

Mobility and Orthopedic Disabilities

6

National Data on Mobility and Orthopedic Disabilities

An orthopedic impairment is considered an education issue when it adversely affects a child's educational performance. These impairments can include congenital anomalies such as club foot or the absence of a limb. They also include impairments caused by disease such as bone tuberculosis, cerebral palsy, muscular dystrophy, juvenile rheumatoid arthritis, lupus, osteogenesis imperfecta, as well as amputations, fractures, or burns that cause contractures.

The Children's Hospital of Wisconsin estimates that each year 8,000 infants, which is approximately two of every 1,000 babies, are born with cerebral palsy (CP). In addition, nearly 1,500 preschool-age children are diagnosed with cerebral palsy (CP) annually. Currently an estimated 500,000 people in America have some form of CP. The incidence rate for muscular dystrophy for boys is one out of every 3,500 births. The Children's Hospital reports that one in every six people, a total of 43 million people, have a form of arthritis, and 70 million have joint problems. More than 300,000 children have arthritis and 70,000 to 75,000 children have juvenile rheumatoid arthritis.

The Osteogenesis Imperfecta (OI) Foundation estimates 20,000 to 50,000 people in the U.S. have OI. The Children's Hospital of Wisconsin estimates five of every 1,000 children have a curvature of the spine, scoliosis, that is serious enough to require treatment. According to the Children's Hospital of Wisconsin, approximately 70,000 Americans have spina bifida. Every day eight babies are born with spina bifida or similar birth defects.

Orthopedic Disabilities 2005-06

Age	Number of Students
3-5	225
6-11	521
12-17	486
18-21	87
Total	1,319

From the IDEA Child Count at <http://dpi.wi.gov/sped/cc-12-1-05.html>

Wisconsin Data on Mobility and Orthopedic Disabilities

In 2005-06 there were 1,319 students in Wisconsin public schools identified with orthopedic disabilities that were significant enough to interfere with the educational process. These students may require adaptive technologies, services of an occupational and/or physical therapist, and an educational aide, depending on the student's abilities and limitations.

Some of these children and many others use the services of school occupational and physical therapists. Almost 10,000 children from the ages of three to 21 receive occupational therapy. Occupational therapists (OT) use purposeful activity to facilitate a child's active participation in self-maintenance, academic and vocational pursuits, and play or leisure activities that occur in school environments. Approximately 400 OT and 100 OT assistants are employed in Wisconsin public school.

Physical therapy is a related service provided to assist children with a disabilities and enable them to benefit from special education. Physical therapy interventions are designed to enable the student to travel independently within the school environment, manage stairs, restrooms, and the cafeteria; participate in classroom activities; and maintain and change positions in the classroom. Approximately 6,158 children receive school-based physical therapy from 280 school-based physical therapists and 40 physical therapist assistants in Wisconsin public schools.

Types of Mobility and Orthopedic Disabilities

Bone Cancer

The most common type of bone cancer that affects children is osteogenic sarcoma or osteosarcoma. It usually affects the long bones in the legs or arms and affects most children after age 10. More boys are affected than girls. One theory is that the growth rate of boys is more rapid after age 10 than it is for girls. Bone cancer cells can spread to other areas, usually the lungs, but can also affect the kidneys, adrenal gland, brain, or heart.

Cerebral Palsy (CP)

Cerebral Palsy (CP) is a broad term that describes a group of brain disorders that affects the communication between the brain and the muscles. This results in permanent uncoordinated movement and posturing. The cause of CP is not always known. It occurs when there is abnormal development or damage to the areas in the brain that control movement. It is not usually diagnosed until babies are between six months to a year old because the babies have not reached developmental milestones, or their newborn reflexes have not disappeared.

More boys than girls are affected, and CP is more prevalent in African-American babies than other ethnic groups. The injury can happen before birth, during delivery, or just after birth. The effects of CP can range from mild to severe. Usually, the greater the injury to the brain, the more severe the CP. However, CP doesn't get worse over time, and most children with CP have a normal life span.

With early and ongoing treatment the effects of CP can be reduced. Many children learn to do things, using parts of their bodies they can control. Other disorders often associated with CP include seizures; respiratory problems; vision, hearing, speech problems; learning disabilities; cognitive disabilities; and bladder and bowel problems. Typically, children with CP may need physical, occupational, and speech and language therapy. There is no cure for CP. Management focuses on minimizing or preventing deformities, maximizing the child's independence, and strengthening self esteem.

For More Information:

Cerebral Palsy. Children's Hospital of Wisconsin. www.chw.org/display/PPF/DocID/22500/router.asp
Cerebral Palsy. MEDLINEplus. National Library of Medicine, National Institutes of Health. www.nlm.nih.gov/medlineplus/CerebralPalsy. National Information Center on Children and Youth with Disabilities. www.nichcy.org/pubs/factshe/fs2txt.htm#whatis
Kelker, K.A., and R. Holt. 2000. *Family Guide to Assistive Technology*. Cambridge, Mass: Brookline Books. www.brooklinebooks.com.

Congenital Limb Defects

The Children's Hospital of Wisconsin indicates congenital limb defects can involve failure of an arm, hand, fingers, leg, feet, or toes to form or to only partially form while the fetus is developing. The exact cause is not known. The most common limb defects include complete absence of a limb, failure of fingers or toes to separate, extra toes or fingers or over growth or under growth of a limb, which results in a limb larger or smaller than it should be. Accidents, injuries, and diseases also can result in amputation or deformity after birth. Treatment may involve artificial limbs, splints, braces, surgery, and rehabilitation.

For More Information:

Children's Hospital of Wisconsin. Congenital Limb Defects. www.chw.org/display/PPF/DocID/22566/router.asp

Juvenile Rheumatoid Arthritis (JRA)

Juvenile Rheumatoid Arthritis is more common in white children than in black or Asian youth. It typically affects youth between the ages of two and 16. There are more than 100 different diseases that fall under the general category of arthritis, which is one category of rheumatic diseases. JRA and other rheumatic diseases are characterized by pain, swelling, and limited movements of the joints and connective tissue. The cause of most rheumatic diseases is unknown. JRA is an autoimmune disease in which the body's immune system attacks its own healthy cells and tissue.

JRA is chronic and lasts a lifetime, but often there are periods of remission. JRA can affect bone development in children. The most common form involves four joints or less, and usually large joints such as knees are affected. Girls under the age of eight have the most incidences. There is no cure for JRA, so the goal of treatment is to maintain a normal activity level.

For More Information:

Children's Hospital of Wisconsin. *Juvenile Arthritis and Other Rheumatic Diseases*. www.chw.org/PPF/DocID/21643/router.asp
—Systemic Lupus Erythematosu. www.chw.org/display/PPF/DocID/21653/router.asp

Lupus

Lupus, like JRA, is an autoimmune disease. Like JRA, Lupus causes inflammation of and damage to the joints, tendons, and other connective tissue. It also can affect the heart, lungs, blood vessels, brain, kidneys, and skin. Children are usually affected by lupus after age 10 and rarely under age five. Children with lupus often have a significant degree of kidney involvement, which can lead to kidney failure. Both genetic and environmental factors are thought to be involved as the causes of lupus. Lupus affects more girls than boys and is more prevalent with African-Americans than with other ethnic groups.

There is no cure for lupus. Rest and naps, stress reduction, and a well-balanced diet can help. In severe cases immunosuppressive medication is used.

Muscular Dystrophy (MD)

Muscular Dystrophy is a broad term describing a genetic disorder that weakens body muscles. MD breaks down the muscle tissue and replaces it with fatty deposits. Heart problems, scoliosis, and obesity are often associated with MD. The most common form is called Duchenne's Muscular Dystrophy, which primarily affects boys, and when it does affect girls it is a much milder form. Typically boys inherit a recessive X-linked gene, but in about one-third of all cases, there is a new mutation, and it is related to genetics.

MD is usually diagnosed before age five because of weakness in the shoulders and pelvic muscles. Preschool-aged children with MD tend to have clumsy movement, frequently fall or trip, and have difficulty going up stairs, jumping or hopping. They also tend to walk on tip toes. Children with MD often have trouble getting from a sitting position on the floor to their feet. They get on their hands and knees and then walk the hands up their legs to brace themselves as they get to a standing position. When these children are lifted under their arms, their shoulders fold upward. They often have large calf muscles because fatty deposits have replaced the muscle tissue.

There is no known cure for MD that will stop the weakening of the muscles. The goal of treatment is to prevent deformity and allow the youth to function as independently as possible. Walking and sitting become more difficult as these children mature, and most need to use wheelchairs by about age 12 because their leg muscles are too weak to allow them to walk. In the late teens or early twenties, youth with MD often begin to have problems with their hearts or lungs.

For More Information:

Children's Hospital of Wisconsin. Muscular Dystrophy. www.chw.org/display/PPF/DocID/22517/router.asp
Duchenne/Becker Muscular Dystrophy. Center for Disease Control and Prevention, U.S. Department of Health and Human Services. www.cdc.gov/ncbddd/duchenne/resources.htm

Osteogenesis Imperfecta (OI)

OI is often called brittle bone disease. It is a genetic disorder in which the bones are so fragile they break very easily. There are four forms of OI. Children with the most common form have a family history of OI. The children have normal height, many have curvature of the spine, the whites of their eyes look blue, and they often have dental problems. Most begin to have severe hearing loss beginning in their 20s or 30s. These children experience most of their bone fractures before puberty.

There is no known cure or treatment that will prevent the fractures. The goal of treatment is to prevent deformities and to help children function as independently as possible. Sometimes rods are put in the long bones to help stabilize them. In 2006 the Osteogenesis Imperfecta Foundation distributed books to every public library in Wisconsin to help raise awareness about OI.

For More Information:

Children's Hospital of Wisconsin. Osteogenesis Imperfecta. www.chw.org/display/PPF/DocID/22567/router.asp
Osteogenesis Imperfecta Foundation. www.oif.org

Scoliosis

Scoliosis causes a curvature of the spine. The curvature can involve a turn toward either side or a rotation of the vertebrae. More girls have scoliosis than do boys. Congenital scoliosis occurs once in every 1,000 births. Scoliosis also can be caused by legs that are different lengths, injury, infection, or tumors.

Children with significant curvatures of the spine may have shoulders, shoulder blades, or hips of different heights. Their heads may not be centered with the rest of their bodies, or their arms are different lengths when they are standing. Back and leg pain are associated with scoliosis, as are bladder or bowel problems. Left untreated, scoliosis can affect the heart or lungs. Some children require braces or surgery to correct the curvature.

For More Information:

Children's Hospital of Wisconsin. Scoliosis. www.chw.org/display/PPF/DocID/22950/router.asp

Spina Bifida

According to the Children's Hospital of Wisconsin, spina bifida is the most common permanently disabling birth defect. Spina bifida is a defect that occurs in the first month of pregnancy, in which the spinal column doesn't close completely. The incidence rate of spina bifida has decreased, but it may be the result of under reporting and terminated pregnancies, rather than an actual decrease in incidences. About 15 to 20 babies are born with spina bifida in Wisconsin each year.

Most people with spina bifida lead normal lives, but many have special challenges. Most will walk but may need braces or use wheelchairs to go long distances. Most will need catheterization for incontinence. In the most severe form, 80 to 90 percent of the babies have hydrocephalus, fluid on the brain, and need to have a shunt inserted to help drain the fluid. Many of these children will have learning disabilities but normal intelligence. Other conditions that often are caused by spina bifida are paralysis and problems with bowel control. Typically babies have surgery to prevent infection before leaving a hospital, if their back is open or their spinal column is exposed. Social and sexual issues sometimes are involved as the child matures, as are depression.

There are three forms of spina bifida. The cause is not known in approximately 30 percent of the cases. Genetics and environment are thought to play a role. The risk can be reduced by 70 percent for all neural tube defects, if women take 400 mcg of folic acid daily before becoming pregnant. Women who have had one pregnancy affected by spina bifida, or have a history of it in the family, are at risk with future pregnancies. Other risk factors include mothers who are insulin-dependent because of diabetes, use anti-seizure medication, are obese, experience high temperatures in early pregnancy or have hot tub use, and low economic status. Hispanic mothers have the highest rates of babies born with spina bifida. Asian mothers have the lowest risk.

Barriers to Services

Non-accessible buildings are the biggest barrier for youth with mobility disorders. Even if these youth can get into the building, often there are other physical barriers that prevent them from using the library independently.

Typical problems with building accessibility even when the library has an accessible entrance, include having non-accessible bathrooms, overcrowding that causes book stacks and furniture to be placed too close together restricting the required “accessible path,” and having activities on a floor or level that is not accessible to people who use wheelchairs unless they go outside and around the building. A few libraries do not have an accessible service desk area. One of the easiest issues to resolve regarding accessibility inside the library is to replace round doorknobs with lever-type handles.

An accessible path should be maintained throughout the building that is no less than 36 inches wide, with 42 inches preferred. Library book stacks should be no less than 36 inches apart, but 42 inches is preferred. Book stacks that form aisles should not be attached to the wall at the end because this creates a “dead end” and forces people who are using a wheelchair to back up to get out again. The minimum turn radius at the end of book stacks should be 36 inches so people using wheelchairs can make the turn at the end of stacks or a minimum turning radius of 60 inches at the end of a book stack if the person is going to have to turn the wheelchair completely around to go back out of the stack or other narrow area. The maximum height of computer workstations is 36 inches to make them accessible to patrons who use wheelchairs.

Strategies for Success

Collaboration

Collaboration is key to all the strategies for success. The local school district’s occupational or physical therapists, or those who work for the area CESA may be able to help librarians with general questions about adapting programs and improving accessibility for youth who have limitations on their mobility. Local chapters

Accessibility Features in Public Libraries

In 2000 DLTCI included questions related to accessible workstation features on the *Public Library Annual Report*, and a follow-up was done in 2005.

Self-reported data from the libraries and regional library systems in 2005 indicates:

- Ninety percent of public library buildings have accessible entrances.
- Eighty-six percent are completely accessible throughout the building.
- Almost 80 percent of public libraries have a computer workstation accessible to people who use wheelchairs.
- Thirty-seven percent have a 19-inch or larger monitor.
- Forty percent have an alternative input device to a mouse, such as a trackball.
- Twenty percent have software that enlarges the text such as ZoomText or screen readers such as JAWS or Window-Eyes.
- Thirty-nine percent have a keyboard cord long enough to place on the tray of a wheelchair.
- Sixteen percent have a keyboard with oversized keys.
- Twenty-one percent have web pages that are accessible to screen readers or browsers.

from DLTCI *Public Library Annual Reports* for 2000 and 2005, and annual data self reported by libraries.

For More Information:

Children’s Hospital of Wisconsin. Spina Bifida.

www.chw.org/display/PPF/DocID/22505/router.asp

of agencies such as Easter Seals, United Cerebral Palsy, and the March of Dimes also may be willing to partner with the public library on various projects.

Planning

Public librarians should turn first to the parents of children who have mobility and orthopedic disabilities to find out what would be most helpful in meeting their needs at the library.

Staff Training

All staff should be familiar with assisting people who use wheelchairs, walkers, canes, or other mobility aides. All public libraries should periodically review the requirements of the Americans with Disabilities Act (ADA) or attend a refresher training workshop on the ADA.

Diversified Collections and Services

Libraries should assure that outdated materials on mobility issues are removed from the collection and new materials, especially parent resources, are purchased as part of routine collection development.

If the library has in-house toys or circulates educational toys, an effort should be made to assure that some of these toys can be used by children who have limited mobility. The Lekotek National Center creates an annual list of recommended toys for children with disabilities, the *Able Play Toy Guide*. The guide is available on their web site and a portion of it is also available at Toys-R-Us stores. Computer access is extremely important to students with limited mobility.

Adapting Story Times

Be pro-active in introducing children who have limited mobility to the other children at programs. Ask the child's parent or attendant to help explain what the child can do without assistance and the things the child may need help doing. Answer questions the children may have in a straight forward and honest way. If the child is comfortable answering the questions, allow him to do so.

Plan activities that involve a way for children with limited mobility to participate and try to capitalize on things the child can do. For example if the child does not have use of her arms or hands but can easily use her legs and feet, use all body movement instead of finger plays as transitional activities. If the child has use of one hand, do finger plays that can be done with one hand. Instead of asking children to raise their hand or clap their hands as a way to respond to a question, ask them to tap their feet or toes. When severe disabilities are involved, it may be necessary to have children respond by smiling or blinking their eyes. Use any movement the child can control. If the child really does not have the ability to control any body part voluntarily, ask the parent or attendant to move the child's limbs or body for her.

If the physical limitations are severe enough to limit speech, use any speech tools the child brings with him to the program—manual speech board, computerized speech, or recorded messages. As explained in the chapter in this publication on Speech and Language, the library can purchase an inexpensive speech tool, such as a pocket-talker and record the refrain for a story, finger plays, or songs for the day. The child can then participate by touching a button at the appropriate time. Be sure to record every day conversational phrases as well—hello, thank you, good-bye, or perhaps the sound of clapping and cheering.

If the program involves physical movement, dance, or games, and it is possible to have one of the participating children move the child in her wheelchair, ask for a volunteer to be a special buddy for the child with the disability and explain how the chair should be handled. The child is likely to feel as if he is more a part of the group if he is interacting directly with the other children instead of having the assistance of an adult.

Accessible Buildings, Equipment, and Outreach

According to self-reported information by public libraries and regional systems in 2006, there are approximately 40 libraries in Wisconsin with non-accessible entrances. Many others have accessibility problems

Greendale Public Library Helps Parents of Children with Special Needs Balance Their Lives

The Greendale Public Library used LSTA funding in 2001 for a collaborative project intended to help children who have special needs and their families. The library partnered with the Greendale Public Schools, the Greendale Health Department, and the Special Needs Family Center at the Children's Hospital of Wisconsin. These groups helped identify materials for the library's collection.

They also co-sponsored a community workshop called "Children with Special Needs: Adults Balancing Family, Personal, and Classroom Lives." The workshop focused on the unique concerns families face when they have a child who has a special need. All the participating agencies helped promote the program with their clients and the families. The workshop was attended by parents, teachers, library board members, school administrators, social workers, day care providers, public health nurses, and public library staff. The schools indicated it was the best attended program they had ever sponsored for families of children with special needs in the district. As a result of interest expressed at the workshop, the Greendale Health Department volunteered to host parent support groups tailored to the particular special needs of the children involved.

once patrons come in the front door. Some do not have accessible bathrooms. Others have a meeting room on a level other than the main floor, and there is not an elevator in the building. Many are overcrowded, and patrons who use wheelchairs can't move easily through the library. Some libraries have stacks that are mounted to the walls, which does not allow for the required turning radius needed by people who use wheelchairs.

It is extremely important that children who walk with braces or crutches, or use wheelchairs be able to access all public library materials and programs. All public library programs should be offered in accessible locations, even if that means moving to a location other than the library.

Youth who have limited use of their hands must have access to library computers and other technologies available to everyone in the community.

Adaptive Technologies

The Internet can be an essential lifeline for many people who have severe limitations on their mobility. Using a computer can give people with limited mobility a great deal of independence. They can keep up with the news, research areas of interest to them, keep in touch with families and friends, and through chat continue to meet other new people who share their interests and concerns.

Using a mouse or keyboard is impossible for people who have no control of their arms, hands, and fingers, or who do not have them. Some of the adaptive devices these people use to access computers are not tools that a public library can provide. Items such as head wands, mouth sticks, sip and puff controls, switches, foot controls, voice recognition software, software that responds to where someone is looking on a computer screen, or software that is controlled by brain waves must be customized for the individual, which is not practical in a public library environment and often require occupation therapists or other professionals to help the individual get these tools adjusted correctly.

Some people with cerebral palsy may have difficulty using a mouse because their arm movements are unpredictable and jerky. They often can use an adapted keyboard. Some people find a feature called "sticky keys" helpful. Sticky keys is an accessibility feature that is an alternative to holding down two or more keys at the same time. This allows input with fewer keystrokes. Sticky keys have function keys that remain active until another key is press.

Another accessibility feature is "slow keys" that adjusts the amount of time between when a key is pressed and when it is activated. This can be extremely useful for people with motor impairments that make it difficult for them to target keys accurately or who have unpredictable motions in their hands or arms. Some people find the use of a keyboard that has dividers between the keys helpful, because it helps them hit only one key at a time.

Adams County Used LSTA Funds to Purchase Adaptive Equipment for Children with Limited Mobility

In 2002 Adams County Library partnered with Adams-Friendship Area Schools Early Childhood Program, the Adams County Birth-to-3 Program, the Family Resource Center, Head Start, and CESA 5 Assistive Technology Specialist on an LSTA grant to serve children with disabilities, including those with mobility limitations. In addition to a large monitor, the adapted workstation purchased as part of the grant included a touch screen, a color printer, a large-key keyboard, and a large "jelly bean" switch. The switch is used by children who have extremely limited control of their hands or feet. The workstation also includes ZoomText to magnify the print on the screen. Eight educational software programs designed to work with the touch screen were purchased in addition to regular programs. Educational toys also were purchased as part of the project. Some of these toys were designed to stimulate visual and auditory skills of children, others fostered eye-hand coordination. Other purchases included puppet and book sets, recorded book sets, and parent resources related to various disabilities.

The library hosted staff training by the CESA 5 Assistive Technology Specialist and Cheri Riehle, an occupational specialist in Waukesha. The training was held on a school in-service day to allow school staff to attend. The library closed to assure all staff could attend the training, and many librarians from the South Central Library System also attended. One result of the project was that the school district created a Parent Support Group for parents of children with special needs. The group met with the school psychologist and social worker. Each month the library staff brought new parent resources to the group's meeting.

Eastern Shores Library System Purchases Adaptive Equipment for Youth with Mobility Disabilities

The Eastern Shores Library System used LSTA funding in 2002 to purchase adaptive equipment for its member libraries to meet the needs of youth with mobility disorders. This project was the third year of a statewide focus on youth with special needs. The previous year the system had provided training on assistive technology in cooperation with the technology consultant from CESA 7, and the project helped libraries make at least one of their computer workstations accessible. The new project required member libraries to work with a local partner to determine what additional equipment and technologies were needed in their community. The system sponsored two field trips to the Lab Resources in Pewaukee, a vendor that supplies assistive technology products. The visits allowed the librarians to try out and ask questions about several types of equipment. The system then purchased the equipment, installed it for the libraries, and provided training. The equipment included software to enlarge text on a computer screen, various types of trackballs, touch screen monitors, headphones, Big Red Switch, Intellikeys, and InteliTalk II, WYNN Readers, Write Outloud, and various Living Books for young readers.

Using a trackball is easier for some people to use than a mouse as an input device. A user rolls a ball in a socket the thumb or palm of the hand to move the cursor. There are buttons around the ball that can be used as function keys. Many portable computers now use a modified trackball instead of a mouse. Some students with limited arm and hand control may find a joy stick easier to use than a mouse or trackball.

Minimum Requirements for an Accessible Workstation

To accommodate people with mobility limitations, DLTCCL recommends as a minimum that public libraries have the following types of equipment on their workstations. Typically all the adaptive technologies are not loaded on one computer. These include:

- workstation tables or carts accessible to people in wheelchairs and preferably adjustable
- an alternate input device such as a trackball or joy stick
- keyboard and mouse cords long enough to allow a patron to put the keyboard and/or mouse or trackball on a wheelchair tray
- 19-inch or larger monitor
- software to enlarge text, such as ZoomText
- software to read the screen such as JAWS or Window Eyes

Marketing

Building accessibility is a prerequisite to marketing efforts. If children in wheelchairs can't get into the public library, no amount of marketing is going to be effective. Parent support groups for children who have specific types of mobility disabilities may have newsletters and be willing to include information from public libraries. Occupational and physical therapists who work with young children in Birth to 3 programs and with students in schools may be willing to distribute information about library services to the families with which they work.

All adaptive technologies and tools and mobility aides should be visible and available for self service when this is practical. When adaptive technologies are available on given computer workstations, they should be clearly indicated. Basic instructions should be available at the workstation, and there should be an indication of the staff person or service desk from which the person can request assistance.

Local chapters of agencies such as Easter Seals, Muscular Dystrophy, and United Cerebral Palsy may be willing to distribute library information to their clients. They may be willing to allow public libraries to set up information tables at their family events.

Some libraries are located in communities with hospitals, specialized clinics, or camps that serve youth with mobility disabilities. Check with these facilities to see if there is a role that the library could play on a regular basis. It might be possible to extend the summer reading program, Children's or Teen Book Week, or National Library Week activities to these organizations. It may be possible to work with these facilities to co-sponsor performances or visits by performers who are performing at the library. Let them know which performers will be in town and see if a discount can be worked out to have a second program on site for the children at the facilities.

Some day care centers and home providers specialize in care for children with mobility limitations or welcome and mainstream these children into their regular programs. There are often respite care providers as well who take children on the weekends to give the family a break from the routines needed to care for children who have significant health problems. If the library is offering services to day care providers, include information on library services to these providers and check to see if there is something the library can offer that would meet the needs of the children in their care.

Getting Started with Little Money or Time: Mobility and Orthopedic Services

Collaboration

- An important component of all the strategies is collaboration. Potential collaborating agencies for serving youth who have mobility disorders are:
 - Birth to 3 programs
 - Local school district or area CESA staff
 - Local chapters of Easter Seals, March of Dimes, and United Cerebral Palsy
- Invite local chapters to hold their meetings periodically at the library.

Planning

- Include parents of children who have physical disabilities in planning sessions or talk to them individually to find out their child's needs.
- Include teens who have mobility or orthopedic disorders in planning processes.

Staff Training

- Review the ADA specifications for physical accessibility of public libraries and evaluate how well the library meets them.
- Walk through the library or sit in a wheelchair and check to see if there is a continuous path that makes it possible to get to all areas of the library.

Diversified Collections and Services

- Weed the collection of dated materials on physical and mobility disabilities.
- Purchase new materials in these areas as part of the routine budget expenditures.

Accessible Buildings, Equipment, and Outreach

- Review the ADA specifications for physical accessibility of public libraries and evaluate how well the library meets them.
- Walk through the library or sit in a wheelchair and check to see if there is a continuous path that makes it possible to get to all areas of the library.
- Review emergency evacuation procedures to be sure they take into account people who might be using wheelchairs or who can't move quickly.
- If the community is aware of a child or teen involved in a procedure that involves extensive recovery time at home, check with the family to see if home delivery of materials for the youth or care givers would be helpful. Arrange for a volunteer to pick and deliver the materials. Often there is a group of volunteers helping the family in these situations, and one of them might be willing to work with the library to get materials back and forth.

Marketing

- Send information about library services or materials that may be of specific interest to support groups and ask them to include the information in their newsletters.
- If the community has an event that benefits children with mobility disorders, check to see if the library can set up an information booth at the event or participate in some way.
- If a local group is raising funds to help offset medical expenses for a child or teen who has had a disorder or accident resulting in limited mobility, try to find a way for the library to be involved. Allow a collection container to be placed at the circulation desk, if it is consistent with library policy.

Observe these Awareness Events:

January

Birth Defect Prevention Month sponsored by the March of Dimes www.marchofdimes.com

February

National Burn Awareness Week sponsored by the American Burn Association www.shrinershq.org

March

Healthy Baby Month sponsored by the March of Dimes www.marchofdimes.com

April

WalkAmerica, sponsored by the March of Dimes (varies by community but usually toward the end of April)
www.walkamerica.org

May

National Alcohol and Other Drug Related Birth Defects Week sponsored by Screening for Mental Health Inc.
www.NationalAlcoholScreeningDay.org

National Occupational Therapy Month sponsored by the American Occupational Therapy Association.
www.aota.org

October

National Physical Therapy Month sponsored by the American Physical Therapy Association www.apta.org

National Spina Bifida Awareness Month sponsored by Spina Bifida Association www.sbaa.org

Fire Prevention Week www.nfpa.org/fpw

National Lupus Awareness Month sponsored by Lupus Foundation of America www.lupus.org

November

Pre-maturity Awareness Month sponsored by the March of Dimes
www.marchofdimes.com

Resources

Print Resources

ABILITY Magazine www.abilitymagazine.com

This publication brings disabilities into the mainstream with celebrity interviews and other information.

New Mobility www.newmobility.com

The focus of this publication is on the full participation of users of wheelchairs in work, love, sex, art, recreation, and travel.

Paraplegia News www.pn-magazine.com/pnnews/

This magazine is for people with mobility impairments, covering all the latest news.

Rubin, R. J. 2001 *Planning for Library Services to People with Disabilities*. ASCLA Changing Horizons Series. Chicago: American Library Association.

Special Living Magazine www.SpecialLiving.com

This is a new quarterly magazine for people with physical disabilities.

WEMagazine www.wemedia.com

WEMagazine is a publication with an innovative approach to cross-disability issues; it is available on audiotape.

National Resources

Adaptive Switches Laboratories www.asl-inc.com

This is a source for adaptive computer switches.

American Association for People with Disabilities (AAPD) www.aapd-dc.org

AAPD is a national organization that represents Americans with disabilities to achieve the goal of full inclusion.

American Epilepsy Society www.aesnet.org/

The society is devoted to the study and treatment of epilepsy.

American Library Association www.ala.org

The American Library Association is the national association for all librarians.

Association of Specialized and Cooperative Library Agencies (ASCLA) www.ala.org/ascla/

Libraries Serving Special Populations (LSSPS) www.ala.org/ascla/lssps/

Planning Services to People with Disabilities (published by ASCLA) www.ala.org/ascla/

Brave Kids www.bravekids.org

This site offers help for children with chronic, life-threatening illnesses or disabilities.

Closing the Gap www.closingthegap.com

This organization is a leader in adaptive technologies and sponsors an annual conference in Minneapolis.

Council for Exceptional Children www.cec.sped.org

The council is dedicated to improving educational outcomes for children with disabilities.

Division for Physical and Health Disabilities (DPHD)

www.cec.sped.org/Content/NavigationMenu/AboutCEC/Communities/Divisions/#13

Disability Resources on the Internet www.disabilityresources.org

This site promotes and improves awareness, availability, and accessibility information for people with disabilities.

Easter Seals www.easterseals.com

Easter Seals provides services to ensure that all people with disabilities have equal opportunity to live, learn, work, and play.

ERIC Clearinghouse on Disabilities and Gifted Education (ERIC EC) www.icdri.org/Education/eric.htm

ERIC focuses on professional literature, information, and resources related individuals who have disabilities.

Family Voices www.familyvoices.org

Family Voices is a network that provides information about youth who have special needs.

Genetic Alliance www.geneticalliance.org

This coalition of parents, professionals, and organizations works for everyone impacted by genetic conditions.

Georgia Institute of Technology www.gatech.edu

The Georgia Institute of Technology hosts an assistive technology program.

College of Architecture and the College of Architecture Technology (CATEA) www.coa.gatech.edu

Goodwill Industries International www.goodwill.org

Goodwill is a network of community-based organizations that serves people with disabilities.

Graphic Artist Guild www.gag.org/resources/das

This online resource includes twelve symbol designs to promote and publicize accessibility.

Great Lakes ADA and Accessible IT Center, Chicago, IL www.adagreatlakes.org

This is a resource center on the Americans with Disabilities Act (ADA)

Lekotek National Center www.lekotek.org

Lekotek National Center is a national resource on toys and play for children with special needs.

Able Play Toy Guide www.ableplay.org/search.asp.

Toys R Us Toy Guide for Differently Abled Kids www.lekotek.org/services/toyind/toysrus.html

Library Media & PR www.ssdesign.com/librarypr/

This site includes two helpful resources—Disabilities Clip Art and the tip sheet, “Serving Patrons Who Have Limited Mobility.”

March of Dimes www.modimes.org

March of Dimes provides information about pregnancy, birth defects, and children's health issues. The site includes information on birth defects and genetic conditions including cerebral palsy, club foot, and spina bifida.

Massachusetts Institute of Technology

The Laboratory for Computer Science within MIT manages the World Wide Web Consortium (W3) dedicated to web accessibility.

World Wide Web Consortium (W3) www.w3.org

W3 pursues accessibility of the web through technology, guidelines, tools, education, outreach, and research.

MUMS-National Parent to Parent Network www.netnet.net/mums/

MUMS is a parent-to-parent support network for parents of children with specific disabilities or problems.

Muscular Dystrophy Association (MDA) www.mdausa.org

MDA is a health agency that provides research and services for families affected by neuromuscular diseases.

National Association of Protection and Advocacy Systems (NAPAS) www.napas.org

NAPAS is an umbrella organization for the federally mandated system in each state that provides protection of the rights of persons with disabilities. In Wisconsin, the Client Assistance Program (CAP) within the Department of Agriculture's Trade and Consumer Protection unit is the agency associated with this system.

National Birth Defects Prevention Network. www.nbdpn.org

This is a national network of programs for birth defects surveillance and research.

National Center of Youth With Disabilities www.peds.umn.edu

The focus of this center is on adolescents with chronic illnesses and disabilities.

National Council on Disabilities. www.ncd.gov

National Dissemination Center on Children and Youth with Disabilities (NICHCY) www.nichcy.org

NICHCY provides information on disabilities and disability-related issues.

National Easter Seals Society www.easter-seals.org

Easter Seals helps more than a million people with disabilities gain greater independence each year. The site includes a helpful tip sheet, *Disability Etiquette*.

National Information Center for Children and Youth with Disabilities (NICHCY) www.nichcy.org

This is a clearinghouse on disabilities and related issues involving children birth to age 22.

National Institutes of Health

National Institute of Arthritis, Musculoskeletal, and Skin Disorders

National Institute of Neurological Disorders and Stroke (NINDS) www.ninds.nih.gov

National Library of Medicine www.nlm.nih.gov

Medlineplus www.nlm.nih.gov/medlineplus

MEDLINEplus is an online service of the National Library of Medicine and provides information on various disorders including cerebral palsy.

National Library Services to the Blind and Physically Handicapped (NLS) www.loc.gov/nls/

NLS is a service of the Library of Congress and provides free recorded materials to people who are blind.

Library Information Service to Individuals with Disabilities. www.loc.gov/nls/reference/

National Organization on Disability (NOD) www.nod.org

NOD promotes full and equal participation of American with disabilities in all aspects of life.

National Rehabilitation Information Center (NARIC) www.naric.com

This information center focuses on disabilities and rehabilitation.

National Spinal Cord Injury Association www.spinalcord.org

The association works to develop better programs and services and advocates for disabled people.

North Carolina State University (NCSU) www.ncsu.edu

NCSU is known for its focus on universal design.

College of Design www.design.ncsu.edu

Center for Universal Design www.design.ncsu.edu/cud

Center for Inclusive Design and Environmental Access www.udeducation.org

Osteogenesis Imperfecta Foundation (O.I.) www.oif.org

The foundation strives to improve the lives of people with O.I.

Parent Advocacy Coalition for Educational Rights (PACER) Center www.pacer.org

PACER is an advocacy group for parents and families of children with disabilities.

Scoliosis Research Society www.srs.org

Seattle Children's Hospital and Medical Center. www.chmc.org

Sibling Support Project www.chmc.org/departmt/sibsupp

The project is dedicated to the interests of brothers and sisters of people with special health or developmental needs.

Spina Bifida Association of America www.sbaa.org

The association supports research and provides information on Spina Bifida.

SPINAabilities www.sbaa.org/site/c.gplLKXOEJqG/b.2021223/k.9AF6/Spinabilities.htm

United Cerebral Palsy (UCP) www.ucpa.org

UCP advances the independence, productivity, and full citizenship of people with cerebral palsy.

U.S. Department of Education www.ed.gov

The U.S. Department of Education promotes excellence in education in the U.S.

Clearinghouse on Disability Information, Office of Special Education and Rehabilitative Services

- www.ed.gov/offices/OSERS/
 National Institute on Disability and Rehabilitation Research (NIDRR) www.ed.gov/offices/OSERS/NIDRR/
- U.S. Department of Health and Human Services** www.dhhs.gov
 Centers for Disease Control www.cdc.gov
 National Center for Health Statistics www.cdc.gov/nchs
 National Center on Birth Defects and Developmental Disabilities (NCBDDD) www.cdc.gov/ncbddd
 The center provides information on birth defects and spina bifida.
 Folic Acid www.cdc.gov/ncbddd/folicacid/index.htm
 National Institutes of Health www.nih.gov
 National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) www.niams.nih.gov
 National Institute of Neurological Disorders and Stroke www.ninds.nih.gov
 Office of Rare Diseases www.cancer.gov/cancerinfo/
- University of Washington** www.washington.edu
 DO-IT (Disabilities, Opportunities, Internet Working and Technology) www.washington.edu/doiit/
 A program of the University of Washington with funding by the National Science Foundation, the state of Washington, and the U.S. Department of Education, DO-IT provides many services promoting the use of electronic and information technology to maximize independence.
- Utah State University** www.usu.edu
 Utah State hosts a Center for Persons with Disabilities.
 Web Accessibility in Mind (Webaim) www.webaim.org/articles/
 Webaim covers web page accessibility issues for people with limited mobility or control of their arms and hands.
- VSA Arts (formerly Very Special Arts)** www.vsarts.org/info/index.html
 VSA Arts provides programs in creative arts for individuals with physical and mental disabilities.
Access and Opportunities: A Guide to Disability 2000
www.vsarts.org/bestpractices/dag/language/suggestions.html
VSA Arts' Disability Awareness Guide 2001. www.vsarts.org/bestpractices/dag/index.html

Wisconsin Resources

- Camp Needlepoint and Camp Daypoint** www.childrenwithdiabetes.com/camps/d_07_2d0.htm
 These camps use the YMCA facilities in Hudson, Wisconsin, and are designed for youth who have insulin-dependent diabetes. The program is sponsored by the American Diabetes Association.
- Cerebral Palsy of Mideast Wisconsin** (920) 261-1895
 With offices in Oshkosh and Wautoma, this organization strives to improve life for persons with CP.
- Children's Hospital of Wisconsin** www.chw.org
 There are currently three Children's Hospitals located in Kenosha, Milwaukee (North Shore), and Neenah.
- Easter Seals Wisconsin** www.wi-easterseals.org
 Easter Seals offers respite programs, including after school, weekend, and summer programs, and community outings.
 Kindcare http://wi-se.easterseals.com/site/PageServer?pagename=WISE_after-School_respite-programs
 Camp Wawbeek, a camping experience for youth with physical disabilities, located near Wisconsin Dells.
- Epilepsy Foundation** www.epilepsyfoundationsewi.org
 Camp Phoenix www.epilepsyfoundationsewi.org/camp/
- Family Voices of Wisconsin** www.wfv.org/fv/
 Family Voices advocates for health care reform as a way to address the issues of youth with special needs.
- Fishing Has No Boundaries** www.fhnbinc.org
 The organization provides specialized adaptive equipment to people who have disabilities who want to fish and offers special programs for youth.
- Goodwill-Wisconsin Chapters** www.goodwill.org/states/wi/
 Goodwill Industries of South Central Wisconsin, Inc., Madison
 Goodwill Industries of Northern Wisconsin and Upper Michigan, Inc., Marinette
 Goodwill Industries of North Central Wisconsin, Inc., Menasha. www.goodwillncw.org
 Goodwill Industries of Southeastern Wisconsin, Inc., Milwaukee www.goodwillsew.com
- March of Dimes-Capitol of Wisconsin Chapter** www.marchofdimes.com
 This is a chapter of the national organization. Other chapters in Wisconsin include:
 March of Dimes-Great Northern Lakes Chapter, Green Bay
 March of Dimes-Southeastern Chapter, Wauwatosa
- Opportunity Inc.** (formerly UCP of Northcentral Wisconsin, Wausau) www.balancinglives.org
 Opportunity Inc. fosters independence and productivity for individuals with disabilities.
- One Step at a Time Camp** www.onestepcamp.org
 This is a summer camp experience for youth with cancer.
- Respite Care Association of Wisconsin** www.respitecarewi.org
 This association identifies local agencies that offer respite for caregivers and families.
- Special Touch Ministry** www.specialtouch.org
 This is a Christian camping experience for people ages 10 and up who have mental or physical disabilities in Waupaca.
 Wisconsin Summer Get Away www.specialtouch.org/getaways/wisconsin.htm

Spina Bifida Association of Wisconsin <http://sbawi.org/>

The association offers information and assistance to Wisconsin residents with spina bifida.

Spinal Cord Injury-Southeast Wisconsin www.nsciagmac.org

This organization provides numerous services to disabled individuals.

Society's Assets www.sai-inc.org/800/index.htm

This association strives to ensure all persons with disabilities to live and function as independently as possible. It has offices in Elkhorn, Kenosha, Middleton, Racine.

United Cerebral Palsy-Wisconsin www.ucpa.org

(NOTE: UCP Wisconsin is operated by the Eau Claire chapter)

UCP of Greater Dane County, Madison www.ucpdane.org

UCP of Southeastern Wisconsin, Milwaukee www.ucpsew.org

UCP of West Central Wisconsin, Eau Claire www.ucpa.org

University of Wisconsin-LaCrosse www.uwlax.edu

UW-LaCrosse offers the Outdoor Connection Summer Adventure Day Camp.

www.uwlax.edu/activeandhealthylifestyles/UWL%20Outdoor%20Connection.htm

University of Wisconsin-Madison

College of Engineering www.engr.wisc.edu

Trace Research and Development Center www.trace.wisc.edu

The center works on ways to standardize information and make telecommunications systems more accessible.

Waisman Center www.waisman.wisc.edu

The institution is both a research and service center dealing with children who have special needs.

"Children with Spina Bifida: A Resource Page for Parents" www.waisman.wisc.edu/~rowley/sb-kids/

Early Intervention Program www.waisman.wisc.edu/cedd/ecfr.html

Family Village www.familyvillage.wisc.edu

This is an online service of the Waisman Center at UW-Madison.

Spina Bifida www.familyvillage.wisc.edu/lib_spin.htm

Parent Projects www.waisman.wisc.edu/earlyint/

The Spina Bifida Action Coalition—SBAC Web Site www.waisman.wisc.edu/~rowley/sb-kids/sbac/

Welcoming Babies with Spina Bifida www.waisman.wisc.edu/~rowley/sb-kids/wbwsb.htmlx

The Yellow Ribbon Campaign for Spina Bifida Awareness

www.waisman.wisc.edu/~rowley/sb-kids/sb-awareness.html

University of Wisconsin-Stout www.uwstout.edu

UW-Stout has a Vocational Rehabilitation Institute and Service Center that offers assessment and assistive technology

Stout Vocational Rehabilitation Institute's Service Center (SVRI) www.svri.uwstout.edu/services/index.htm

University of Wisconsin-Whitewater www.uww.edu

UW-Whitewater offers a summer transitional camp for high school students with disabilities.

My Future, My Life www.uww.edu/conteduc/camps/myfuturemylife.php

Warhawk Wheelchair Camp—Wheelchair Sport Camp, and Warhawk Basketball Camp

www.uwlax.edu/activeandhealthylifestyles/warhawk%20wheelchair%20camps.htm

VSA of Wisconsin www.vsawis.org

VSA works to expand the capabilities, confidence and quality of life for children and adults with disabilities.

Early Childhood www.vsawis.org/ec.htm

Wheel Chair Recycling Program www.wrp.org

This program recycles mobility devices, refurbishing and distributing them to people who cannot afford to purchase. There are offices in Madison and Milwaukee.

Wisconsin Assistive Technology Initiative (WATI) www.wati.org

WATI is a statewide project to make assistive technology and services more available to children with disabilities. WATI's newsletter is *The Monitor*.

Wisconsin Child Care Resource and Referral Network www.wisconsinccrr.org

This network of 16 community-based CCRR agencies offers leadership to create inclusive child care.

Wisconsin Council on Physical Disabilities www.pdcouncil.state.wi.us

The council develops and implements plans or services to people with physical disabilities.

Wisconsin Cystic Fibrosis www.cff.org/wisconsin.htm

This organization provides information and support to families affected by Cystic Fibrosis.

Wisconsin Department of Health and Family Services <http://dhfs.wisconsin.gov/>

DHFS provides social services to individuals and children who has a significant orthopedic or mobility disability.

Assistive Technology Program (WisTech) <http://dhfs.wisconsin.gov/Disabilities/Physical/assistive.htm>

Birth Defects Prevention and Surveillance Program

http://dhfs.wisconsin.gov/DPH_BFCH/cshcn/bdsdesc/bdpsystem.htm

Birth to 3 <http://dhfs.wisconsin.gov/bdds/birthto3>

Governor's Committee for People with Disabilities(GCPD)

<http://dhfs.wisconsin.gov/Disabilities/Physical/gcpd.htm>

This committee advises on ways to improve employment opportunities for people with all disabilities.

Katie Beckett Program <http://dhfs.wisconsin.gov/bdds/kbp/index.htm>

This program helps certain children with long term disabilities or complex medical needs living at home.

Office for Persons with Physical Disabilities (OPPD) <http://dhfs.wisconsin.gov/Disabilities/Physical/oppd.htm>
Disability Resource Centers <http://dhfs.wisconsin.gov/Disabilities/Physical/centers.htm>

Eight pilot counties offer these “one-stop shopping” centers.

Programs for Children with Special Health Care Needs http://dhfs.wisconsin.gov/DPH_BFCH/cshcn/

This unit identifies system barriers and provides leadership for people with physical disabilities

Spinal Cord Injury Project, Office for Persons with Physical Disabilities

<http://dhfs.state.wi.us/Disabilities/Physical/SCI.HTM>

Wisconsin Assistive Technology Program (WisTech) <http://dhfs.wisconsin.gov/disabilities/wistech/index.htm>

Independent living centers provide information and access to assistive technology as part of the WisTech.

Wisconsin First Step http://dhfs.wisconsin.gov/DPH_BFCH/schen/CntrsFrstStep.htm and

www.specialneedsfamilycenter.org/firststep.htm

This site serves as the information and referral hotline for Children With Special Health Care Needs (CSHCN). CSHCN centers in Wisconsin include:

Northern Regional CSHCN Regional Center, Rhinelander

Northeastern CSHCN Regional Center, Green Bay

Southern CSHCN Regional Center, Madison

Southeastern CSHCN Regional Center, Milwaukee

Western CSHCN Regional Center, Chippewa Falls

Wisconsin Department of Public Instruction <http://dpi.wi.gov>

Cooperative Educational Service Agency (CESA) <http://dpi.wi.gov/cesa.html>

Division for Learning Support: Equity and Advocacy www.dpi.wi.gov/dlsea/index.html

IDEA Child Count <http://dpi.wi.gov/sped/cc-12-1-05.html>

IDEA provides a child count for state special education by category

Orthopedic <http://dpi.wi.gov/sped/ohi-oi.html>

Special Education <http://dpi.wi.gov/sped/index.html>

This site features programs for children with disabilities ages three through five.

Wisconsin Family Ties www.wifamilyties.org

Family Ties works to promote greater understanding and acceptance of children with special needs.

Wisconsin Lions Club www.wilions.org

Paws with a Cause www.pawswithacause.org

Wisconsin Lions Camp www.wisconsinlionscamp.com

Started in 1956, this camp is dedicated to providing a quality camping experience for Wisconsin residents with disabilities at no cost.

Wisconsin Special Olympics www.specialolympicswisconsin.org

The Special Olympics provides sports training and competition for nearly 10,000 athletes with cognitive disabilities in 18 different sports year-round.