A Special Needs Approach

A Study of How Libraries Can Start Programs for Children with Disabilities

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The Census Bureau reports that 5.2 percent of school-age children (2.8 million) were reported to have a disability. The American Community Survey defines a person with a disability as a person having a "vision, hearing, cognitive, ambulatory, self-care, or independent living difficulty."[1] Per the American Community Survey, the most common type of disability diagnosed in school-age children is cognitive disability, which they define as "serious difficulty concentrating, remembering, or making decisions."[2]

The Individuals with Disabilities Education Act uses a specific definition for a child with a disability, and entitles them to a "free and appropriate public school education" while they are aged three to twenty-one.

> Child with a disability means a child evaluated . . . as having intellectual disability, a hearing impairment (including deafness), a speech or language impairment, a visual impairment (including blindness), a serious emotional disturbance . . . , orthopedic impairment, autism, traumatic brain injury, and other health impairments, a specific learning disability, deaf-blindness, or multiple disabilities, and who, by reason thereof, needs special education and related services.[3]

According to the National Center for Education Statistics, students with disabilities accounted for 6,481,000 public school students in 2009–10, with the most common type of disability being a "specific learning disability" (4.9 percent), followed by "speech or language impairments" (2.9 percent), and "intellectual disability" (0.9 percent). The number of students with disabilities in US public schools has increased from 8.3 percent of total enrollment in 1976–77 to 13.1 percent of total enrollment in 2009–10.[4] However, while school libraries are legally obligated to serve children with disabilities, public library services to children with disabilities are less well-coordinated and more reliant upon individual choices. We wanted to see if there were any common reasons why libraries add programs for children with disabilities, and if there were common experiences from which other librarians could learn.

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Literature Review

Much of the literature on serving children with disabilities comes from school library–oriented sources. However, public libraries are also active and creative in providing programming, materials, and services for children with disabilities, including general programming, special needs storytimes, collection building, and technological and other assistive approaches.

Cynthia A. Robinson and Frances Smardo Dowd surveyed libraries about general services to children with disabilities in 1997. They found that 27 percent of libraries had programming aimed at children with disabilities, 25 percent of their library respondents offered summer reading clubs for children with disabilities, and 17 percent offered puppet shows using "Kids on the Block" puppets designed to specifically represent children with disabilities. Other programs included crafts, games, and storytelling for children with disabilities.[5]

More recent articles describe successful programs and implementations at individual libraries or systems. However, these articles have some commonalities. The Library Services and Technology Act (LSTA) is a key source of funds for public libraries increasing their services to children with disabilities. Grant funds are used for program development, staff training, and purchasing materials, including books and computer workstations with adaptive technology.[6] Libraries are also partnering with volunteers for program staffing and advertising programs at local children's services agencies.[7]

Programming techniques used by public libraries have included adapted board games and video games, retelling stories with puppets, using sensory stimulation, and incorporating play into programming.[8] Staffing for programs is an issue: one library used volunteers to reach a 1:1 staff-child ratio, while others deliberately keep programs small and focused.[9] Accommodations have taken the form of having mats for defined individual space and having children hold weighted dolls to help with fidgeting, using large books with clear pictures, and converting digital texts into alternative formats for children's particular needs.[10]

Methodology

We used a survey distributed to a broad audience of public libraries to determine what services were being provided, and used phone interviews to hone in on the personal stories behind programming for children with disabilities. Surveys are a common method to obtain descriptive data from a relatively large population, and the survey method has previously been used to learn about library services for children with disabilities.[11]

Our survey was distributed to a sample of medium- and large-size public libraries in the United States. This library size was chosen to ensure both that libraries would have a reasonable chance of having children with disabilities in their service population and that they would have resources available to provide for those children's needs. We downloaded the data file for the 2010 Public Libraries Survey from the IMLS website and limited our choice to the 540 libraries in the fifty United States and the District of Columbia with service populations of one hundred thousand or more. We sent our survey to 185, or approximately one-third of those libraries.

We designed our survey based on other surveys and literature about library services to special needs children. We pretested the survey with some public librarians who were not in the sampling frame, refined the survey, and pretested again with a different children's librarian who was also not in the sample frame. Survey questions asked what types of disabilities were found in the library's child populations and which ones librarians were called upon most often to accommodate, whether the library offered separate or mainstreamed programs for children with disabilities, how the library's programming for children with disabilities was initiated, whether librarians had the opportunity to attend training to provide services to children with disabilities, and what challenges librarians had faced in implementing programs for children with disabilities.

Librarians who had more to say were invited to contact us, so that we could learn more about the process of providing accommodations to children in public library programming. We conducted five semi-structured qualitative interviews, each interview taking thirty to sixty minutes. We had some starter questions, but were interested in what the librarians had to tell us about the details of starting and maintaining a program with accommodations. All interviews took place approximately two months after the distribution of the survey, after which we coded for themes and commonalities.

Results

Four weeks after our survey request was sent out to 185 libraries, we had thirty-nine responses, plus an additional handful of e-mails from libraries indicating that they did not offer specialized services for children with disabilities. This 22 percent response rate was surprising because those who did answer the survey were very responsive and seemed eager to discuss the services they offered. Two months later, we interviewed six librarians from five different libraries about the services they provided to children with disabilities. These interviews put a personal face on the delivery of programs for children with disabilities.

What Disabilities Are Present in the Child Population?

Survey respondents reported disabilities in their child populations as speech or language impairments (35), autism (33), mental retardation (31), hearing impairment (28), orthopedic impairment (26), and visual impairment (26). Autism was the most prevalent disability and the disability librarians were most frequently asked to accommodate. The second-most common

accommodation request was for hearing impairment. Typically, though, multiple disabilities were present in the child population served, and our respondents were not able to specialize in programming designed to accommodate only one type of disability. Each of our interviewees talked about various kinds of disabilities present in their child communities, visible impairments such as blindness or wheelchair use, and invisible impairments such as autism or chemical dependency at birth.

Children's Programming

Thirty-seven of the thirty-nine respondents indicated that their library provides mainstreamed children's programming such as storytime, summer reading program, and crafts programs, open to children with and without disabilities. Fifteen respondents said their library offered separate programming for children with disabilities, and some respondents indicated that they would do programming "upon request" when a parent or caregiver for a group of children with disabilities requested it.

Our interviewees talked about what they did to adapt programs for children with special needs. Using music is a popular choice. Carla Kirby of Rapides Parish Library in Alexandria, Louisiana, said, "Music has never failed me. We do a lot of songs with movements and motions." Tammy DiBartolo, also of Rapides Parish Library, said, "We read a lot of books. Humor tends to be the most popular, and any repeating book that has a response that they repeat back to us."

Kirby noted that implementation was "trial and error. Sometimes I would read a book that didn't go over so well. But you know what? Sometimes that book does work for the next group. It's really about getting to know your groups, and that's a process."

The librarians indicated working with teachers and aides to customize programs for each specific audience. Sheila Dickinson of Richmond (CA) Public Library said, "If there was someone who couldn't use their hands, I would do a different kind of finger play, maybe a whole body activity." Adrienne Gardner of Hunterdon County (NJ) Library said, "Sometimes we have students who don't want clapping or don't want singing, and it all depends. If it's just one student, the teacher might take the student out and we'll still do the activity. Other times, if there's more, the teacher will tell me at the beginning and we just won't do those activities."

Elizabeth Zuelke of the Public Library of Cincinnati and Hamilton County (OH) told us about special programs their libraries were doing including Autism Night Out, which allows families of kids with autism to visit the library after hours, in a private situation without the pressure of feeling they might be distracting the library's traditional clientele. Their department was also developing sensory kits for Sensational Storytimes, to appeal to multiple senses during storytime. Zuelke said that sensory storytimes "are great for kids who have a lot of different types of special needs, and yet they're something that other kids can attend as well."

Sometimes programming doesn't go well, as Kirby shared. During a storytime, she began making growling noises as part of her storytelling. The growling noises got a child with special needs overly excited. Kirby recalled, "He lurched at me and bit me on the arm and wouldn't let go." She said it took the child more than a year to return to the library because of embarrassment.

Kirby said, "I've learned from that, I need to know . . . are voices going to be too intense for some of them? Is some of the music? Is clapping?"

Initiating Library Programs for Children with Disabilities

Twenty-five librarians responded on how their library started programs for children with disabilities. Fifteen said that the children's department and the librarians themselves had started offering these programs, while another nine indicated that these programs had been requested by parents or caregivers. Most respondents (25) indicated that their library had not done a community analysis, so it seems children's librarians are themselves seeing the needs in their communities.

Our interviewees gave us a more personal perspective on how their library services got started. Sometimes it was a personal connection. One of our interviewees noted that her library director had a child who is wheelchair-bound, and she had a son with Attention Deficit Disorder. These family circumstances made the issue of services for children with disabilities stand out for her. That led them to develop their children's programming and to expand it to developmentally disabled adult groups. Adrienne Gardner of Hunterdon County (NJ) Library noted the presence of a politically active teenager in the community who worked to make sure the library and the high school were doing all they could to comply with the Americans with Disabilities Act (ADA).

Frequently, however, the initial impetus came from a parent's or teacher's request. While Gardner's building had been remodeled to ensure compliance with ADA, programming started when the local school's autism program brought students over to the library for a visit. DiBartolo said, "We kept having special needs groups come in, and there was no real service for them, so we started doing a storytime." She also indicated that they made it a goal to increase outreach to special needs groups. Zuelke gave a different answer: "[The Public Library of Cincinnati and Hamilton County has] provided services for special needs kids for more than fifty years. Our administration is proud of the fact that we have such a long history in this area."

Marketing

In survey comments, two respondents mentioned a fear of low turnout for these programs, and two others mentioned that it was hard to get the word out about these programs. By contrast, interviewees indicated that they had attracted significant

audiences for their programs for children with disabilities. Zuelke noted that she had three outreach librarians who spent the school year doing nothing but programs for special needs children and teens. Their history of providing special needs services has worked in favor of that high service use; they have connections to multiple associations in the Cincinnati area that refer parents and teachers to the library's services. She named eight agencies off the top of her head that the library was working with, and indicated that there were others.

Several survey respondents worked with local public and private schools, including the special education departments of those schools, and preschools and Head Start schools in their communities. Some worked with schools dedicated to serving children with disabilities, such as state schools for the blind. Many worked with state or community agencies such as Autism Centers, Disability Alliances, and Deaf Services Centers. One person indicated working with a Diabetes Camp, while another worked with the YMCA camp. One librarian indicated working with a local college program in American Sign Language. Another reported making children's programs available at the hospital.

In interviews, DiBartolo and Kirby said their connections were primarily through care centers asking if the library could provide any services to their clients. Kirby said, "Once the word spread that we were doing special needs programs, they just started calling more and more. Now we rarely go a month without a new school or special needs facility calling us." They mentioned that they had expanded their programming to include developmentally disabled adults when they realized that audience was ignored by groups doing adult programming. Dickinson of Richmond Public Library said she started out doing storytimes for special needs kids at a Head Start daycare facility near a library branch, before encouraging the class to come to the library for storytime. She was also contacted by an early childhood school to speak to their special needs classes and parents, and now she does a special storytime or library visit for that school once or twice a year.

Another concern was the difficulty of advertising programming for children with disabilities in a sensitive fashion. One librarian commented, "It's tricky to promote programs for children with disabilities without stigmatizing it at the same time." Most of our interviewees indicated working directly with special needs classes or agencies serving children with disabilities. They advertised their programs through those connections.

Equipment

Thirty-three respondents provided specialized equipment for children with disabilities. Audiobooks, large print books, talking books, and Braille books were most commonly provided, and about half of the libraries provided computers with assistive technology. Three provided Kurzweil readers. The "other" category indicated the variety of needs seen in children's

programming. Respondents mentioned videophones, American Sign Language software, headphones for children who need them, film captions and sign language interpreters, sensory and tactical items, and items to ensure the comfort of the children who participated in programs. However, one respondent noted that the high cost of adaptive resources meant they could not offer as much as they would like.

Two of our interviewees noted that they had special funds for programming for special needs children. Zuelke described a dedicated library trust fund specifically for providing services for children with disabilities. "Over the last several years, we've been buying special seating, special games and puzzles, things like switches so they can press to participate [instead of verbalizing], sound-deafening headphones, calming devices. We buy all these things in the Outreach Department, and they're available to our branch libraries if they have special needs children attending their programs," she said. "We used some of our money last year to put together sensory kits. We're unveiling those later in the year for Sensational Storytime."

Because they have that trust fund, they tend not to apply for grants for special needs children's services. Cheri Crow of Montgomery (MD) County Public Library had applied for and gotten grants to provide services for children with disabilities. The grant allowed her library to purchase specialized computer equipment as well as some American Sign Language interpretive services for programs. "Unfortunately, once the grant isn't around anymore, most of our libraries don't have the funds to continue those programs."

Challenges

Twenty-three respondents reported that a lack of library staff education was a challenge for implementing programs for children with disabilities; twenty-two said that they lacked money, time, or other resources. Two respondents reported resistance from library staff, but seven reported resistance from other patrons. However, two of our interviewees said parents and children appreciated the integrated experience, using mainstreamed programs as a way to learn about differences and acceptance. Of her mainstreamed programs, Dickinson said, "It was good, I think, for everyone [in the program] to be mixed in together. Sometimes kids would have crying fits, but you know, that happens with every toddler storytime."

Regarding library staff education, twenty-one survey respondents said they had attended some kind of training for services to special needs children, while fifteen had not. When we asked who had provided the training, the variety of responses suggested that there was no organized agency taking the lead on this. The most common answer was that training was given by school representatives, and two indicated that libraries for the visually impaired had provided some training. Others indicated that their municipality provided training or that they had participated in webinars on the subject.

Implications

Survey results suggested that children's librarians see the need for providing services to children with disabilities and are coming up with ways to fill that need. Our interviews strengthened that perception, with our interviewees telling us what they did and how they looked at their communities. Most of our survey respondents indicated that their libraries had not done a community analysis. This suggests that children's librarians themselves are instrumental in documenting the presence of children with special needs in their communities, and that children's librarians can serve as a conduit between parents and agencies for children with special needs.

Starting Library Programs for Children with Disabilities

For librarians who want to get started in offering programming for children with special needs, the first step might be to find community allies—schools, services, and parents who work with children with disabilities and who can support the library in its efforts. These community allies will provide attendees for programs, and may also provide training in working with special needs children and resources or materials for those groups. Support for outreach efforts is necessary. Many of our librarians mentioned that they provided these services in classrooms, hospitals, and various other agencies outside the library. A librarian who is unable to leave the building may have difficulty establishing these kinds of programs.

Library and administrative support greatly eased the burden for children's librarians. Two of our interviewees were district-wide coordinators: Crow (District Consultant, Montgomery County Public Library) and Zuelke (Outreach Services Manager for the Public Library of Cincinnati and Hamilton County). This district-wide oversight allowed them to provide programs and services across several libraries, and provided a general support structure for branch librarians who were faced with new populations and new challenges.

By contrast, some interviewees were responsible for the entirety of children's services in their libraries, without institutional support for working with children with disabilities and were limited in the services they could provide.

Flexibility, diplomacy, and an easygoing nature are also key elements to providing programs for children with disabilities. Our interviewees indicated that they often had to change program ideas on the fly. They had to be able to handle children's periodic outbursts without becoming distracted or flustered, while at the same time educating others about children's needs and limitations.

Education and Support

Autism is the disorder librarians are most frequently called upon to accommodate, and librarians may wish to focus

their attention and their resources. However, a librarian who wishes to focus on children with special needs will also want to broaden her skills to accommodate the needs of children with other disabilities. Given increases in the population with disabilities, the LIS profession might use these results to develop a clearinghouse for programs and services for children with disabilities, documenting the trends in programs that are successful, and for which audience they succeed.

If our survey response rate is an indicator, it seems that few children's librarians are providing programs for children with disabilities, but those who do, provide those services with gusto. Children's librarians serve as the gatekeepers to the library for children with disabilities and their parents. Sometimes grant money or parental involvements were the impetus for program initiation. Sometimes it was a librarian having a child with special needs as part of her personal life. However, it was usually the library staff who kept the programs going. Their determination and creativity allowed the programs to thrive. Making community connections was extremely valuable for successful libraries. Many libraries did not advertise their programming for children with special needs to the wider public. Because of this choice, libraries had to locate and maintain positive relations with special needs classrooms, schools, group homes, and the like.

Our interviewees generally had a positive experience in serving children with special needs. Kirby advised librarians considering expanding their services to special needs populations, "I know it may be scary at first to start doing that kind of program. But just do it and you will not regret it. It's my favorite thing that we do at the library."

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