Including Families of Children with Special Needs

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Including Families of Children with Special Needs

A How-To-Do-It Manual for Librarians®

REVISED EDITION

Revised by Carrie Scott Banks

Sandra Feinberg, Barbara Jordan,
Kathleen Deerr, and Michelle Langa

Neal-Schuman

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This book is dedicated to our families: Richie, Jake, and Teddy; Fred, Courtney, and Eric; Al, A. J., and David; Frank and Zach; and Katie and Paul, who did without us so much of the time during the creation of this work. Thanks for your support, understanding, and good humor.

It is also dedicated to Reggie and his mother, Sharon.—C. B.

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Preface

When Anthony and his mother first came into the library, I didn't have a clue how to communicate with them. They were both profoundly Deaf and did not speak, although both could read lips a bit. After some back and forth with a pen and some scrap paper, I was able to help them find the book Anthony needed for school. When they left, I was both relieved and embarrassed: relieved because they had gotten what they came for and embarrassed because it had been such a difficult process.

Realizing that Anthony would be back to return the book, and facing a long boring week of jury duty, I borrowed a book on American Sign Language (ASL). When they did come back, I shocked Mrs. C. by signing "OK" in response to a question and asking her name. That was all it took. They became regulars at my library and brought the rest of the Deaf community with them. Six months later, when I had learned a small but targeted ASL vocabulary, I found out the C. family had been to three other branches in our system before they got to my library. They kept coming back to ours because I had learned those first four signs. One year later, we hosted the National Theater of the Deaf and crammed over 100 people into the small, storefront library. Two years after that, I became the librarian in charge of The Child's Place for Children with Special Needs at the Brooklyn Public Library.

The C. family's visit was not my first insight into the limits of my library school education. In my previous neighborhood library, I was appalled that a 10-year-old with an intellectual disability had been told that he could not get a library card because he could not write his name. Parents asked me if I knew any good books for children with Down syndrome. I did not. Did I know any other parents of a child

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with Cri du chat syndrome? As it happened, I did—but not because it had been part of my formal training for librarianship.

It had, however, been part of my personal background. People with disabilities have always been a part of my life. My best friend in elementary school had cystic fibrosis. I had volunteered to tutor a child with a learning disability and interned at an inpatient pediatric psychiatric facility and as a special education teacher's aide. One more piece of the puzzle fell into place when I was in high school; after years of being told by teachers that I was sloppy, lazy, unmotivated, and not living up to my potential, I was diagnosed with dyslexia and dysgraphia. For me, disability has always been natural.

In the first children's room I worked in, I met a child who used a wheelchair and could not get into the library. One of the pages and I developed a system: I would speak with the patron outside the library, and the page would find the books and bring them out. It was an imperfect system. Later, at my next library, a father of a child with AIDS asked me to read to his son in the hospital. The hospital would not let me. It was with the hope of addressing situations like these and helping other librarians avoid the mistakes I made that I came to revise *Including Families of Children with Special Needs*. I bring to it my own beliefs that disability is natural, inclusion is a civil right, and Universal Design is the tool to get the job done.

Those of us working in public libraries, school library media centers, and hospital libraries are most concerned with serving children and youth with disabilities and their families because they are in our communities. In the 2008–2009 school year, 13 percent of public school students aged 6 to 21 years received special education services nationally. This translates into 6.5 million children in the United States (Institute of Education Sciences, 2011). In any given community, approximately one child out of every six will get speech therapy, go to counseling, go to the resource room, attend classes exclusively with other children with disabilities, be taught by a teacher in a hospital, or receive some other service that allows him or her to learn. Hundreds of thousands more require special accommodations, such as a quiet place to take a test or an electronic note taker. Note that the Institute of Education Sciences (2011) count did not include those children under the age of five who have a disability. Each child with a disability has a family that is also affected.

This revised edition of *Including Families of Children with Special Needs* is a step-by-step guide to serving those children and youth with disabilities as well as the brothers, sisters, parents, grandparents,

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and other people involved in their lives. By integrating the methods of educators, medical and psychological therapists, social workers, librarians, and parents we can enable children with disabilities and their families to make full use of the library's resources. In the end, you will come away with an understanding of the needs of children and youth with disabilities and of those of their families and with the knowledge to meet those needs in the library. This book will give you an overview of what frameworks, tools, and materials are needed to successfully welcome children with disabilities into your library.

Part 1, "Understanding Inclusion," lays the groundwork. We will look at the philosophy of inclusion and how it benefits children with and without disabilities, their families, and our libraries, as well as the legal requirement to serve all children. Next we look at the research in child development and supporting families. This section concludes by presenting the framework for developing inclusive library services: Multiple Intelligences theory and Universal Design.

Part 2, "Getting Your Library Ready," helps you examine where you are now. It covers assessing your library's current ability to serve youth with disabilities and their families and the needs of this community. The next step is staff training, and we provide an overview and specific tools. Involving the community in these processes follows. Finally, we present specific guidelines and ideas for designing fully inclusive services and programs.

In Part 3, "Developing Collections and Services," we move to specifics. How might inclusion work in your library? How can you make your library barrier free? What equipment do you need? How does Assistive Technology work? Where can you find the books you need? How and where do you find reliable electronic resources?

Much has changed since the first edition was published in 1999. The basic disability rights laws have been renewed and updated. We have solid research to support the benefits of inclusion. Multiple Intelligences theory has become part of mainstream educational practice. Universal Design has moved from the field of architecture to education. We are recognizing the unique needs of siblings of people with disabilities. More libraries have had success with model inclusive services. There are more children with autism, and they are much more visible. Computer technology has become integral to the work of all libraries, and Assistive and Adaptive Technology has substantially improved. This revised edition addresses all of these issues.

This revised edition is considerably wider in scope than the original, which was limited to preschool children and their families. The

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current work includes school-age children and teens as well and covers an expanded range of disabilities. Previously, the focus was on children with developmental disabilities, but this revised edition addresses the needs of children with all types of disabilities. This edition also covers the needs of Spanish-speaking children with disabilities and their families, looking at cultural competency as well as Spanish-language resources.

As librarians we tend to know a little about a lot of things and a lot about very few things, but we need to know enough to get the job done and, more important, enough to look for what we do not know. It is my hope that this revised edition of *Including Families of Children with Special Needs* will be enough to get you started in providing services to children and youth with disabilities and their families and that you will continue to learn more throughout your career.

The last time I saw Anthony was when I visited his high school. He was doing well and thinking about going to college or becoming a carpenter. He still loved to read. It did not take much to turn Anthony, his sister Cleopatra, and their parents into regular library patrons. Once they felt welcome, you could not keep them away. This is the crux of the matter. Ramps, Adaptive Technology, and Braille books lay only the physical basis for including children with disabilities and their families in the library. Ultimately, it is the attitude of the staff, the seamlessness of the services, and the welcoming environment that will keep them coming back.

Reference

Institute of Education Sciences. 2011. "Children and Youth with Disabilities." National Center for Education Statistics. http://nces.ed.gov/programs/coe/indicator_cwd.asp.

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Acknowledgments

For the 2012 Edition

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For the 1999 Edition

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(Centereach, NY), especially Lois Eannel, Mary Schumacher, Ellen Friedman, Doreen Holmes, and Carolyn Liljequist; the staff of the Mastic-Moriches-Shirley Community Library (Shirley, NY), especially Rachel Catan and Eileen Curtin; project coordinator Noreen Buckhout and Ellen Paige Horst; Steve Held, Christine Clarke, Tom McMath, Barbara Morgan-Salvador, Amy Toole, and Amira Simha-Alpern of Just Kids Early Childhood Learning Center (Middle Island, NY); Ellen Woodward, Joan Smart, Tina Malone, and Patricia Davison of Starting Early, Developmental Disabilities Institute (Selden, NY); Janice Orland and Barbara Ross of the Bureau of Services for Children with Disabilities, Suffolk County Department of Health Services, as well as the many Early Intervention service providers who participated at various stages of the project; and to the New York State Department of Health, Bureau of Child and Adolescent Health, particularly Donna Noyes, Wendy Shaw, and Dan Frering. Their collaborative efforts resulted in positive change and enhancement of library-based services to the families and children with special needs who reside in these communities.

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Contributors

Special recognition is given to the following professionals for contributing their expertise and authorship:

Chapter 11
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Anna Lobosco, New York State Developmental Disabilities Planning Council

Their knowledge and commitment to services for families and children with disabilities are exemplary and greatly appreciated by the families and professionals with whom they work. Our manuscript is more valuable because of their willingness to share their expertise.

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PART 1
Understanding Inclusion

What's Inclusion All About?

1

This is the first time my daughters have attended a program together.

—Father of two daughters, one with a developmental disability, at a music program at the Brooklyn Public Library

Take a moment to observe children in the library. They watch each other as often as they look at books. They talk to other children or adults in the children's areas and interact with staff in a storytime program. They form attachments and make new friends. Children are, by nature, social beings. They need to play with and observe peers. Being part of a group is almost as important as eating or sleeping. Simply put, children want to be included with other children. For children with disabilities, this need is often unfulfilled.

Children with disabilities are often segregated from their typically developing peers because of their "special needs." In many situations, they are denied the opportunity to grow and learn from friends and peers in their neighborhood, schools, and other community settings. When they become adults, having been educated in segregated special education classrooms or residential schools, these children can lack the basic social skills for interaction with peers without disabilities. They and their families may continue to be isolated within their communities.

This kind of segregation and isolation is detrimental not only for families and children but also for society as a whole. An inclusionary philosophy recognizes that children have more things in common than not: all children need some form of accommodation. Keeping children with disabilities apart from their typically developing peers creates bigger problems later in life and does not take advantage of the

IN THIS CHAPTER:

- ✓ Definition and Benefits of Inclusion
- ✓ Benefits for Children with Disabilities and Their Families
- ✓ Benefits for Children without Disabilities and Their Families
- ✓ Benefits of Inclusion for Libraries and Librarians
- ✓ Resources
- ✓ References

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One History of Inclusion

1918 Soldiers Rehabilitation Act enshrines the concept of job training for veterans with disabilities.

1935 The League for the Physically Handicapped stages sit-ins at Works Progress Administration (WPA) offices demanding jobs for people with disabilities; several thousand are created.

1954 *Brown v. Topeka Board of Education et al.* defeats the principal of "separate but equal" in education when it comes to race.

1961 The American National Standards Institute publishes the first standards for architectural accessibility. This is the culmination of a movement begun by veterans in the 1950s.

1962 Edward Roberts, a polio survivor with quadriplegia, sues to gain admission to the University of California.

1963 President Kennedy calls for the deinstitutionalization of people with mental retardation and mental illness.

1971 *Pennsylvania Association for Retarded Citizens v. Pennsylvania* establishes that educational segregation is unconstitutional.

1973 Rehabilitation Act requires reasonable accommodations for people with disabilities in employment, education, and telecommunications by entities that receive federal funding.

1974 The last of the laws, known as "ugly laws," allowing for the arrest of people for simply looking different or

wonderful openness of young children to new experiences and their nonjudgmental attitude toward differences. Inclusion and opportunities for typical social experiences during childhood are critical for the healthy development of all children and of society.

Definition and Benefits of Inclusion

Inclusion, as a philosophy and a national movement, reflects the efforts of parents, professionals, and people with disabilities to reverse the isolation experienced by those with disabilities. What is the meaning of inclusion? In humanitarian terms, inclusion is a welcoming, a celebration of diverse abilities, and a profound respect for the contributions all children can make. It is a belief that more diverse communities are richer, better, and more productive places in which to live. Inclusive communities can create a future with a better life for everyone.

In the legal sense, inclusion is a term that advocates that children, regardless of their diverse abilities, have the right to participate in typical community settings where children without disabilities are found and will benefit from that participation. It supports families of children with special needs and their efforts to join in community life, have access to unbiased information, and participate fully in the decisions surrounding the education of their child. Inclusion encourages the child with a disability to participate in playground activities, child care settings, nursery schools and public schools, and activities at the local library.

Inclusion, as a national movement, encompasses the humanitarian and the legal perspectives. Inclusion creates communities that "are filled with individuals who are different from one another. But their shared participation in a given community connects them to one another" (Snow, 2001: 392). Indeed, the most compelling expression of inclusion is the fulfillment of a child's desire to have a friend and be accepted and valued as an individual. For families of children with special needs, this is a priority.

The concept of inclusion is integral to providing library services. An individual's prerogative to participate in activities and have access to resources is a basic tenet of library service. The American Library Association's (1996) Library Bill of Rights opens: "Book and other library resources should be provided for the interest, information,

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and enlightenment of all people of the community the library serves." Inclusion expands on this principle by encouraging librarians to welcome diversity within the library environment and to design services based on individual needs. As with any group of library patrons, children with disabilities and their families may or may not want to be included in all library programs. The principle of inclusion means that librarians will make it possible for any child, with or without a disability, to participate in library service.

Inclusion benefits not only families and children with disabilities but also the other participants in an inclusive activity and the staff that make it happen. The library vignettes in the following sections, collected during parent focus groups (*Early Childhood Quality Review Initiative for Public Libraries*, 1995), through individual interviews with parents (Langa, 1996), through Carrie Banks's experience in inclusive library settings, and through research, help paint a picture of how inclusion works and what it looks like in the library.

Benefits for Children with Disabilities and Their Families

Motivation to Gain or Practice a Skill

A child with a disability benefits from playing with peers without disabilities, because the interaction often motivates the child with a disability to gain or practice needed skills. In addition, the opportunity for the development of inappropriate behavior derived from social exclusion can be reduced or eliminated.

One little boy and his mother attended the library's early childhood program from the time he was six weeks old. The boy had gross motor skill delays and needed to practice climbing steps with his physical therapist. He did not have any accessible steps on which to practice where he lived. Because of their regular involvement in library programs, the mother knew the library's Early Childhood Room had a loft area with steps. It was the perfect opportunity to encourage this skill in a natural way. The mother asked the library staff if the physical therapist could accompany the family to the library's workshop or meet at the library to practice step climbing, much in the way typically developing children do. A time was selected that did not conflict with other library service, and the therapist sometimes participated while

demonstrating a disability in public, is repealed in Chicago, Illinois. / *Halderman v. Pennhurst* establishes the right to community-based services for people with developmental disabilities.

1975 Head Start is established, with the provision that 10 percent of the seats must go to children with disabilities.

1976 Linda Bove, a Deaf actor, signs a long-term contract with the Children's Television Network.

1983 Americans Disabled for Accessible Public Transit (ADAPT) stages protest at the American Public Transportation Association conference demanding equal access to public transportation.

1988 Federal Fair Housing Act is amended to include, among other things, provisions prohibiting discrimination against people with disabilities. This is the first time disability rights are addressed in broader civil rights legislation.

1990 Americans with Disabilities Act takes effect, providing for equal rights for people with disabilities.

1999 The Supreme Court rules that individuals with disabilities must be offered services in the most integrated setting in *Olmstead v. L.C. and E.W.* / Ryan Taylor, a nine-year-old in Oklahoma, wins his lawsuit and the right to play soccer with his walker.

2007 New York State designates the third week of October as Disability History Week.

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the workshop was going on to help the child in his natural environment. The mother further related that her son missed a ranch exhibit previously on display in the library. He looked for it repeatedly. She was so pleased that he had made attachments and connections based on his library experience—an important step for him!

At the Brooklyn Public Library's The Child's Place for Children with Special Needs, a child on the autism spectrum first demonstrated mastery of a skill he had been working on for years during a garden program at which he was a regular. One day he and his mother were late, and the librarian took a few minutes to reread a book just for him. When she asked him to point out the purple flower, he did. His mother was skeptical when told this story, because his teachers had been working on this skill in class since pre-K. So, the librarian asked him to point to the red flowers and he did. In this natural environment, it quickly became clear that he reliably knew his colors, just like the other kids. His mother was very proud. After attending programs supported by the Building Bridges Project in Upstate New York, parents reported that their children with disabilities became more independent in the library (Wemett, 2007: 16–17).

Increased Choices and Options

A child with a disability has access to a greater range of choices and increased opportunities to develop language, social, and problem-solving skills, when using the wide array of library programs, collection, and services. For example, a mother of a child who was hard of hearing approached the children's library wondering if the library would provide a sign language interpreter so that her child could attend storytime. The interpreter was provided, and the child was able to attend storytime. She was introduced to a variety of books and fingerplays and interacted with the other children in the program, many of whom wanted to learn this special new way of talking too! The mother and child continued to participate in library programs and learning activities, working with the librarian to design these programs and activities so that they were accessible to her child.

Through a collaborative program between the library and a local Early Intervention provider, an Early Intervention teacher became familiar with the library's services and asked if she could bring some children to storytime to enhance their language and social interaction skills. She and the librarian decided on the most appropriate program

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and, after attending storytime, these children brought their families back to select books and to use the library on their own.

Opportunities for Friendship

Friends are essential to our lives. They "open the door to social and emotional growth, they help smooth the rocky road of life, and they let us know we are valued" (Snow, 2001: 424). Not long after the Brooklyn Public Library started its internship program for teens with and without disabilities, two volunteers, one with a disability and one without, who often worked together, became friends outside of the library. One day the mother of the teen with the developmental disability called the librarian to chat about her daughter. Her daughter was spending too much time on the phone and neglecting her chores because she was at the mall with her friend. The mother was thrilled to be dealing with these typical teenage problems that she thought her daughter would never have. The price of friendship was one this mother was happy to pay. The Building Bridges program validated this result, noting that inclusive programs "promoted socialization between typical peers and the youth with disabilities" (Wemett, 2007: 17).

Source of Acceptance and Support

For children with disabilities and their families, the library can be a vital source of acceptance and support in the care of their children. It can also be an access point for balanced information and resources. Strong collections, a welcoming environment, and knowledgeable, open staff can open our doors to these potential patrons.

During a parent/child workshop, the children's librarian noticed that one child did not seem to be verbalizing at all (Feinberg and Deerr, 1995). The librarian spoke with the mother about the child's language development, and the mother expressed a great deal of anxiety over the child's lack of speech. During the workshop series, a visiting speech therapist approached the mother at the request of the librarian. She gave a pack of information to the mother and told her about a center where she could take her child for testing. The mother did so, and it was found that the child was experiencing a delay in language development. The mother was able to enroll the child in a special program. She came back to the librarian to express her thanks and seek out further information and resources. She also shared the

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difficulty her husband was having accepting the problem. The librarian gathered the information the mother needed about the child's speech delay and also located parenting books on raising a child with special needs, known as exceptional parenting, that specifically discussed the acceptance issue. The mother was pleased to be able to pass these books on to her husband.

The mother of a child with a serious physical disability shared this story: She remembered having a casual conversation with a children's librarian regarding her child's equipment needs. Several weeks later, the librarian mailed her the catalog of an agency that deals with Assistive Technology for children. The parent stated that this extra effort was totally unexpected and reinforced her feeling that the library and staff really had accepted her child and were genuinely concerned about his needs.

Paula Holmes, a library trustee and the mother of two children with disabilities, put it this way:

> When librarians interact with a child who has a disability they are modeling behavior for every patron in the library as well as building trust with that child and that family. . . . In building trust with a child, librarians help the child become an advocate for himself. They reassure the parents that they are not alone in this journey. (Holmes, 2007: 24)

Benefits for Children without Disabilities and Their Families

Acceptance of and Pride in Diversity

When inclusion is the library's norm, children without disabilities learn at a young age to appreciate and accept the diverse abilities of all children. One mother described her child's wonderful imaginary play that reenacted her visits to the library. Her daughter played library at home, arranging books to be checked out. She organized activities with herself as teacher/librarian and her dolls as attendees. The children read for friends, parents, and toys in attendance. She even read to her dolls using sign language.

The Brooklyn Public Library's The Child's Place includes the Picture Exchange Communication System (PECS), primarily used with

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people on the autism spectrum, in its program. One day, the use of this system with a child led to a broader discussion of the different languages spoken in that city in a single day. When a child asked about the system, the librarian responded that that was how Dominick talked. She then asked everyone there which of them spoke another language at home. Over half of the children raised their hands. When the librarian told them that she had grown up speaking German at home and also knew sign language, a lively discussion ensued with each child demonstrating his or her language with pride. Everyone went home knowing a new word in a new language that day. Dominick's new word was "amigo," which was printed on his PEC board below the picture and English word for "friend."

Better Understanding of People with Disabilities

Families of children without disabilities gain a greater understanding of disabilities, and they also develop a sense of pride in their children's natural ability to accept and appreciate differences in others. A parent focus group participant related that her child had learned to "behave and interact with others" and had also learned that "all children are not the same as her" after attending a library program that included children with disabilities. The parent expressed pride in her child's acceptance of differences and was pleased that this opportunity was offered at the library. It has often been documented that children without disabilities develop empathy, positive attitudes toward people with disabilities, and improved social skills when they participate in inclusive school and recreation activities (Powers, Singer, and Sowers, 1996: 349).

Benefits of Inclusion for Libraries and Librarians

Impetus to Reexamine Library Practice

What works for children with disabilities and their families, works well for others as well. This is a basic tenet of Universal Design, which is covered in Chapter 6. Learning to identify ways and design programs to include children with disabilities encourages us to examine

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rules, procedures, policies, facilities, programs, collections, and services. Any resulting improvements often benefit all patrons.

A library received a grant to develop a circulating toy collection for children with special needs, birth through age three. The children's librarians responsible for building the collection were excited about providing this new service. Toys arrived daily and were processed and made ready for circulation. A brochure was designed and a colorful notebook assembled. Just before the availability of the collection was announced to the public, the librarians thought about the child and parent checking the toy out at the circulation desk. How would other children feel? Wouldn't a child who wasn't qualified for the program want to check out such an attractive item? In fact, wouldn't the child with special needs stand out as "special" or "different"? The librarian approached the director and presented her dilemma, asking if it would be possible to purchase toys from the regular budget and allow all children to check out toys. The director agreed. Inclusion, in this instance, instigated the development of a new and exciting collection for all of the children in the community. Likewise, an FM system purchased to make library programs accessible to people who are hard of hearing can be used for simultaneous interpretation into another language, increasing the potential audience for the program.

Expansion of User and Support Base

Inclusion offers the opportunity for libraries to widen their circle of users and supporters while satisfying the needs of children with disabilities and their families. When one library conducted parent focus groups, some of the most active participants were parents of children with disabilities. They made suggestions such as streamlining registration procedures, relocating the library's suggestion boxes to elicit regular customer feedback, and conducting support groups for parents. These focus group parents became part of the library's regular user base and continue to interact with staff and administration on improvement of services. They brag to others outside of the library district about how supportive the library has been. They are staunch library supporters and can be counted on to vote in the library's annual budget adoption and trustee election.

This type of support is particularly important in times of tight budgets. It can encourage agencies to work together rather than compete for shrinking funds. At a meeting of Brooklyn Developmental Disability service providers during the height of the Great Recession in

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2012, a speaker made an offhand remark to the effect that her agency did not spend money frivolously like the library. As a groundswell of murmured objection grew in the audience of over 80 people representing at least 45 local service provision agencies, the chair of the meeting, which was already running late, interrupted the speaker and announced that disrespect toward the library was not tolerated in this group because the library is "our friend."

Expanding our patron base also expands our fundraising opportunities. Governmental agencies that fund disability issues become potential funders. Private foundations with interests in accessibility, inclusion, and specific disabilities welcome applications from libraries pursuing these goals. One library's collection of books on autism spectrum disorder was funded by the Autism Society of America. Another used money from the state's Developmental Disability Council to purchase hi-lo books for teens with developmental disabilities that were used by a much broader audience, including English-language learners and new adult readers.

Opportunities for Staff Development

Through experiences with children with disabilities and their families, library staff have an opportunity to increase their competencies and skills. One library, after reaching out to families and children with special needs, was overwhelmed at the response it received. The support staff expressed anxiety over how some of these children behaved in the library, and there was resistance that needed to be overcome. The head of the department realized that her staff needed skills to interact appropriately with these families and children and to integrate them into the library environment. She contacted staff from the developmental disabilities school with which she was working. They provided a social worker who met with the library staff to sensitize them on issues surrounding families and children with disabilities. They discussed specific problems and designed practical solutions. This type of training is crucial to making libraries a welcoming place. As one disability rights advocate told Carrie Banks, "It's all about attitude. Nothing else matters."

Welcoming families and children with disabilities into our libraries and designing inclusive services is not a fad. All children select resources and activities to participate in at the public library based on individual interests. Children with disabilities need and have a right to these same choices. The reality is that children with disabilities

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are either proactively included or they are in practice excluded. It is incumbent upon us to develop a greater understanding of various types of disabilities and be sensitive to the needs of youth and their families. We can take the lead in ensuring that children with disabilities are welcomed and served and effect the change needed to create a truly inclusive library culture.

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