern must be to protect that person's dignity, and if there is some information that the family is not comfortable sharing, you must maintain absolute confidentiality.

hildren with disabilities are part of God's family, but people don't always treat them that way. In this book you'll discover how to help kids and their leaders welcome and include kids with disabilities at church or school. This revised edition of *Helping Kids Include Kids with Disabilities* contains a wealth of helpful information for understanding disabilities such as

- autism spectrum disorder
- **attention** deficit/hyperactivity disorder
- behavioral challenges
- hearing, visual, and speech/language impairments
- intellectual disabilities
- physical disabilities
- learning disabilities
- severe or multiple disabilities

This book also includes guidelines and forms to help churches identify and meet needs, lesson plans for presenting information on each area of disability, fact sheets about specific disabilities to share with adult leaders, and much more. It's an indispensable resource for teachers, Sunday school leaders, church staff, and anyone who works with children.

"Helping Kids Include Kids with Disabilities is an important companion piece to Autism and Your Church. Together they outline a comprehensive method for developing a disability ministry to children and youth. This book includes valuable information and lesson plans that promote awareness and acceptance of children and youth with disabilities.

Developing an understanding of how we are all uniquely made and part of God's kingdom is an important ingredient in successfully welcoming and including kids with disabilities."



Nella Uitvlugt
Executive Director, Friendship Ministries
www.Friendship.org

"Barb takes complex information and translates it into a practical guide for the church leader unfamiliar with the world of special education and disability. Children's ministry teachers will appreciate the lesson plans and analogies to help children understand their peers with differences. Church leaders will benefit from countless best practices offered, such as the Parent Interview Guide and suggested word choices throughout the book. This handbook belongs on the shelf of every children's ministry leader."

Amy Fenton Lee
Special Needs Columnist,
Children's Ministry Magazine
Special Needs Consultant, Orange

**Barbara J. Newman** is a church and school consultant for CLC Network. She is the author of many books, including *Autism and Your Church*, *G.L.U.E. Training Manual*, and *Body Building: Devotions to Celebrate Inclusive Community*. She also is a frequent national speaker at educational conferences and churches. In addition to writing and speaking, Barb enjoys working in her classroom at Zeeland Christian School in Michigan.



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