

## **“But they don't look like they have a disability.” Serving People with Dyslexia - Best Practices from the United States**

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### **Abstract**

*Dyslexia is the “hidden disability.” Unlike other disabilities, it cannot be identified easily after minimal interaction. Many children do not know that they are dyslexic; just that they can’t succeed in school. It takes a teacher or a parent noticing the problem and asking for testing that can make the diagnosis. Most adults learn ways to adapt to their disability with varying degrees of success. You may know an adult for years and not realize the person has dyslexia unless he/she self-discloses.*

*This paper focuses on library services to people with dyslexia in the United States. It will cover three topics.*

- *Issues in serving people with dyslexia*
- *National programs in the United States that focus on serving people with dyslexia*
- *Examples of some local libraries that intentionally serve people with dyslexia*

### **Key Words**

Dyslexia, National Library Service, Learning Ally, Bookshare, ASCLA

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### **Introduction**

My son did not learn to read until he was 9 years old. He had the misfortune to enter public school when the “whole language” method was used to teach reading. It might as well have been Chinese for my son. When he was finally diagnosed with dyslexia, we discovered a teaching

method that focused on phonics and phonemes. Jonathan's dyslexia is compounded by hyperactivity, reflecting his mental struggles with physical twisting and turning.

Jonathan rarely reads for enjoyment. Once, while we were driving, he asked me why I liked reading so much. I told him because I could see the pictures in my head while I read the story. Jonathan asked "What pictures?" I believe the only fiction books he ever willingly read are *A Hitchhikers Guide to the Universe* and the *Harry Potter* series (thank you J.K. Rowling.)

So helping Jonathan succeed or just complete high school was a challenge. Reading textbooks was agony for him. What helped was the US Library of Congress National Library Service, a special program for the blind and reading handicapped.

This paper will cover three topics:

- Issues in serving people with dyslexia
- National programs in the United States that focus on serving people with dyslexia
- Examples of some local libraries that intentionally serve people with dyslexia

## **Issues in serving people with dyslexia**

### Identifying people with dyslexia

Dyslexia is the "hidden disability." Unlike other disabilities, it cannot be identified easily after minimal interaction. Many children do not know that they are dyslexic; just that they can't succeed in school. It takes a teacher or a parent noticing the problem and asking for testing that can make the diagnosis. Most adults learn ways to adapt to their disability with varying degrees of success. You may know an adult for years and not realize the person has dyslexia unless he/she self-discloses.

It is difficult to estimate the number of people with dyslexia in the United States. Learning Ally, a national non-profit organization, estimates that 20 percent of American elementary school children have significant, continuing difficulties with learning to read, reading fluency and/or reading comprehension, which includes dyslexia. They also estimate that only 5 percent are referred for special help in reading. Most are boys between 65 percent and 75 percent.

The Dyslexia Research Institute (DRI) estimates 10 to 15 percent of the US population has dyslexia and agrees with Learning Ally that only about 5 percent are recognized and receive assistance. DRI also estimates that 60 percent of those diagnosed with attention deficit disorder are also dyslexic but this is masked by the behavioral issues of the hyperactivity.

### Passive vs. active library services

Because of this invisibility, most specific library services to people with dyslexia are aimed at children because their disability has often been identified in the educational system. Specific services for adults with dyslexia are rare.

In seeking examples of library services for people with dyslexia, I found many libraries that offer “passive” library services. What we now call adaptive technology can be used by people with dyslexia, whether they disclose their disability or not. Audio books and magazines, large print books, dual format (print and audio) all serve people with dyslexia as well those with visual impairment. Children’s story hours are basically dual format presentations –visual and audio. Maker-spaces and crafts encourage children and teens with dyslexia to be successful using skills other than reading.

Fewer libraries recognize dyslexia or learning disabilities specifically and offer specific services for this population. Four examples are described below.

Libraries that offer passive services do not attempt to identify people with learning disabilities or dyslexia in their community and make no attempt to reach this audience through publicity. When I contacted one library who I knew subscribed to special accessible collection, no one on the staff could answer any questions about it, said it had never been used, and did no publicity. Two other libraries said they thought they had accessible collections. One directed me to a web like that was broken; the other referred me to multiple people, trying to find someone who could answer a simple question: how do I use this collection if I want to.

#### Access to Resources - legal barriers

The Library of Congress National Library Service and Learning Ally (described in more detail below) both provide extensive resources, both hardware and software, for people with visual impairment, including people with dyslexia. However, US copyright law requires that these resources only be provided to people who have been certified as needing them. For people with dyslexia, this means a medical doctor or osteopath. Public libraries that offer these services, usually do this through a special service program that allows them to segregate the resources from the general library collection that is open to all. Learning Ally works mainly with school districts and their resources are acquired and managed by special education programs, although the school library can be involved.

Public libraries most often acquire media for the general population that can be used for people with dyslexia along with adaptive technology for people who wish to access them.

#### Publicizing library services for people with dyslexia

It can be difficult to publicize services to people with dyslexia. The Dyslexia Research Institute suggests that without proper diagnosis, many dyslexics are functionally illiterate limiting their ability to find jobs and function. This population is unlikely to be aware of the library as a source of assistance. The move to multi-media in libraries makes it easier. There is no stigma to checking out media; everybody does it. Specific resources that fit the needs of people with dyslexia (page color, certain fonts and font sizes, spacing on the page) can be purchased or put on specific shelves with directional signs or posted on a website. For example, a search of the internet came up with several lists of “dyslexia-friendly books.” Barrington-Stoke publishers describes the books on their list as:

*Our books can help dyslexics get to grips with reading. Our cream paper reduces glare, which is a factor in visual stress and may make words seem to 'jump around'. Dyslexia can make it hard to remember the shape of words and letters on the page, so our font and spacing are carefully designed to make everything as clear as possible. We use very thick paper so that words and illustration don't show through from other pages and confuse the eye. Our edit process is also very special and has been developed by dyslexia and speech and language experts in response to research and feedback from thousands of readers on hundreds of Barrington Stoke manuscripts over the years.*

*Most importantly of all, we pitch our stories at the 'real' age of the reader and not their reading age. People who experience difficulties with reading can experience low self-esteem and even depression as a result. We believe that no child or adult who struggles with reading should have to read books written for children many years younger than themselves. <http://www.barringtonstoke.co.uk/dyslexia-friendly.html>*

## **National organizations in the United States that assist libraries to serve people with dyslexia**

There are many organizations in the United States that serve people with dyslexia. A national Center of Learning Disabilities, state associations for people with dyslexia and new media publishers all attempt to provide services and resources for children with dyslexia and their caregivers and for adults with dyslexia. Three national organizations work specifically with libraries in some way.

### The National Library Service for the Blind and Physically Handicapped

The mission of the NLS, as it is known, is: *Through a national network of cooperating libraries, NLS administers a free library program of braille and audio materials circulated to eligible borrowers in the United States by postage-free mail.*

Founded in 1931, NLS is sponsored by the Library of Congress. The service is authorized and funded in part by the US government and allows NLS to record copyrighted material for use by people who qualify for the service. NLS provides several services:

- Records books and magazines for eligible users
- Pays the cost of the recorded materials
- Provides digital players, both standard and advanced, which includes navigation options
- A searchable catalog of all their holdings
- Access to the Braille and Audio Reading Download (BARD) service which allows users to download material (braille and audio) onto their own digital talking book cartridge, an authorized commercial digital talking book player, or an iOS device. Braille books may be downloaded and played on a device with a refreshable braille display
- A braille transcription certification course through a contract with the National Federation of the Blind

- NLS has a network of state libraries that administer the service on a local level
- Cooperates with other national organizations to serve this audience

In addition, states add services that meet the needs of their own users. For example, some provide braille services, summer reading programs for children and special equipment for local libraries.

In addition to visually impaired, NLS provides services to “other physical handicapped persons” including “Persons certified by competent authority as having a reading disability resulting from organic dysfunction and of sufficient severity to prevent their reading printed material in a normal manner.”

All people must be qualified for NLS services by a “competent authority.” In the case of blindness, visual impairment, or physical limitations this is defined to include multiple types of doctors, nurses, therapists, institutional staff, and even librarians. In the case of a reading disability, however, a competent authority is defined as “doctors of medicine and doctors of osteopathy who may consult with colleagues in associated disciplines.” This is a point of contention for some people with dyslexia who feel they are not treated equally or fairly.

A special “kid’s zone” offers material specifically for young children including

- A Kids’ Catalog with books for children pre-school through 8<sup>th</sup> grade
- Good reads – major award winning books
- Bibliographies
- Series books
- Children’s magazines
- Library of Congress sites for children
- State programs with special programs for children

NLS works with the states to publicize its programs widely. School and public libraries know that their users with special needs, including dyslexia, can get assistance and the libraries facilitate the eligibility application.

Karen Kenninger, Director of NLS, in an email, said that NLS “does not track dyslexia as a separate eligibility criterion. However, it does fall under reading disability.” As of the end of FY 2013, 6.0 percent of registered NLS patrons nationwide have a reading disability.

### Learning Ally

Established in 1947 as Recording for the Blind, Learning Ally is a national non-profit that supports students with print and learning disabilities and their families. It is a membership organization so there is a charge to receive its services. Working primarily with students through schools and colleges, Learning Ally serves more than 10,000 institutions. Specializing in core curriculum material, Learning Ally’s collection is comprised of 65% textbooks and 35% literature and supplemental material. The National Library Service, which does not provide

textbooks, refers people to Learning Ally who want textbooks. Learning Ally uses the DAISY format which allows more dynamic navigation of resource content.

Learning Ally provides a variety of services to its members. For parents it provides:

- One-on-one consultations with parent support specialists, each of whom has a child with dyslexia and can help you with the information, insights and options you need
- Exclusive webinars from learning disability experts
- Guidance on the special education process in US public schools
- For the student, Learning Ally provides access to 80,000 audiobooks including fiction, nonfiction, literature, and textbooks as well as original source documents used for Common Core and more practical print materials like drivers manuals.
- More than 2,000 VOICEtext titles feature the full printed text that's highlighted as it's being read

Similar to the National Library Service, recipients of Learning Ally services must follow eligibility requirements. Students must be diagnosed by a competent authority as having an organic print disability which would generally allow them to fit into one of three categories including; blind/low vision, learning disability, or other physical disability. Most of the members of Learning Ally are school districts or higher education. Because of the openness of public library collections, public libraries are not likely to be members.

Learning Ally does not work with libraries directly. In an email, Paul Edelblut Vice President of Education Solutions, described this relationship with libraries:

We hear anecdotes like this quite often but don't typically focus on reaching out to librarians because, while they are extremely supportive, often cannot make the diagnosis or share the necessary paperwork that authorizes a user to access the catalog. We often end up with librarians but our conversations begin with a reading specialist, assistive technology expert, instructor of the vision impaired or special educator.

### Bookshare

Bookshare® describes itself as providing “the world’s largest online library of accessible reading materials for people with print disabilities. Individuals can sign up for membership and access the library on their own. Organizations that serve individuals with print disabilities (schools, libraries, community centers, etc.) can sign up and provide access to their students or clients.”

Bookshare offers access to books, textbooks, newspapers, magazines, and technology. Like NLS and Learning Ally, Bookshare offers its services to people with reading disabilities who must qualify for the service. Students with qualifying disabilities and schools and colleges receive the services free through a grant from the U. S. Department of Education. All other organizations, including libraries, must pay a membership subscription fee.

People can download materials on their own computer or get free software for reading DAISY digital books. There is also software for other hardware options such as Book Wizard or eClipse Reader and downloadable software to transfer the books in embossed braille.

Libraries can participate in Bookshare by becoming a member if they serve qualifying individuals who have a print disability. As with other national organizations, the qualification must be certified. However, the list of professionals who can provide this certification is broader than medical doctors. Libraries can install Bookshare's free reading software applications or use compatible reading tools.

Read: Outloud Bookshare and Victor Reader Soft are free reader software for Bookshare members that is specifically designed for people with learning disabilities. They are PC and Mac compatible and there are a variety of text to speech voice options. There are different e-book style options, background color, and font size and color. There are also study tools, including outlining, text notes, and a bibliographer function. And there are some research tools, including a dictionary lookup and the option to browse the web.

### **Examples of libraries serving people with dyslexia**

#### The Brooklyn Public Library, Brooklyn, New York

The Brooklyn Public Library created *The Child's Place for Children (and Teens) with Special Needs* in five branches specifically to serve children and teens with disabilities. Carrie Banks is the Director of the Center. The program began in one BPL Branch and has expanded to five branches 11 years after Banks became director of the program.

The information in this description came from a lengthy interview with Ms Banks.

The Child's Place for Children (and Teens) with Special Needs serves all children, however, the Center design, resources, and services are designed to specifically meet the needs of children with disabilities. They do not keep statistics on the number of children served by disability but Banks knows that many of their users are children with dyslexia.

The Child's Place uses what they call Universal Design which uses seven principles in designing services for people with disabilities:

1. Equitable Use: The design is useful and marketable to people with diverse abilities.
2. Flexibility in Use: The design accommodates a wide range of individual preferences and abilities
3. Simple and Intuitive Use: Use of the design is easy to understand, regardless of the user's experience, knowledge, language skills, or current concentration level.
4. Perceptible Information: The design communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities.
5. Tolerance for Error: The design minimizes hazards and the adverse consequences of accidental or unintended actions.
6. Low Physical Effort: The design can be used efficiently and comfortably and with a minimum of fatigue.

7. Size and Space for Approach and Use: Appropriate size and space is provided for approach, reach, manipulation, and use regardless of user's body size, posture, or mobility.

The Child's Place implements these principles in this way:

- All facilities are barrier free to accommodate children who use wheelchairs, walkers, etc. Seating is arranged accordingly and positioning cushions and mats are available
- Staff members have backgrounds in special education and years of experience working with children with disabilities
- Three branches have fully accessible sensory gardens
- Multisensory programs include books, movement, music, and hands-on activities
- Adaptive toys are available at all locations
- Puppets, toys, and other items are used to illustrate stories and books in a hands-on fashion
- Twin vision and braille books, and audio books are available
- Craft projects include visual and textural appeal
- Adaptive scissor, paintbrushes, and other tools are available at all craft programs
- Interpreters are available at libraries upon request
- Staff is adept at using communication boards
- Weekday after-school programs begin at 4:30 pm to accommodate children with varied commutes and schedules

Some of these are more relevant to people with dyslexia than others, however, this list demonstrates that the library considers the total library presentation to make the Center friendly and welcoming to all children and teens.

The mission of the Center is two-fold: 1) assist children and teens in getting resources that will help them develop reading skills and 2) to build their self-esteem to help them recognize skills they have independent of reading.

The Center has an enhanced collection of audio books and dual format sets. They particularly like the dual format because it meets multiple needs of children. It includes resources for both young children and teens. In addition to providing services for their users, they also make referrals to other resources such as Learning Ally and Book Share. They also observe the children who use the service and refer them for testing and diagnosis when appropriate.

Bookflix is an online literacy program that pairs classic Weston Woods storybook films with related nonfiction e-books from Scholastic. Users of all ages can read along with the narrator, play educational games, read author biographies, or check related web links.

In serving children with dyslexia, this library tries to meet their needs in two ways. Children with dyslexia often do not do well on school tests. Part of the service is to help them develop skills that allow them to improve. The Center also wants to provide an opportunity for the children to learn they have skills and abilities beyond their reading difficulties. They believe in a multiple intelligence approach to their services and to give the children opportunities to improve their self-esteem. Thus, in addition to reading resources, the library offers story hours, a garden, maker-space, and other programs to capture the interest of the children and give them



opportunities for success in areas not valued by the schools. Even in these seemingly non-reading activities, Banks says there is always a literary component.

With teenagers, The Children's Place encourages use of the maker-space area so that kids struggling with reading can experience creative success by making a t-shirt, or graphic novel, or experiment with photography, etc. They also choose games that would be attractive to youth with dyslexia. They also adapt games to make them more user-friendly, for example, building in cues for directions that aren't just left/right, as this can be a problem for some teens with dyslexia.

Parents and caregivers are welcome to come to the Center and can get access to resources for learning disabilities if they need them. The Center does not offer literacy classes, however, some of the libraries are used by literacy tutors to teach language skills.

The Children's Center publicizes "any which way we can." They have a database of associations, organizations, institutions and teachers that serve youth with disabilities and they ask these groups to share information about the library. They also have contact information for their users. They send a newsletter once or twice a month and have a website and Facebook page. However, Banks says that most successful publicity is word-of-mouth – people and organizations telling other people about their successful and pleasant experience at the library.

The Children's Place doesn't track individual users. They know that about 22,000 people used the Center in 2013.

Banks described one young child young man who came to the library with his grandmother. He was 8 years old. Banks brought him to the Child's Place and showed him how to use bookflix. He was captivated and said to his grandmother "I've been wanting to read this one forever and now I can."

### New Jersey State Library Talking Book and Braille Center

The New Jersey State Library Talking Book and Brail Center (TBBC) is a Regional Library of the Library of Congress' National Library Service for the Blind and Physically Handicapped. Adam Szczepaniak, Director to TBBC, described their services in a personal interview. In addition to the services offered by all Regional Libraries, TBBC received a grant from the Comcast Foundation to purchase software upgrades for 40 computers that the State Library has placed in local public libraries across the state. This cooperative program between the State Library and public libraries allows patrons to view the FREE services available to the state's "Print Disabled" population. These computers will be upgraded to the latest Microsoft operating system and will feature the accessible software called Zoom Text. Zoom Text is a product from AI Squared.

Zoom Text comes in two versions, a magnifier that enlarges and enhances everything on a computer screen and Zoom Text Magnifier/Reader that also reads aloud anything on a computer screen, including email documents and email messages. They call these computers Outspoken Libraries. Zoom Text also allows the user to change the colors on the screen to make them easier to read. TBBC publicizes the Outspoken Libraries in partnership with local libraries. TBBC maintains a mailing list of all of the clients and encourages them to use these

enhanced computers in their local libraries. TBBC staff also make presentations to organizations that serve people with disabilities. They teach people how to download books on to their own devices so they are not limited to using the library's computer. In addition, they train local librarians to use the system and teach their users.

### Woodlynde School, Strafford, Pennsylvania

*This is an article posted on the Learning Ally website about how Woodlynde School is implementing the connection between Learning Ally and the physical library. The article was written by the school librarian, Gretchen Schroeder.*

When I came to the Woodlynde School as the new librarian in 2006, one of the jobs that was handed to me was to promote and coordinate the use of Recording for the Blind and Dyslexic (now Learning Ally) for our students. As a parent of a student in the school who was a candidate, I immediately saw some of the challenges with getting the students to take on the program. One of those included getting the books that students wanted to read into their hands. I knew that while the books they *needed* for schoolwork were important, if I really wanted them to buy into the technology, I needed to make it as easy as possible to access the books they might *want* to read.

One of my first moves was to start shelving my fiction by genre, making it easier for student to find the type of stories they liked, and the second was to begin to label books in our library that were available in Learning Ally. This would allow students to easily identify the books that were available for download from Learning Ally without having to ask for assistance. This was especially important with new users who were self-conscious about using Learning Ally.

With permission, I incorporated the Learning Ally logo into a simple spine label with space for the Learning Ally shelf number for the book. To further assist me with identifying and locating the books, I added catalog records for the books as well.

This was a big job at first, so I started with the most widely circulated books in the school, and searched for them in the Learning Ally catalog, then I moved to award winners and popular authors. Labeling books was a first priority, so I kept a barcode list of all labeled books and would follow up as time permitted with cataloging. When I catalog the books, I add the information into two fields. I add a simple note with Learning Ally and the shelf number. I also add a listing into the 530 tag in MARC records (additional formats available), listing Learning Ally as the source, restricted by membership and indicating the shelf number.

Now that the system is in place, I search all new books [in the Learning Ally database] as they come in for cataloging and add the fields as part of my standard cataloging procedure. If a student user selects a book that is not listed, we do a quick search for that book. If it is in the Learning Ally catalog, I immediately label the book, scan it to the cataloging list, and send the book out with the student.

The result is that Learning Ally compatible books are more visible, students are more likely to select Learning Ally books for their outside reading, and as a result are more comfortable using the technology when they need it.

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