

Special Addition



children with special health care needs winter/spring 2006

A NEWSLETTER FOR MICHIGAN FAMILIES

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This publication replaces the April 2006 *Heart-to-Heart Information Update* from Mary Marin, Parent Participation Program (PPP) executive director. PPP is a section of the Children's Special Health Care Services program of the Michigan Department of Community Health. The update resumes in May. Request it by mail at 1-800-359-3722. Or, read it online at www.michigan.gov/cshcs.

Federal Viewpoint

Coping with a traumatic brain injury

by Jane Martin Heppel, Director,
Traumatic Brain Injury Program

The day after Thanksgiving 2000, Jeneesia, a high school student, was in a car struck head-on by a drunk driver. Jeneesia survived, but she wasn't unscathed. Jeneesia sustained massive damage to the right side of her body, and the frontal lobe of her brain was severely injured. Jeneesia now has challenges with pragmatic language (i.e., knowing what to say, how to say it, and to whom to say it).

Jeneesia's story is one of millions that occur each year with the same result—a traumatic brain injury (TBI). According to the Centers for Disease Control and Prevention (CDC), because of a TBI at least 5.3



Most traumatic brain injuries in children occur in motor vehicle crashes where the child is a pedestrian, bicyclist, or passenger. Other causes include sports-related injuries, gunshot wounds, and physical abuse such as shaken baby syndrome.

million Americans need long-term or lifelong help to perform activities of daily living, such as eating, dressing, etc. The CDC's most recent statistics

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State Viewpoint

TBI Project aims to improve public services

Michigan families coping with a traumatic brain injury (TBI) quickly learn a startling fact: *how* the injury happens can make a difference in services.

If a car crash is the culprit, TBI patients who survive typically get good,

comprehensive services through automobile insurance companies. Michigan is the only state with unlimited personal injury protection benefits through no-fault insurance policies. Auto accidents cause 35 to 50 percent of Michigan's

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show that 475,000 TBIs occur in children each year, with children under the age of four and youth between the ages of 15 and 19 the most likely to sustain a TBI. Of the 475,000, approximately 30,000 children each year are left with long-lasting, significant changes in social, behavioral, physical, and cognitive functioning that impact their ability to learn and perform in their daily lives.

Treatment difficulties

Treating a TBI can be complicated for several reasons. It is not an injury that can be seen. Unlike broken bones, a TBI cannot be mended. Additionally, it needs more than medication to heal. Further, TBI can cause a wide array of symptoms, some of which take years to appear.

Individuals with TBI may need services that cross multiple programs including comprehensive health

Traumatic brain injury defined

The medical definition of a traumatic brain injury (TBI) is an injury to the head from a blunt or penetrating trauma, such as a gunshot wound, or from acceleration-deceleration forces, such as motor vehicle crashes. Its severity can range from mild (a brief change in mental status or consciousness) to severe (an extended period of unconsciousness or prolonged amnesia after an injury). The Individuals with Disabilities Education Act (IDEA), the federal law that guides schools in providing special education and related services to youth with disabilities, defines TBI as "an acquired injury to the brain caused by an external, physical force, resulting in total or partial functional disability or psychosocial impairment, or both, that adversely affects a child's educational performance."

care, education, vocational rehabilitation, employment, Medicaid, mental health, and substance abuse treatment. Because of a lack of coordinated systems of care, individuals with TBI are often inappropriately placed into nursing homes (regardless of their age); or are returned to their families, who frequently must provide care with little support or assistance. In some instances, individuals with TBI receive no posthospital care at all.

Another major problem is that there are individuals, many of whom are children, who have a TBI that has not been identified. Because brain injuries vary widely in their severity, changes that accompany the injury also vary. Often, children with an unidentified TBI are thought to have a learning disability, emotional disturbance, or mental retardation. As a result, they don't receive the educational help and support they need.

The Federal TBI Program

Coping with the life-changing consequences of TBI can present a great challenge for the individual with the TBI, for the family, and for the physicians, therapists, and society. For this reason, the Brain Injury Association of America, its nationwide affiliates, and numerous advocates urged the White House, Congress, and federal agencies to recognize the effects of TBI, and address the needs unique to individuals with TBI and their families.



Children with an unidentified traumatic brain injury may present new problems as they grow since they are required to use their brain in new and different ways. Damage to the brain from the earlier injury can make it hard for the child to learn new skills that come with getting older. These difficulties become more apparent when the child is in school.

In 1996 Congress passed the Traumatic Brain Injury (TBI) Act (the only federal law that specifically addresses the issues faced by individuals with TBI) to expand studies and to build systems of care that meet individual needs in a way that is user-friendly, person-centered, and community-driven. The TBI Act created the Federal TBI Program, administered by the Maternal and Child Health Bureau of the Health Resources and Services Administra-

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Special Addition is a free newsletter published twice a year for families of children with special health care needs. MedWrite News, Inc., Cincinnati, Ohio (513-791-8582), provided the newsletter design and layout of the national news.

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This newsletter is partially funded by the Maternal and Child Health Bureau (MCHB).

U.S. Department of Health and Human Services

HRSA

Health Resources and Services Administration
Maternal and Child Health Bureau

Events

Detroit-area families of children with all types of special needs are welcome at an ongoing daytime and evening meetings of the **Family Support Network of Michigan** (FSN).

FSN parents gather from **10 a.m. to noon every third Thursday** at the Children's Special Health Care Services (CSHCS) office at the **Detroit Health Department**. For details of the meeting on **April 20** and after, phone FSN Coordinator Vickie K. Eaddy.

A second FSN chapter meets monthly from **6 to 8:30 p.m.** on varying **weeknights** at **Children's Hospital of Michigan** in **Detroit**. Upcoming dates are **May 22** and **July 24**. The chapter's annual picnic is set for **June 24**. For information, phone FSN Coordinator Dorothy Baker.

Elsewhere in Michigan, FSN chapters are organized around specific diagnoses. A parent also can ask to be matched with a trained FSN support parent. For details, phone FSN State Coordinator Randy Krause. Randy is both a parent and grandparent of children with special needs.

Randy and all FSN volunteers can be reached toll-free on the CSHCS Family Phone Line at 1-800-359-3722.

Youth with visual impairments can attend two Michigan overnight camps tailored to their needs.

Lions Bear Lake Camp near **Lapeer** kicks off its three-day and two-week sessions with an Open House on **July 9**. Get details at www.bearlakecamp.org or email dtkins@bearlakecamp.org.

Near **Greenville**, nine different sessions at **Camp Tuhsmeheeta** include **Family Camp, July 6-9**. For more information, go to www.campt.org or email strider@campt.org.

Children with special needs can explore the world-class **Frederik Meijer Gardens & Sculpture Park** in **Grand Rapids** from **10 a.m. to 2 p.m.**, Saturday, **May 13**. That's when the site hosts *Open House for People with Disabilities: ANYBODY CAN – No Boundaries, Unlimited Exploration and a Day of Learning and Fun*.

The event includes an accessible tour at 10:30 a.m. and 12:30 p.m. Community organizations will host information tables. A noon performance features pianist Elizabeth Kazmierski, Very Special Arts of Michigan's 2006 Young Soloist of the Year.

For more information, reach Heidi Holst Leestma at (616) 974-5225 or hleestma@meijergardens.org.

Children's activities are part of the *Michigan Disabilities Council's* third annual **Family Gathering** on **July 11** at Hawk Island Park in **Lansing**. In a fun, inclusive setting, families can network and increase their awareness of statewide resources and supports. Topics include respite, recreation, assistive technology, financial support, self-advocacy and legal support. For details, phone the DD Council at (517) 334-6123.

Resources

A course explaining the new Medicare Part D is online at www.training.mihealth.org. Also on that site is the 45-minute or less course, *What is Children's Special Health Care Services?*. It continues to get good reviews from persons who take it.

The Autism Society of Michigan's website includes a *Legislative Update* at www.autism-mi.org.

Michigan's *Autism Spectrum Disorder Work Group* now has a website at www.cenmi.org/ASD.

Dose of Humor

Aired by WWJ-AM Weathercaster Sonny Eliot

Man is the only animal that goes to sleep when he isn't sleepy and gets up when he is.

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9,000 non-fatal TBIs each year.

When there is an unintentional fall, assault or other cause of TBI, families often must piece together local, state and federal programs. That is true for some 200,000 Michigan residents living with TBI. About 38 percent are children under age 14.

“It shocked all of us that the figures are that high,” said Manfred Tatzmann, director of Michigan’s TBI Project. Michigan is the first of any state to carry out extensive TBI data investigations. The groundbreaking study brought together state government’s Community Health, Education and Human Services departments and the private, nonprofit Brain Injury Association of Michigan (BIAM).

The data cited above and much more are in the TBI Project’s 2004 report, *Addressing Michigan’s Public Service Gaps for Persons With Traumatic Brain Injury*. It outlines how to best address the needs of Michigan citizens living with a disability due to TBI. One of five case studies profiles a high school student severely injured in a motocross race. He received CSHCS case management services and funding for medical equipment and home modifications from the Children with Special Needs Fund.

Reach the 157-page report online at www.michigan.gov/ltc by clicking “People with Disabilities,” then “Traumatic Brain Injury.” It is among a wealth of TBI resources, including educational and training materials plus links to project partners. The pages are part of state government’s comprehensive Long Term Care website.

In response to its findings, Michigan’s TBI Project is working to improve public services. A major form of help for consumers is its *Michigan Resource Guide for Persons with Traumatic Brain Injury and their Families*.

Michigan’s project also promotes TBI prevention and awareness. It helps distribute BIAM education materials.

“Families ought to know that no injury to the head is insignificant,” said Tatzmann. “Whenever there is a head injury, they should not minimize it. They should make sure that they have it thoroughly checked out by a medical professional if there is any loss of consciousness, even a brief one.”

Michigan’s TBI definition

A traumatic brain injury (TBI) is an injury to the head arising from blunt or penetrating trauma or from acceleration-deceleration forces, such as from a fall, car crash, or being shaken. TBI may or may not be combined with loss of consciousness, an open wound, or skull fracture. TBI is complex and unpredictable in its outcomes. Both mild and severe TBI can result in lifelong impairments – requiring long term care services.

Source: MDCH TBI Project Report, page v

TBI Resources for Families

■ Michigan Resource Guide for Persons with TBI and Their Families

For a copy of the free, 70-page guide, families may call the CSHCS Family Phone Line (1-800-359-3722) or e-mail ppp@michigan.gov. Download it at www.michigan.gov/documents/combined_67025_7.pdf.

[CSHCS stands for *Children’s Special Health Care Services*, a program of the Michigan Department of Community Health (MDCH). PPP, or the *Parent Participation Program*, is the parent-directed information and support arm of CSHCS.]

■ The Long Term Care section of the State of Michigan’s website: www.michigan.gov/ltc

Reach the TBI information by choosing “People with Disabilities,” then “Traumatic Brain Injury.” The comprehensive site includes several TBI educational and training materials in Arabic, English and Spanish, plus links to project partners.

■ Annual conference of the Brain Injury Association of Michigan (BIAM)

This year’s event is set for Sept. 28 - 29 in Lansing.

■ TBI Support Groups

A list of groups run by BIAM and other organizations in Upper and Lower Michigan is at www.biami.org/documents/supportGroups.pdf.

■ BIAM eLibrary

At www.biami.org/downloads.htm, the site offers downloadable documents on many topics. Many are in Arabic and Spanish.

■ Children with Special Needs Fund

The fund provides services and equipment to children with special health care needs that no other resource – including state or federal programs – provides. For details, click to www.michigan.gov/csnfund or dial 1-800-359-3722.

■ Free self-advocacy training for TBI survivors and their family members may be available.

Check with Michelle Mull at *Michigan Protection and Advocacy Services* at 1-800-288-5923 or go online to www.mpas.org.

TBI RESOURCES FOR PROFESSIONALS

■ TBI is the theme of the March 2006 issue of *Focus on Results*, published by the Michigan Department of Education's *Office of Special Education and Early Intervention Services*. Reach the issue via the index page at www.cenmi.org/focus/index.asp. The issue includes a TBI Resources list.

■ Michigan's TBI Project is developing the **nation's first web-based TBI training for educators** and other professionals. Check for its release date by contacting TBI Project Director Manfred Tatzmann at tatzmannm@michigan.gov or (517) 241-2534.

BRAIN INJURY ASSOCIATION OF AMERICA

PREVENTION MATTERS

The most common causes of TBI are vehicle crashes, falls, sports injuries, and violence. Each year, 50,000 persons die from brain injuries and 80,000 to 90,000 people experience long term disability. Numbers do not convey the true extent of brain injury. Lives, hopes, dreams, families, and friendships are often altered in the wake of a brain injury.

Most brain injuries can be prevented. Injury prevention is one of the most significant health care issues in the United States.

Spring Safety Facts and Advice

- ▶ Bicycle incidents are most likely to occur within five blocks of home. Teach by example. A bicycle helmet is a necessity not an accessory. Baseball has the least amount of safety equipment required of any youth sport. **Check that your child's baseball helmet meets standards of the National Operating Committee on Standards for Athletic Equipment.**
- ▶ Falls are the most common cause of playground injuries. Check the surface under playground equipment. Avoid asphalt concrete, grass and soil surfaces. **Look for surfaces with shredded mulch, pea gravel, crushed stone and other loose surfaces.**
- ▶ Two-thirds of all-terrain vehicle accidents have involved children under age 16. **Model safe behavior by always wearing helmets with face protection and protective clothing.**
- ▶ Brain injuries occur when skaters fall and hit their heads on the pavement. **Wear a helmet for protection against falls.**
- ▶ Brain injury is the leading cause of death among children hit by cars. **Teach children to always stop at the curb or edge of the road; never run into the street.**

The **Brain Injury Association of Michigan (BIAM)** strives to further its mission of brain injury prevention through community education and public awareness campaigns. Its fact sheets include up-to-date statistics on topics such as bike safety, falls, sports and recreation, violence, and transportation safety, and recommendations on how to prevent injuries. Contact BIAMI at 1-800-772-4323 or info@biami.org.

Source: "Prevention" at www.biami.org

Michigan Family to Family Health Information and Education Center

A *Real Choice Systems Change Grant* from the federal Centers for Medicaid and Medicare Services established the *Michigan Family-to-Family Health Information and Education Center* (F2FHIEC) in late 2005. PPP is the coordinating Center partner. So far, a series of four training sessions are set. Highlights follow. For a brochure with full details, phone 1-800-359-3722.

HOW TO ACCESS MENTAL HEALTH SERVICES FOR YOUR CHILD USING PUBLIC OR PRIVATE HEALTH CARE COVERAGE

The training provides families with detailed information on how to effectively utilize or get health care coverage in order to access mental health services for their child. Information includes:

- How and where to access mental health services
- What is Community Mental Health and how can it help me?
- Eligibility criteria for publicly funded programs
- Array of services provided by specific programs
- What to do if you are uninsured
- Understanding your private or public mental health care benefits
- How Michigan's public mental health system operates
- Tips to maximize your benefits

May 31, 1 - 3 p.m., Lansing

July 18, 1 - 3 p.m., Mount Pleasant

August 9, 1 - 3 p.m., Auburn Hills

August 16, 5 - 7 p.m., Bad Axe

To register,
phone **Terri Henzri**
at **1-888-226-4543** (ACMH)

WILL YOUR TEEN BE READY FOR ADULT LIFE?

This session is for parents of teens with serious mental health conditions. Those teens often report that they would like help finishing school, getting a good job, finding a place to live, living on their own, and making friends. Information and practical suggestions will be shared for helping your teen prepare for the transition from high school to employment or higher education; from home to independent living; and from child to adult community services. Topics include:

- School-based transition planning
- Mental Health Programs
- Substance Abuse Programs
- Post Secondary Training
- Employment
- Housing
- Human Services
- Family Planning & parenting assistance

May 31, 3 - 5 p.m., Lansing

July 18, 3 - 5 p.m., Mount Pleasant

August 9, 3 - 5 p.m., Auburn Hills

August 16, 7 - 9 p.m., Bad Axe

To register,
phone **Terri Henzri**
at **1-888-226-4543** (ACMH)

HEALTH & EDUCATION

The training provides parents and professionals with basic information needed to plan and advocate for a child's education and health needs. It covers:

- Types of public health care coverage available
- Special education laws and rules
- Individualized Family Service Plan (IFSP) and Individualized Education Plan (IEP) processes
- Educational due process
- Health Preparedness resources

April 12, 9 a.m. to noon, Inkster

April 19, 11 a.m. - 2 p.m., Detroit

April 26, 8 - 11:30 a.m., Dorr

June 6, 11 a.m. - 2 p.m., Baraga

To register,
phone **Frances Spring**
at **1-800-221-9105** (CAUSE)
or **Lisa Cook-Gordon**
at **1-800-359-3722** (PPP)

HEALTH RESOURCE SUPPORT PARENT TRAINING

The session prepares "Support Parents" to share resources and information with fellow Michigan parents of children with special needs. Trained parents will provide support primarily by phone.

Topics include types of public health care coverage, how private health care coverage works with public insurance, transition to adulthood, services available to children and families with hereditary disorders, and emergency preparedness for children with special needs. Presenters include representatives of CAUSE, CSHCS, the MDCH Hereditary Disorders Program, Michigan Protection and Advocacy Services, PPP and the Social Security Administration.

The training runs from **9 a.m. to 2 p.m.** on **April 8** in **Okemos**, **June 3** in **Indian River**, **June 10** in **Southfield** and **July 29** in **Marquette**. For details and to register, phone the CSHCS Family Phone Line at 1-800-359-3722.

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tion (HRSA). Until now, the Federal TBI Program had provided state agencies with money via grants to care for individuals with TBI and their families. This year the Federal TBI Program created a new grant category for state agencies, the Partnership Implementation Grant, which will take the place of the other grants. The new implementation grants will allow states and territories to expand and improve their state-wide and local resources devoted to TBI. The goal of the Federal TBI Program is to have all individuals with TBI and their families obtain accessible, available, acceptable, and appropriate services and supports.

State agency grant accomplishments

Since 1997, 48 states, two territories, and the District of Columbia have received at least one TBI grant. States have used the planning grants to build systems of care where an individual can access a “seamless” system of services—meaning that an individual and his or her family can easily move from one setting within the system to another. For example, if a toddler is hospitalized from a playground injury and a TBI is diagnosed, the child’s family can count on the transfer of services from the hospital to the child’s pediatrician.

Jeneesia is one of the beneficiaries of the Federal TBI Program’s state agency grants. As an Alabama resident, she was directed to the Alabama Children’s Rehabilitation Services. Because of her injuries, Jeneesia had to relearn how to speak, and she still struggles with language difficulties.

After working with educators and others, she is currently plotting her

career map by working with a vocational rehabilitation counselor. The three-year TBI Implementation grant enabled the Alabama children’s program to expand its services to more than 518 children with TBI.

When students go back to school after sustaining a TBI, many teachers may be aware of the unique challenges these students present, but are not prepared or trained to meet their needs. In response to this, Iowa, Kansas, and Oregon developed a model called the TBI Resource Team Model in which team members (family members, individuals with TBI, school nurses, and others) are recruited and trained to be knowledgeable about issues related to TBI. In addition training and direct consultation is given to teachers who have a student with a TBI. A webcast discussing the model is available online (see box at left on page 8).

Parents of students with TBI applaud the states’ efforts because they’ve found the TBI Resource Team Model meets their children’s needs. One father praised the model after regional team specialists helped develop an Individual Education Plan (IEP) tailored to his child’s unique needs and changed learning style. An IEP is one of many strategies that can be used to help children continue to learn effectively after a TBI. Parents



have also praised the TBI Resource Team Model for its help in establishing camaraderie among people who have a TBI, or who have an interest in helping those with TBI.

Protection & Advocacy grant successes

With the Children’s Health Act of 2000, Congress created a mechanism for the Federal TBI Program to also provide grants to Protection and Advocacy (P&A) services. Its purpose is to ensure that P&A services could provide assistance to individuals with TBI and their families, regarding their rights related to education, employment, housing, transportation, and other issues. Sometimes P&A services only provide correct information and a referral to the correct helping agency. In other instances, it is necessary to engage in litigation to support the rights of an individual or group of individuals with TBI.

Just as adults with TBI may need protection or advocacy to get their needs met, children and youth also have an array of advocacy needs related to providing a supportive learning environment, or to getting needed assistive technology (see box at right on page 8), or ensuring that public places such as libraries are accessible. Protection and Advocacy services can encourage needed changes in making facilities acceptable to those with a TBI, just by making some phone calls and advising others of what the law provides for persons with a disability such as a TBI. In some instances, children and teenagers have been inappropriately placed in facilities

please see page 8



Families and individuals with traumatic brain injury (TBI) need a well-traveled path for them to follow, one that is peopled with other individuals with TBI and their families who can offer friendly support and comfort. One that has everything that will be needed, conveniently located with well-marked signs to guide them on their journey.

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designed primarily for the aged and infirm. The P&A services have fought to have these young people released from such institutions, so that they can receive the necessary services and supports they need within their own home and community.

The HRSA P&A grants have allowed 57 states, territories, and the Native American Protection and Advocacy Project to assess their state P&A systems' responsiveness to TBI

issues and provide advocacy support to individuals with TBI and their families. Although all protection and advocacy cases are compelling, one P&A advocate said, "Cases involving children and youth bring great satisfaction since they [children and youth] are much more vulnerable than adults."

The road ahead

A TBI is just that—traumatic for both the survivor and the family. Everyone involved in the acute aftermath of a TBI feels stressed and bewildered as to how to cope with an event that can change life forever. It is especially painful for parents who have invested their hopes in a child who is now injured in ways that will unfold over a period of months to years. They fear for their child's possibly unrealizable potential, and for their suddenly magnified responsibilities.

With continued authorization and appropriations from Congress, the HRSA TBI programs will be able to help more individuals with TBI, like Jeneesia and Brian (see box above),

A success story

One young person who would not have had a proper education had it not been for the existence of the Protection and Advocacy (P&A) grant is Brian, an eleventh grader from Tennessee. Brian has both a TBI and quadriplegia and uses a wheelchair. Brian's father contacted the Tennessee P&A services because the school was not allowing the use of a communication device (the Dynavox), which was part of Brian's Individual Education Plan (IEP). The school had refused to send staff to free trainings on how to use the equipment. The Tennessee P&A services convinced the school to allow Brian to use the Dynavox, and to obtain the necessary training on how to use it. Brian also received further assistive technology and occupational, speech, behavioral, and cognitive evaluations. He was able to begin the 2004-2005 school year with all services and supports in place and, therefore, have an increased amount of independence.

and their families. Just as important, because of these programs, the public will have a heightened awareness of TBI, which could ultimately result in measurable progress in TBI prevention. ⁶

A webcast discussing the TBI Resource Team Model is available online at <http://www.mchcom.com/archivedWebcastDetailNewInterface.asp?aeid=335>

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