National Data on Cognitive Disabilities, Autism, and Traumatic Brain Injuries

Cognitive Disabilities (CD)

Incidence Rate for Cognitive Disabilities

In general, 2.5 to 3 percent of the U.S. population, which is about 6.2 to 7.5 million people, have a cognitive disability, according to The Arc, a national advocacy organization for people with cognitive disabilities. Twenty-five times more people have a cognitive disability than are blind. About 85 percent of people with cognitive disabilities are mildly or moderately affected and will only be a little slower than average in learning new information and skills. The remaining 15 percent have serious limitations on their intellectual functioning.

According to the American Association for Mental Retardation, a person is considered to have a cognitive disability based on three criteria. One is intellectual functioning (IQ). Other factors include significant limitations in two or more areas such as daily living skills, communication, self-care, social skills, academic skills, or work skills; and the condition must be present from childhood.

Cognitive Disabilities Terminology

Many terms are used to describe youth who have disabilities that limit their potential to learn and reason and who have intellectual function that is significantly below average. At DPI and in this publication “cognitive disability” is used. Several other terms also are used to describe this population including “mentally retarded,” “intellectually disabled,” and “developmentally delayed.” “Developmentally delayed” includes individuals who have a cognitive disabilities, but it also includes many students who have normal intelligence, for example, many students with cerebral palsy or autism. “Mentally retarded” is not used very often by Wisconsin school districts, however several federal educational agencies still use it, as do some national service agencies.

Causes of Cognitive Disabilities

The cause of cognitive disabilities is known in about two-thirds of all incidences. Damage that results in a cognitive disability can occur before, during, or after birth. The three known major syndromes identified as causing cognitive disabilities are Fetal Alcohol, Down, and Fragile X. Cognitive disabilities also can be the result of infection while a woman is pregnant or chromosome mutations.

Alcohol consumption by pregnant women is the leading preventable cause of cognitive disabilities. Smoking during pregnancy, low birth weight, rubella, syphilis, oxygen deprivation, injuries during birth, and damage caused by x-rays during pregnancy can all cause cognitive disabilities.

Some childhood diseases such as whooping cough, chicken pox, measles, and Hib disease (one of any bacterial infection such as pneumonia or epiglottitis) can lead to meningitis or encephalitis, which in turn often cause brain damage. Head injuries and near drowning are responsible for causing some cognitive disabilities. Certain environmental toxins like lead and mercury also cause damage to the brain. Poverty is associated with cognitive disabilities because of the high incidence of malnutrition, conditions that produce disease, inadequate access to medical care, and increased exposure to health hazards in the home environment.

Fetal Alcohol Syndrome (FAS)

FAS is the leading preventable cause of mental retardation and birth defects, and is completely preventable. Alcohol related disorders affect more newborns every year than Down syndrome, cystic fibrosis, spina bifida and sudden infant death syndrome (SIDS) combined. FAS affects about one baby in every 1,000 births in the U.S., which is about 40,000 per year.

The Centers for Disease Control and Prevention’s information on fetal alcohol and spectrum disorders (FASD)
indicates FASD is characterized by abnormal growth deficiencies and central nervous system disorders. The National Organization on Fetal Alcohol Syndrome indicates that heart, liver, and kidney defects are all common, as are vision, hearing, and communication problems. Fetal alcohol syndrome (FAS) falls in the severe end of the spectrum.

**Down Syndrome**

The Arc, a national organization serving people who have cognitive disabilities, estimates the incidence of Down syndrome is about one in 1,000 births. Each year approximately 3,000 to 5,000 children are born with this chromosome disorder in the U.S. It is believed there are about 250,000 families in the U.S. who are affected by Down syndrome.

Children with Down syndrome are usually small, and their physical, mental coordination, and language development is slower than their peers. They often have characteristic facial features, short fingers and toes, and may have other abnormalities, including hearing and heart defects. Most function in the mild to moderate range of intellectual ability, while some have severe intellectual limitations.

Some professionals believe that hormonal abnormalities, x-rays, viral infections, immunologic problems, or genetic predisposition may all be causes of the improper cell division that results in Down syndrome. Risk is known to increase with the age of both the mother and father, however, more than 85 percent of babies with Down syndrome are born to mothers younger than 35 years of age.

**Fragile X Syndrome**

Fragile X syndrome, also called Martin-Bell, is a chromosome disorder that is the leading inherited cause of cognitive disabilities. It is a sex-linked genetic abnormality in which a mother typically transmits the disorder to her sons. It affects approximately one in every 1,000 to 2,000 males. Boys affected typically have moderate to severe cognitive disabilities. Girls also may be affected, but generally have a mild form.

Approximately 15 to 20 percent of children with fragile X syndrome exhibit unusual behaviors, such as poor eye contact, hand-flapping or gesture movements, and poor sensory skills. Behavior problems and speech or language delays also are common. Most boys with fragile X have a number of recognizable physical features, including a high arched palate, strabismus (lazy eye), large ears, long face, loose joints, poor muscle tone, flat feet, and, sometimes, mild heart valve abnormalities. Fragile X is not always obvious at birth and can go undiagnosed until the child is older.

**Autism**

**Incidence Rate for Autism**

The U.S. Centers for Disease Control estimates one child in every 166 in the U.S. exhibits signs of autism, which is about 1.5 million children. A May 2006 article in *Time* magazine indicated no one knows why the incidence of autism is increasing so rapidly not only in the U.S., but also in Japan, Denmark, England, and France. The U.S. rate has doubled in the past 10 years, and is 10 times higher than a generation ago.

**Causes of Autism**

Autism was first identified by Leo Kanner in 1946. The causes are still unknown, and there does not seem to be a single trigger. Researchers believe that some people are born with a susceptibility to autism. According to a 2006 article in *Time* magazine by Claudia Wallis, current research indicates there are many causes, as is true of cancer. Some types of autism run in families, indicating a genetic relationship. It is thought that dozens of genes could be involved.

### Characteristics of FAS

- Low birth weight
- Alcohol withdrawal symptoms at birth
- Poor sucking response, sleep disturbances
- Heart, kidney, or genital defects
- Small head with low nasal ridge
- No groove between the nose and upper lip
- Narrow eyes and flat mid-face
- Cognitive and learning disabilities
- Short attention span
- Restlessness and irritability
- Muscle, bone, and joint problems

### Other Conditions Frequently Associated with Down Syndrome

- 60%-80% have hearing deficits.
- 40%-45% have congenital heart disease
- 15%-20% have hypothyroidism
- 3% have cataracts and other vision disorders

For More Information:
- Center for the Study of Autism. [www.autism.org](http://www.autism.org)
- Centers for Disease Control and Prevention. [www.cdc.gov/ncbddd](http://www.cdc.gov/ncbddd)
- Fetal Alcohol Spectrum Disorders. [www.cdc.gov/ncbddd/fas/](http://www.cdc.gov/ncbddd/fas/)
- National Organization on Fetal Alcohol Syndrome. [www.nofas.org](http://www.nofas.org)
The *Time* article cites environmental factors as playing a role in the increased incidences of autism. Researchers are looking at pesticides, mercury, and other toxins as possible environmental triggers. In the past, attention focused on the low levels of mercury used in children's vaccines as a potential cause of autism because they can trigger irregularities in the immune system cells. However, Isaac Pessha, a toxicologist at the University of California who is doing research on the causes of autism, doubts that the mercury in immunizations is the sole cause of autism because there is no one gene involved with all the autistic spectrum disorders. Because there are many causes of autism, as well as a broad range of behaviors and skills, scientists prefer to use the term autistic spectrum disorders (ASD) rather than autism.

It was not until 1992 that autism was first recognized as a special education category in Wisconsin, which is when DPI began to keep data on the students affected by it. DPI data indicates the incidence of children with autism has increased 19 percent each school year since 2000. However in the early 1990s, the annual increases was between 21 and 49 percent, so the incidence rate has actually slowed. One reason for the increase during the 1990s was better awareness and identification.

**Characteristics of Autism**

According to the Autism Society of America web site, autism impacts the normal development of the brain in the areas of social interaction and communication skills. Children with autism typically have difficulties in verbal and non-verbal communication, social interactions, and leisure activities. The disorder makes it hard for them to communicate with others and relate to the outside world. In some cases, aggressive and or self-injurious behaviors may be involved.

The Autism Society indicates autism is a complex developmental disability that appears in the first three years of life. It is the result of a neurological disorder that affects the normal functioning of the brain. Autism is one of five disorders that fall under the umbrella of pervasive developmental disorders (PDD). The other four are Asperger disorder, childhood disintegrative disorder (DDD), Rett disorder, and some unspecified disorders. Autism is the most common.

The symptoms and characteristics of autism range from mild to severe. Some children with autism engage in repetitive behaviors such as head banging, biting, spinning, rocking, scratching, and repeating phrases. Researchers now suggest that the behaviors could be sensory coping mechanisms. The children's senses may be over- or under-active. Hypersensitivity to visual stimulation causes some children with autism to look at things using peripheral vision. Autistic children also can be very sensitive to sound and touch. They may be hyper-focused on details and be unable to perceive the larger picture. Texture may be experienced as painful; some smells may make them gag. Some children with autism are particularly sensitive to sound, so even the most ordinary daily noises can be disturbing or painful. More information on sensory integration problems is included in this publication in chapter five, Learning Disabilities.

Many children with autism have difficulty integrating the cognitive functions of the brain. They also may have unusual responses to people or attachments to objects, and resist changes in their routines or environments. Children and adults with autism process and respond to information in unique ways.

Children who are mildly affected often exhibit slight delays in language, but are challenged by social interactions. They may have difficulty initiating or maintaining a conversation. Some talk at people instead of with them, somewhat like giving a monologue. Others have difficulty expressing needs, and may use gesture or pointing instead of words.

The Autism Society of America stresses that it is important to understand that regardless of what terms are used to describe the various functioning levels and behaviors of children with autism, and regardless of the diagnosis, children with autism can learn and function productively and show gains given appropriate education and treatment.

**Traumatic Brain Injury (TBI)**

**Incidence Rate for Traumatic Brain Injury**

The Brain Injury Resource Foundation's data indicates that every 15 seconds someone in the U.S. suffers a brain injury, which is 1.4 million people each year. The foundation estimates there are 5.3 million Americans who are living with brain damage as the result of an injury. Falls account for 28 percent of all brain injuries and vehicle
crashes for 20 percent. Something striking the head or the head hitting something accounts for 19 percent of the injuries, and 11 percent are the result of an assault.

**Causes of TBI**

The term “brain injury” is typically used in a medical context to describe the result of an injury that caused brain damage. In an educational setting the term “traumatic brain injury” (TBI) is used more often and reflects the on-going learning issues that are a result of the initial trauma. The DPI’s information on TBI indicates that a trauma to the brain can result in a multitude of brain damage that can impact cognition, speech, language, memory, and attention. A brain injury also can affect reasoning and judgment, as well as information processing and abstract thinking. Other areas that may be affected are behavior, physical functions, organization, evaluating, and carrying out goals.

The Brain Injury Resource Foundation indicates children ages one to four, and teens, ages 15 to 19 are the two age groups at highest risk of having a TBI. Shaken baby syndrome is the most common cause of severe TBI in young children. Injuries to school-aged children often happen after school and during the summer, and most of the incidences take place on roads or in the home. Teens and young adults most often suffer a TBI in vehicle accidents. African Americans have the highest death rates from TBI. Males are one-and-half times as likely to have a TBI than are females.

The Brain Injury Association of America indicates that there are two types of brain injuries; those that penetrate the brain and those that result from a blow to the head, such as when a head hits the windshield in a car accident. Brain injuries can be the result of such things as oxygen deprivation, heart attacks, strokes, and brain tumors. Electrocution or autoimmune and degenerative diseases also can cause a TBI, as well as some infectious diseases such as meningitis, AIDS, viruses, and encephalitis. Additional causes include anorexia, diabetes, seizures, poisoning, and use of cocaine, ecstasy, or the sustained use of marijuana.

**Effects of TBI on Learning and Life Skills**

The Brain Injury Association explains that TBI can make learning new concepts and skills difficult due to memory problems and the inability to concentrate. Often students with a TBI have difficulty anticipating what is going to happen and remembering their schedules and appointments. Their motor skills are affected, so they have difficulty with timed activities such as tests. Injuries to the brain often cause long-term fatigue making it very difficult for students to maintain the attention and effort needed to complete assignments or to pay attention in class. These injuries also may cut the visual field so that a student only sees one side of the page or the other. Social communication is also problematic. Students may not take turns in conversation, follow the topic, use inappropriate tones of voice, and have difficulty keeping up with the speed of the conversation. These students are often unaware that their conversation and behavior are inappropriate.

**Adaptive Behaviors are more Important than IQ Scores**

There has been recognition for many years that an IQ score has very little to do with how well a child or teen functions in life. Being raised in poverty increases the likelihood children will be behind others of the same age when they start school and the likelihood the children will qualify for special education services. In the past the IQ score artificially separated the intellectual abilities of a child from all other factors in the child’s life. Current emphasis is on assessing adaptive behaviors and taking into account cultural and linguistic factors. Often youth have strengths in some behavioral areas and personal capabilities that offset their deficits in other areas. With appropriate support and services over a sustained period of time, the life functioning skills of these youth usually improves. Progress often is seen in communication, self-care, home-living skills, social interaction, and use of community resources. Other areas that show improvement over time involve health and safety behaviors, use of leisure time, and employment for older youth.

Youth who are cognitively delayed, have autism, or have a brain injury may need various types of support throughout their lives. Some will need intermittent assistance to work on specific tasks such as finding a new job or to deal with a crisis. Some youth will need limited support to help them get through transitions such as moving out of home and as they leave school. Others act independently in some areas of their life, but will need extensive support on a daily basis throughout their lifetime, but just at home or work. There are others who will need pervasive support in all areas of their lives throughout their lifetime.
Related Issues

Children and teens with cognitive disabilities and brain injuries are vulnerable to sexual abuse. They may not understand what is happening during an assault, may not be able to choose to stop it, or are not be able to act out of fear, or they may have a dependent relationship with the abuser. Girls are more often victims than boys, and many assaults occur before the children are 18 years old. Ninety percent or more of the abusers are known and trusted by the victim. They might include family members, friends, residential care staff, transportation providers, or personal care attendants.

Medical advances have addressed several problems that resulted in a cognitive disability in the past. Good pre-natal care for mothers and dietary supplements that include folic acid help assure normal brain formation for a fetus. This has reduced the rate of anencephaly, failure of the brain to develop, and reduced the risk of damage to neural tubes that result in disorders such as spinal bifida. Newborn screening can identify PKU, Rh disease, jaundice, and hypothyroidism before damage occurs. Vaccines prevent Hib diseases, measles, and rubella. Lead is no longer used in water pipes or in paint. Car seats and bike helmets reduce the incidence of head trauma. Reye’s syndrome is now more readily recognized, and parents are discouraged from using aspirin-based products to treat children’s fevers. Educational programs on the dangers of shaken baby syndrome have helped raise awareness and have reduced injuries.

Wisconsin Data on Cognitive Disabilities, Autism, and Traumatic Brain Injuries

The Wisconsin Council on Developmental Disabilities uses a CD incidence rate of 1.8 percent, or about 100,000 people in Wisconsin. According to DPI data, about one-sixth of students in Wisconsin public schools do not have the potential for average intellectual functioning. These students, as well as a large number of students with autism and traumatic brain injuries, do not have the ability to achieve at the proficient level on standardized tests. During the 2005-06 school year, a combined total of 17,057 students had cognitive disabilities, autism, or a traumatic brain injury. Not all children who are autistic or who have a TBI have cognitive disabilities, but many function socially and in some other areas at the same level as children who do.

Residential Centers for People with Severe Cognitive and Physical Disabilities

The Division of Disabilities and Elder Services within the Department of Health and Family Services operates three centers for people with cognitive and severe physical disabilities. Residents include both adults and children at Central Wisconsin Center in Madison, Northern Wisconsin Center in Chippewa Falls, and Southern Wisconsin Center in Union Grove.

The Waisman Center and Trace Research and Development Center

Wisconsin is fortunate to have two nationally renowned centers that focus on issues related to cognitive disabilities and communication: the Waisman Center and the Trace Research and Development Center. The Waisman Center, at the University of Wisconsin–Madison, is one of nine national facilities that include a Mental Retardation Developmental Disabilities Research Center and a University Center of Excellence in Developmental Disabilities. The center encompasses 60 laboratories for biomedical and behavioral research, seven specialty clinics, outreach programs, and a model pre-school for children with developmental disabilities.

The clinics within the Waisman Center include Biochemical Genetics, Cerebral Palsy, Communication Aid and Systems, Developmental Disabilities, Fetal Alcohol Spectrum Disorders, Genetics, Child Development,
and Phonology. The University Center of Excellence in Developmental Disabilities offers pre-service training programs, clinical and intervention services, continuing education programs, technical assistance, and consultation services. The Early Childhood Unit services include Wisconsin Birth to 3 Training and Technical Assistance program, Parents as Leaders (PALS) training, coordinates the Waisman Early Childhood Program, and provides information on early childhood products.

An important Waisman Center service is the Family Village Project, a web site for children and adults with disabilities and their families. The project provides thousands of online resources for more than 300 diagnoses with an easy-to-use directory. There also is information on assistive technology, legal rights and legislation, special education, and leisure activities.

The Trace Research and Development Center is part of the College of Engineering at the University of Wisconsin–Madison, and is funded primarily by the National Institute on Disabilities and Rehabilitation Research. It is a pioneer in the field of applied communication technology for people who have disabilities. The center’s mission is to use current and emerging telecommunication technologies to create an accessible and usable workplace for as many people with disabilities as possible, and to prevent and break down other social barriers.

**Barriers to Service**

Lack of transportation and supervision often prevent children and teens with cognitive disabilities, traumatic brain injuries, and autism from using the library. Inappropriate behavior of some of these youth can be a challenge for parents, caregivers, and library staff when they do come to the library. Some youth who have cognitive disabilities cannot read, or do not read very well, leading to the misconception that a public library does not have appropriate resources of interest to them.

**Strategies for Success**

**Collaboration**

When planning, training staff, developing diverse collections and services, and designing accessible buildings, there are many organizations and agencies that can provide libraries with advice and assistance. Local school district staff and regional CESA consultants are often good resource people. Some of the agencies that might be able to help a library adapt services and collections for youth with cognitive disabilities, autism, or traumatic brain injuries include:

- Agencies that provide teen job training placements for older students
- ARC of Wisconsin
- Autism Society of Wisconsin
- Local chapters of United Cerebral Palsy, Easter Seals, the Epilepsy Foundation, and the Brain Injury Association of Wisconsin.
- Local Councils on Developmental Disabilities and Disability Boards, Goodwill Industries
- Local chapters of the Knights of Columbus or Kiwanis clubs.

**Planning**

Planning can often include teens with CD, TBI, or autism because many function at a fairly high level. They have preferences, can articulate them, and can give insight into the problems they have in using a library. Parents of children who have these disabilities, special education teachers, and representatives from social service agencies all can be contacted for input in planning inclusive services for these youth. This collaboration is critical to getting information about library services and encouraging the participation by these children and teens in library activities.

**Staff Training**

Youth with CD, TBI, and autism may have limited contact with other people outside of their classrooms, immediate families, and small group of friends. Library staff can become part of their network of acquaintances. In her book, *Information Services for People with Developmental Disabilities*, Linda Lucas Walling points out that for many people with these types disabilities, the social interaction is more important than the activity itself. She says that public libraries can play a significant role in enhancing the quality of life for these youth. The collection and service options offered at a public library can be used by the individuals, their family members, and the professionals who work with them.

Youth with CD, TBI, and autism often have a great deal of leisure time, especially in the summer, and need outlets to pursue their interests. Safe public places where they are welcome are important to youth with cognitive
disabilities, and the public library may be one of the few public facilities where they can spend unstructured time. This opportunity helps them follow their personal interests, make choices, and practice their social skills.

Rules and limits may have to be explained frequently and consistently enforced to help youth with CD adjust their behavior to the public library environment. The Guidelines for Library Services to People with Mental Retardation publication, produced by ALA, suggests that staff training recognize that some youth cannot control their own behavior. Their behavior may appear bizarre and may occasionally startle staff and other patrons, or make them uncomfortable. In general, the behavior expectations for youth with cognitive disabilities should be guided by the library’s policy on behavior for all patrons.

These young patrons may require extra time and guidance to make decisions and to use library services. They may need assistance in getting information from the library’s catalog and locating materials on the shelf. Public librarians may need training on meeting the needs of this group of patrons and the best ways to interact with them. Staff should appreciate that their interactions with these youth can serve as a model for other people in the community.

Some youth who have CD, TBI or autism have other types of disabilities as well, including mobility, vision, speech, or hearing problems. Personal adaptive equipment for people who have cognitive disabilities often involves communication technology, which could be as simple as a speech board with pictures or as sophisticated as an electronic voice used with a computer. Because memory is often a problem for youth with CD and TBI, they may use a visual activity list to get through the day. Library staff needs training with adaptive devices, especially those for speech, in addition to understanding the general characteristics and behaviors of youth with CD.

Diversified Collections and Services

The library should have information on the prevention and treatment of cognitive disabilities for the parents, families, and professionals who work with youth who are autistic, have brain injuries, or who have cognitive disabilities. Families need different types of information to address their concerns at different stages of their children’s lives and into their adulthood.

Materials that can be especially useful are large print collections, high interest/low vocabulary books, recorded books, and music. The Guidelines for Library Services to People with Mental Retardation by ALA recommends that tactile materials and items that involve more than vision are very helpful, such as book-and-tape or book-and-video combinations. Teens with low reading levels often do not like to ask for assistance in locating materials, so it is helpful if high interest/low vocabulary materials are shelved together. Materials in a Bi-fokal kit may be of interest to teens with cognitive disabilities.

The Oshkosh Public Library and the DeForest Public Library Serve as Work Training Sites for Students with Cognitive Disabilities

Both the Oshkosh and the DeForest public libraries have long standing cooperative training programs with their local school districts for high school students who have cognitive disabilities, autism, brain injuries, or who have multiple disabilities.

At Oshkosh the high school students who are in special education programs at West High School attend classes off-site at the United Cerebral Palsy headquarters. They take the bus to come to the library once a week to work on various tasks, depending on their abilities. Many work on an ongoing project that involves wiping down the covers of books in the youth department. Under the supervision of their teachers, they work one section at a time washing and drying covers and returning books to shelves. At the end of the school year, the library often treats the workers to a pizza party. Some of these students return after they graduate and work at the library as their job training placement through a Community Action Program (CAP).

The DeForest Public Library offers numerous family packets that promote readiness skills, science, and math activities. Several hundred of these packets are given away each month. The students in the cognitive disabilities class at the high school come to the library on a regular basis to prepare these packets. Their teachers and aides set up an assembly line operation, and each student participates to the degree that they can. Some students who function at a higher level may be assigned other tasks such as simple shelving duties.

The library ends up with the packets it needs, and the students gain job skills. Some of the participants who never used the library before become library users because their work there makes them comfortable, and they see things that interest them while they are working.
Picture directories with auditory commentary are very helpful. A special directory packet might include photos of staff and their last names so youth and adults with memory problems can refer to them as memory cues. Programs can be planned to accommodate these youth and consider creating a system to pair youth with CD with either a peer or adult partner. Middle or high school service groups sometimes are willing to act as volunteers. The Knights of Columbus or Kiwanis clubs might be willing to arrange volunteers, because both organizations have a special emphasis on serving children with cognitive disabilities. Church groups with special outreach programs for youth with these types of disabilities also may be willing to send volunteers. Volunteers also could help these students work on the Internet or play educational computer games or board games with them.

Parents of young children with cognitive disabilities may be working during the day and unable to attend programs unless they are offered in the evening. Attending programs of general interest to children and families, helps the families of children with cognitive disabilities feel part of the community.

Walling’s publication, Information Services for People with Developmental Disabilities, indicates that watching television and listening to the radio and recorded music are the most common leisure-time activities for people with cognitive disabilities. Librarians can make an effort to point out videos and music selections to youth who have special interests but may not be aware of how to find new materials.

Walling recommends youth collections include toys that encourage tactile-kinesthetic exploration for children with cognitive disabilities. Teens with these disabilities sometimes enjoy using tactile learning materials too. These materials might include magnifying glasses, tactile globes or maps, jigsaw puzzles, board games, electronic math toys, as well as video and computer games, or models of things such as the brain or heart.

**Adapting Story Times**

One consideration regarding story times is the need to be flexible with age restrictions within about a two-year age span. It is appropriate to allow children who are in first or second grade and have a cognitive disability, are autistic, or have a traumatic brain injury, to continue to attend preschool story times. However, beyond about second grade, professionals who work with these youth generally recommend they attend programs or activities designed for children their own age, even if they enjoy going to preschool programs.

Libraries should adjust their programs for older elementary, middle, and high school students to allow youth with these types of disabilities to participate. They should also be encouraged to attend family programs or programs of interest to all ages. If older students are at preschool programs, they should be there in a “helper” role, rather than as a participant.

It is more appropriate for older youth with profound multiple disabilities to sit in on programs for older youth, than for them to be in the back of the room during a preschool story time. When it is difficult to assess their level of understanding or for them to interact or respond, the content probably isn’t as important as the social context. They should attend programs where the social context is most appropriate and more closely matches their chronological age.

When including preschool children who have a CD, TBI, or who are autistic in story times:

- Plan on extra time and assistance to help children find their name tags, follow finger plays and song movements, and to participate in group activities.
- If a child’s behavior or appearance is going to draw the attention of the other children, be pro-active in introducing the child to the group, explaining the child’s special needs, and how the group can help the child. Work with the parent or caregiver to help explain the child’s needs and preferences.
- Ask the parent or caregiver who brings the children to explain how best to handle them if they get upset, frightened, or are misbehaving.
- Plan at least some activities that capitalize on the child’s strengths or interests, and in which the child can participate and succeed.
- Using a set format for story time, the same opening and closing routine or songs, helps all preschool children develop a sense of sequence and time, but is especially helpful for children with these types of disabilities.
- Be consistent with all the children about story time rules to help children with these special needs understand and practice being part of a group, and to follow group rules.

**For More Information:**

- www.ala.org/ala/orls/standardsa/standardsguidelines/standguide.htm
Assisting Older Youth with Cognitive Disabilities Participate in Group Activities

The Brain Injury Resource Center suggests the following ways to help youth with brain injuries participate in group activities. They also are appropriate for youth with cognitive disabilities:

- Give directions one step at a time. For complicated projects, give written instructions as well as verbal ones. If activity stations are involved, number the stations and have written instructions at each one.
- Check to make sure the youth understands the instructions after the others have started.
- Reduce distractions by working in an area that is not open to the rest of the youth department.
- Be flexible and patient.
- Pair youth who have cognitive disability, TBI, or who are autistic with a peer or adult “buddy” or volunteer who can help them maximize the chances for success with a project.
- Set rules that require all participants interact respectfully with each other.

School Visits by Groups of Older Youth

Many public libraries collaborate with their local middle and high schools in allowing the teachers to use the library to practice socialization skills. They may also collaborate with other community organizations that provide activities for young people and adults who have cognitive disabilities, TBI, or who are autistic. Typically, staff stay in the library with the group to help manage any problems that arise. The young people are encouraged to use the library on their own.

Some libraries offer programs for these groups of students when they visit. The programs should be age appropriate, rather than based on preschool story times. Finger plays would not be appropriate, although using some American sign language would be acceptable, and part of the program might include singing familiar songs that adults might sing together. Rather than using stories intended for younger readers, read short segments from age appropriate books instead. Use non-fiction, magazines, and adult “table top” or picture books rather than preschool picture books, age appropriate videos, and computer games. The use of Bi-fokal kits, or other hands-on materials, also would be appropriate. General programs for older teens should more closely resemble a program of general interest or one that might be targeted for adults, rather than very young children. Additional programming suggestions are included in DLTCL’s Adults with Special Needs: Resource and Planning Guide in the chapter on serving adults with cognitive disabilities.

Managing Behavior Problems with Teens

If an older child or teen is using inappropriate language, explain the words and give some acceptable alternatives. Coach the youth on appropriate social remarks, and provide direct feedback about the impact of the youth’s efforts at social communication. Reinforce use of appropriate language. Practice social interaction scripts for some situations. If a teen demonstrates impulsive behaviors, develop physical and verbal cues to help the student wait and reinforce appropriate behaviors.

Some youth with brain injuries may engage in confrontational behaviors. Set clear rules for activities. Give the youth choices if behavior problems arise, such as leaving or specifically stopping certain behaviors, or engaging in appropriate ones. Don’t argue, because it often sets up a power struggle.

If a teen with a brain injury, cognitive disability or who is autistic behaves inappropriately, try to figure out
possible triggers for the behavior, and structure things to avoid the triggers in the future. Tell the teen the behavior is not acceptable and explain alternative acceptable behaviors. Watch for cues that the youth’s behavior is beginning to escalate and move to intervene as needed. Try to reduce the stimulation of the situation by adjusting the noise level or the pace of the activity. Assure that there is sufficient adult supervision for the activity involved.

A brain injury can result in a lack of self-confidence and frustration because of the deficits the injury causes. Teens can be very embarrassed by their inability to handle or keep up with a group activity. They might be unsure of what to do or what their role is in an activity. It may help to allow them to observe the group for awhile before expecting them to join. Inviting someone in the teen’s circle of friends may help reduce the anxiety level. Additional information on managing challenging teen behaviors is included in this publication in chapter four, Emotional Behavioral Disabilities.

Useful Adaptive Technologies

Adaptive computer equipment that can be very helpful for youth with cognitive disabilities, autism, or brain injuries include oversize and/or colored keyboards, 19-inch or larger monitors, alternate input devices that are easier to use than a mouse such as a joystick or switches, and screen reading software that highlights text and reads it aloud. Computer memory games are especially appropriate for youth who have brain injuries. Many computer games can be adjusted to play at a slower speed when needed.

Accessible Buildings, Equipment, and Outreach

The ALA publication Guidelines for Library Services for People with Mental Retardation notes that complex interior decoration and complicated floor plans may be confusing for people with cognitive disabilities, and they may need assistance finding their way around. Youth who can read and understand the classification numbers, may need very little assistance. If the students cannot read well, they may need assistance finding the items. Changing the location of a particular collection like videos or music cds may cause some confusion, or even distress for some children who are autistic. Staff can help by greeting the youth as they walk into the library, tell them there have been some location changes, and then show them the new areas.

Marketing

Request the assistance of special education teachers and parent support groups to target youth with cognitive disabilities. Social service agencies mentioned previously in this section also may be able to help get information to the families of these children and teens.

Getting Started with Little Money and Time: Cognitive Disabilities, Autism, and Traumatic Brain Injuries

Collaboration

• Invite parent support groups to hold one of their meetings at the library and put appropriate materials on display during their meeting.
• Ask the local schools, CESA, or Independent Living Center to provide free training for staff to learn to work comfortably and confidently with various types of speech boards and other aids.
• Check with the local middle school or high school to see if the library can be used as a service learning location. Match a volunteer with a student who has CD, autism, or TBI, to allow them to more fully participate in special programs, such as a summer library program, or assist them on a computer.

Planning

• Identify the number of children and teens in the community who have cognitive disabilities, traumatic brain injuries, or are affected by autism. The local school district can provide numbers, but will not be able to identify the children by name. Another source is the DPI’s Federal Student Data Count data at http://dpi.wi.gov/sped/cc_data.html.

Staff Training

• Have a local professional talk to the staff about general aspects of autism and to give general suggestions on interacting with youth who are autistic.
• If the staff have problems working with a particular behaviors, consult with the special education teacher for ideas on how best to improve the quality of the time the youth spends while at the library for both the staff and the student.
• Assure all staff has a working knowledge of the assistive technology owned by the library, especially computer features.
• Many youth with CD, TBI, or autism enjoy being welcomed by name when they visit the library, and like having materials that might especially interest them held for them. They often appreciate personal attention, but staff should respect the preferences of youth who prefer to avoid interacting with library staff.

**Diversified Collections and Services**
• Routinely purchase youth materials in large print, book and recorded format sets, tactile versions of globes and maps, high interest/low vocabulary items, and educational games that automatically respond to the speed of the user or can be set to run at a slower speed.
• Host a public informational program on autism.
• Weed the collection of outdated materials on cognitive disabilities, autism, and traumatic brain injuries and add purchase of replacement items into the general materials budget.
• Review patron behavior policies to assure they are not overly restrictive and take into account the needs of youth who have CD, TBI, or autism.
• Review program procedures to assure flexibility for children who have CD, TBI, or autism.
• Review summer library program procedures to assure children who are not reading at their grade or age level, can participate and succeed. Allow older children to include titles that someone reads to them, or accept listening to a recorded book or watching a video based on a book as an alternative to reading a title if a child is struggling with reading.

**Accessible Buildings, Equipment, and Outreach**
• Use simple, clear signage throughout the library and include visual cues whenever practical.
• Create a visual or audio-recorded, self-guided tour of the library describing each area or department.

**Marketing**
• Send information about appropriate library materials, services, or programs relevant to social service agencies. Ask them to include the information in their newsletters.
• Give inexpensive items like a bookmark, book bag, stickers, or a temporary tattoo to youth with cognitive disabilities when they visit the library, to encourage regular visits or participation in programs. These little things go a long way in terms of motivating youth who have cognitive disabilities.
• Create links on the library’s web page to the web sites of the agencies in the community and region that provide services to the families of children who have cognitive disabilities, are autistic, or who have a traumatic brain injury.

**Observe these Awareness Events:**

**January**
National Folic Acid Awareness Week sponsored by the March of Dimes [www.folicacidinfo.org/campaign/](http://www.folicacidinfo.org/campaign/)

**February**
Brain Awareness Week [www.dana.org/brainweek](http://www.dana.org/brainweek)

**March**
Mental Retardation Awareness Month sponsored by The Arc [www.thearc.org](http://www.thearc.org)

**April**
National Autism Awareness Month sponsored by the Autism Society of America [www.autism-society.org](http://www.autism-society.org)

**September**
International Fetal Alcohol Syndrome (FAS) Awareness Day [www.fasworld.com](http://www.fasworld.com)

**October**
Brain Injury Awareness Month sponsored by Brain Injury Association of America [www.biausa.org](http://www.biausa.org)
National Down Syndrome Awareness Month sponsored by National Down Syndrome Society [www.ndss.org](http://www.ndss.org)

**December**
Resources

Magazines
This magazine is published five times annually by the Autism Society of America.

National Resources

Autism
Asperger Disorder  www.Aspergers.com
This site presents information about Asperger in a question and answer format.
Autism Society of America  www.autism-society.org
The society promotes education, awareness, and advocacy on critical issues related to autism.
Center for the Study of Autism (CSA)  www.autism.org
The center provides information about autism and conducts research on various therapeutic interventions.
Maryland Asperger Advocacy and Support Group (MAASG)  www.Aasperger.org
MAASG is committed to providing information on Asperger syndrome and related conditions.

Brain Injury
Brain Injury Association of America  www.biausa.org
The association acts as a clearinghouse of information for persons with a brain injury, legislative advocacy, and prevention awareness.
TBI Challenge!  www.biausa.org/tbichallenge.htm
TBI Challenge! is a quarterly publication.
Brain Injury Center  www.braincenter.org
The center is a resource for how the brain works and how it can be injured, and the effects of the injury.
Brain Injury Information Network  www.tbinet.org
This network supports mailing lists related to brain injury, stroke, coma, and Down syndrome.
Brain Injury Resource Center  www.headinjury.com
A service of Head Injury Hotline, the center provides difficult-to-find information about head injuries.
Brain Injury Resource Foundation  www.birf.info
The foundation provides education, advocacy, and support for persons affected by a brain injury.
National Brain Injury Research Treatment and Training Foundation  www.nbitrtt.org
The foundation supports research, treatment, and training in the area of brain injury.
National Rehabilitation Information Center (NARIC)
NARIC Databases: Brain Injuries  www.naric.com/search/i04.html
NeurologyChannel.com  www.neurologychannel.com
The NeurologyChannel is a source of information on seizures, stroke, coma, and other brain system disorders.
Coma  www.neurologychannel.com/coma
University of North Carolina  www.unc.edu
Department of Recreation and Leisure Studies  www.unc.edu/depts/recreate/
One project of this department is to decrease the social isolation and loneliness of people with brain injuries.
The Brain Spot  www.unc.edu/depts/recreate/spot/
The Brain Spot offers games, activities, and computer instruction for people with memory loss.
Services and Support for Persons with Brain Injury  www.unc.edu/depts/recreate/crds/SSBPI/index.html
U.S. Department of Health and Human Services  www.hhs.gov
Administration on Developmental Disabilities  www.acf.hhs.gov/programs/add/states/ddcouncils.htm
The agency ensures access to services and assistance that promotes independence, productivity, and inclusion.
Centers for Disease Control and Prevention  www.cdc.gov/ncbddd
National Institutes of Health  www.nih.gov
National Institute of Neurological Disorders and Stroke  www.ninds.nih.gov
The institute supports research in the areas of brain injury and strokes.

Cognitive Disabilities
American Association on Mental Retardation  www.aamr.org
The association gives information about the mental retardation and related disabilities.
American Library Association  www.ala.org
Association of Library Services to Children  www.ala.org/ala/alsc/
Association of Specialized and Cooperative Library Agencies.  www.ala.org/ala/ascla/
Guidelines for Library Services to People with Mental Retardation  www.ala.org/ala/ors/standdsa/standardsguidelines/standguide.htm
Young Adult Services Section [www.ala.org/yalsa](http://www.ala.org/yalsa)
Selected Audio Books for Young Adults [www.ala.org/ala/yalsa/booklistsawards/selectedaudio/selectedaudiobooks.htm](http://www.ala.org/ala/yalsa/booklistsawards/selectedaudio/selectedaudiobooks.htm)
Selected Videos and DVDs for Young Adults [www.ala.org/ala/yalsa/booklistsawards/selecteddvds/selecteddvdsvideos.htm](http://www.ala.org/ala/yalsa/booklistsawards/selecteddvds/selecteddvdsvideos.htm)
Quick Picks for Reluctant Young Adult Readers [www.ala.org/ala/yalsa/booklistsawards/quickpicks/quickpicksreluctant.htm](http://www.ala.org/ala/yalsa/booklistsawards/quickpicks/quickpicksreluctant.htm)

**The Arc of the United States** (Formerly the Association for Retarded Citizens) [www.thearc.org](http://www.thearc.org)

The Arc is a national organization of and for people with mental retardation and related developmental disabilities.

**Association for Children with Down Syndrome (ACDS)** [www.acds.org](http://www.acds.org)

ACDS is a service provider in Long Island, New York, dedicated to providing resources on Down syndrome.

**The Association for Persons with Severe Handicaps (TASH)** [www.tash.org](http://www.tash.org)

TASH is an association of people with disabilities, their families, advocates, and professionals fighting for inclusion.

**Center on Human Policy** [http://thechp.syr.edu/](http://thechp.syr.edu/)

The center promotes the full inclusion of people with developmental disabilities in community life.

**Council for Exceptional Children** [www.cec-sped.org](http://www.cec-sped.org)

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

**FRAXA Research Foundation** [www.fraxa.org](http://www.fraxa.org)

FRAXA furthers scientific research to find treatments for Fragile X Syndrome.

**Hydrocephalus Association** [www.hydromass.org](http://www.hydromass.org)

The association provides support, education, and advocacy for families affected by hydrocephalus.

**Indiana Institute on Disability and Community** [www.isdd.indiana.edu](http://www.isdd.indiana.edu)

The institute supports and empowers people with disabilities and family members.

**International Rett Syndrome Association** [www.rettsyndrome.org](http://www.rettsyndrome.org)

The association advocates for those who are affected by Rett syndrome.

**Kiwanis International** [www.kiwanis.org](http://www.kiwanis.org)

The Kiwanis organization has a special emphasis on helping children with disabilities, including cognitive.

**Lekotek National Center** [www.lekotek.org](http://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](http://www.ableplay.org/search.asp)

**Toys R Us Toy Guide for Differently Abled Kids** [www.lekotek.org/services/toyind/toysrus.html](http://www.lekotek.org/services/toyind/toysrus.html)

**National Association for Down Syndrome (NADS)** [www.nads.org](http://www.nads.org)

NADS is the oldest national organization to offer information and advocacy for families affected by Down syndrome.

**National Down Syndrome Society (NDSS)** [www.ndss.org](http://www.ndss.org)

NDSS is the largest non-governmental supporter of Down syndrome research in the U.S.

**National Fetal Alcohol Syndrome (NFAS)** [www.nfas.org](http://www.nfas.org)

NFAS is dedicated to eliminating birth defects caused by alcohol consumption during pregnancy.


The foundation promotes public and professional awareness, and research for fragile X.

**National Institute for Children and Youth with Disabilities (NICHCY)** [www.nichcy.org](http://www.nichcy.org)

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

**National Organization on Fetal Alcohol Syndrome (NOFAS)** [www.nofas.org](http://www.nofas.org)

NOFAS is dedicated to eliminating birth defects caused by alcohol consumption during pregnancy.

**National Resource Center on Community Integration, Syracuse University** [http://thechp.syr.edu/slogan.htm](http://thechp.syr.edu/slogan.htm)

**O.A.S.I.S. (Online Asperger Syndrome Information and Support)** [www.udel.edu/bkirby/Asperger/](http://www.udel.edu/bkirby/Asperger/)

**Prader-Willi Syndrome Association (USA)** [www.pwsausa.org/index.html](http://www.pwsausa.org/index.html)

The association serves individuals affected by Prader-Willi syndrome, their families, and interested professionals.

**Special Olympics** [www.specialolympics.org](http://www.specialolympics.org)

Special Olympics empowers individuals with mental retardation to become physically fit through sports training and competition.

**Spina Bifida Association** [www.sbaa.org](http://www.sbaa.org)

The association provides information, advocacy, training and scholarships for families affected by spina bifida.

**United Cerebral Palsy (UCP)** [www.ucpa.org](http://www.ucpa.org)

UCP advances the independence, inclusion and self-determination of people with cerebral palsy and other disorders.

**U.S. Department of Health and Human Services** [www.hhs.gov](http://www.hhs.gov)

Administration for Children and Families [www.acf.hhs.gov](http://www.acf.hhs.gov)


This program ensures access to services and assistance that promotes independence, productivity, and inclusion.

Centers for Disease Control and Prevention [www.cdc.gov/ncbddd](http://www.cdc.gov/ncbddd)

Fetal Alcohol Spectrum Disorders [www.cdc.gov/ncbddd/fas/](http://www.cdc.gov/ncbddd/fas/)

National Center on Birth Defects and Developmental Disabilities [www.cdc.gov/ncbddd](http://www.cdc.gov/ncbddd)

National Institutes of Health [www.nih.gov](http://www.nih.gov)

**Williams Syndrome Association** [www.williams-syndrome.org](http://www.williams-syndrome.org)

WSA supports research and educational materials for all facets of Williams syndrome.
Wisconsin Resources

Autism
Autism Society of Greater Madison www.autismmadison.org
Autism Society of Wisconsin (ASW) www.asw4autism.org
ASW provides support and information to the autism community.

Brain Injuries
Brain Injury Association of Wisconsin www.biaw.org
The association serves as a clearing house of information for persons with a brain injury in Wisconsin.

Cognitive Disabilities
The Arc-Wisconsin danenet.danenet.org/arcw/
The Arc (formerly the Wisconsin Association for Retarded Citizens) provides advocacy, training and information and referral services for people with developmental disabilities.
Attainment Company www.attainmentcompany.com
The Attainment Company creates products and resources for parents who have a family member with a disability.

Down Syndrome Association of Wisconsin (DSAW) www.dsaw.org
DSAW provides support to families and individuals with Down syndrome through education and information.

Easter Seals Wisconsin http://wi.easterseals.com
Easter Seals Wisconsin offers a variety of services to help people achieve their personal goals.

Good Will Industries www.goodwill.org
Good Will helps people with disabilities overcome barriers to employment, individualize needs, maintain their independence, and become more fully contributing members of society.

Knights of Columbus, Wisconsin State Chapter www.wikofc.org
Knights of Columbus is a Catholic organization with a special focus on people with cognitive disabilities. The state organization makes grants between $3,500 and $4,500; public libraries are eligible. Contact the Knights to get the current name of the Chairman of Committee to Aid State Citizens with Mental Handicaps.

Kiwanis International in Wisconsin www.kiwanis.org/clublocator/
This site identifies and links to all Kiwanis clubs in Wisconsin.

Madison Area Down Syndrome Society (MADSS) www.madss.org
MADSS provides support and information for families affected by Down syndrome.

Milwaukee Center for Independence www.mcfi.net
The center offers programs that teach independent living skills including a camp for youth ages 12 to 16.
Adventures for L.I.F.E. Camp www.mcfi.net/life/adlife.htm

People First Wisconsin www.peoplefirstwi.org
People First Wisconsin is a statewide advocacy organization for people with disabilities to help have their voices heard.

Respite Care Association of Wisconsin www.respitecarewi.org
This association identifies agencies that offer respite for caregivers and families.

United Cerebral Palsy(UCP)-Wisconsin www.ucpa.org
The web address for all Wisconsin affiliates is the national organization web page. UCP Wisconsin is operated by the Eau Claire chapter.

University of Wisconsin–Madison www.wisc.edu
University Hospital and Clinics www.uwhealth.org
Waisman Center www.waisman.wisc.edu/cedd/cs.html
The center offers information, resources for persons with cognitive disabilities, their families, and professionals.
Family Village Community Center www.familyvillage.wisc.edu
College of Engineering www.engr.wisc.edu
Trace Research and Development Center www.trace.wisc.edu

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.

Wisconsin Badger Camp www.badgercamp.org/
Located 10 miles south of Prairie du Chein, the camp serves people with developmental disabilities.

Wisconsin Council on Developmental Disabilities www.wcdd.org
The council is dedicated to the independence, productivity, and integration of people with developmental disabilities. **Wisconsin Department of Health and Family Services** [www.dhfs.state.wi.us](http://www.dhfs.state.wi.us)

DHFS coordinates services for children and teens with cognitive disabilities, brain injuries, and autism. **Bureau of Developmental Disabilities Services (BDDS)** [www.dhfs.state.wi.us/bdss](http://www.dhfs.state.wi.us/bdss)

**Centers for People with Developmental Disabilities** [www.dhfs.wisconsin.gov/Disabilities/dd_ctrs/DDcenters.htm](http://www.dhfs.wisconsin.gov/Disabilities/dd_ctrs/DDcenters.htm)

The centers are responsible for services and supports for people with developmental disabilities in terms of independent living and preventing placement in institutions. The Division of Care and Treatment Facilities operates three centers for people with developmental disabilities in Wisconsin—Central in Madison, Northern in Chippewa Falls, and Southern in Union Grove.

**Bureau of Long-Term Support: Developmental Disabilities Services and Children’s Services Section** [http://dhfs.wisconsin.gov/bdds/index.htm](http://dhfs.wisconsin.gov/bdds/index.htm)

**Birth to 3** [http://dhfs.wisconsin.gov/bdds/birthto3](http://dhfs.wisconsin.gov/bdds/birthto3)

**Community Integration Program (CIP)** [www.dhfs.state.wi.us/bddscip.htm](http://www.dhfs.state.wi.us/bddscip.htm)

CIP helps pay for adaptive and communication aids, day and respite care, supportive home care, placement in group homes, supportive employment services, and specialized transportation.

**Supported Employment** [www.dhfs.state.wi.us/bdds/supempl.htm](http://www.dhfs.state.wi.us/bdds/supempl.htm)

This is an employment service for individuals with disabilities.

**Wisconsin Department of Public Instruction** [http://dpi.wi.gov](http://dpi.wi.gov)

**Cooperative Educational Service Agency (CESA)** [http://dpi.wi.gov/cesa.html](http://dpi.wi.gov/cesa.html)

**Special Education** [http://dpi.wi.gov/sped/](http://dpi.wi.gov/sped/)

**IDEA Child Count** [http://dpi.wi.gov/sped/cc-12-1-05.html](http://dpi.wi.gov/sped/cc-12-1-05.html)

IDEA provides a child count for state special education by category.


**Wisconsin Tourette's Syndrome Association** [www.touretteweb.com](http://www.touretteweb.com)

**Wisconsin Special Olympics** [www.specialolympicswisconsin.org](http://www.specialolympicswisconsin.org)

The Special Olympics provides sports training and competition for athletes with cognitive disabilities.