

# Special Addition



children with special health care needs

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## 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 show that 475,000 TBIs

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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,

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## 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."

some of which take years to appear.

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



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.

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.

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LOCAL VIEWPOINT

When it comes to special-needs kids, there's no place like "home"

Pilot program takes a new approach to pediatric care

by Kathy Sanabria, Illinois Chapter of American Academy of Pediatrics (ICAAP)

Nearly 400,000 kids in Illinois live with asthma, diabetes, epilepsy, cerebral palsy, attention-deficit hyperactivity disorder (ADHD), autism, and other conditions. For these kids with special needs, there is no one-size-fits-all medical treatment and support plan. After all, that's why these kids are special, and why their care must be special, as well.

Pediatricians and parents are usually on the frontline addressing the needs of children with chronic physical, developmental, behavioral or emotional conditions. Yet they're often there alone. Fortunately, the medical community is increasingly recognizing that the needs of these children are best met when diverse healthcare professionals, caregivers, and family members with wide-ranging perspectives work

together to provide care, organization, and hope.

To encourage this sort of 360-degree

care, the Illinois Chapter of the American Academy of Pediatrics (ICAAP) is supporting an innovative new program called the Illinois Medical Home Project (IMHP). The word "home" refers not to a brick-and-mortar building, but a home-like medical practice approach to treatment.

**“IMHP has helped me do a better job of listening to families and responding to their special needs.”**

—Dr. Mark Rosenberg, Children's Healthcare Associates Chicago, Illinois

The child's pediatrician acts as the home's "general contractor," communicating directly with patients and parents to create a "blueprint" for the child. The pediatrician also coordinates all of the child's care, making sure the "sub-contractors"—specialists, schools, community service providers, and others—follow the plan. Dr. Charles Onufer, Director of the Division of Specialized Care for Children in Springfield, IL, explains, "The goal is to build better lives for children."

The medical home project is as much an attitude as it is a way of approaching a complicated set of intertwined health care needs. "It's a way of building a foundation upon which care can be planned and provided. There's nothing routine about it; it's customized for each child and family," says Dr. Sara

Parvinian of the Children's Health Center in Gurnee, IL.

The IMHP is working with six pediatric

practices that have formed teams made up of physicians, nurses, office staff, and parent partners. Combined, these medical-home practices serve approximately 15,000 Illinois children, of which an estimated 2,250 have special needs.

ICAAP and the IMHP provide a framework to help these teams de-



liver care, seek out new resources, and break down barriers, all while building a closer relationship with caregivers, other healthcare professionals, patients, and parents.

"IMHP has helped me do a better job of listening to families and responding to their special needs," said Dr. Mark Rosenberg, Children's Healthcare Associates in Chicago, IL. "I can now anticipate these needs in other patients and make special accommodations more accessible to them."

The IMHP promotes seven distinct yet complementary elements. A true medical home is:

- **accessible**, with health providers who are available when and where parents and children need them;
- **continuous**, with pediatricians who provide ongoing support, ideally from birth through early adulthood;

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- **comprehensive**, offering high-quality care, which includes education, mental health and community referrals, as well as help with government and public assistance resources;
- **coordinated**, sharing information on care, progress, and resources freely so that everyone is “on the same page”;
- **family centered**, with health professionals who encourage caregivers to be partners in healthcare decisions;
- **compassionate**, showing patients respect and empathy at all times; and
- **culturally competent**, recognizing differences in language, heritage, and values to provide the best treatment possible.

“IMHP has given me a voice in my child’s care,” says Mona Bernhardt, a Lake County parent of an IMHP special-needs child. “Now when I meet with my child’s doctor, I have a better sense of not only where we are in my child’s treatment, but where we’re going for long-term care.”

To learn more about the Illinois Medical Home Project or the medical home concept, visit: [www.illinoisap.org](http://www.illinoisap.org) and click on the “medical home” link to a brighter future for kids. 🦋



## When families spoke, DSCC listened

by Nancy Hall, DSCC



When the Division of Specialized Care for Children (DSCC) asked, families who have children with special health care needs answered.

In December 2004, DSCC sent over 8,000 surveys to families of children receiving services from DSCC or newly eligible for SSI. The survey, used as a part of the five-year needs assessment required by the Maternal Child Health Block Grant, provided an opportunity to hear the voices of families and their experiences, according to Thomas M. Wilkin, Associate Director for Administration, who chaired the Family Needs Assessment effort. “With recent budget cuts, re-examining DSCC’s services through activities such as the survey helps us to determine whether we are using our limited resources as best as we can to meet families’ needs.”

DSCC staff modified the questionnaire used to survey DSCC and SSI families in 1997, including additional questions such as medical home and family-physician partnership questions. DSCC’s Family Advisory Council advised the committee on the drafted questionnaire and the survey process. The final eight page questionnaire asked about general family information, community health care access, care coordination needs, payment for healthcare services, primary care services, including family-physician partnerships, barriers to accessing needed care and for youth with special health care needs,

and transition planning needs. By March 2005, families returned over 4,000 surveys—nearly 52% of DSCC families and 22% of SSI families. Dr. Onufer, Director of DSCC, was pleased with the families’ response to the survey.

To assure independent analysis, DSCC contracted with the Survey Research Office, Center for State Policy and Leadership at the University of Illinois at Springfield to receive, analyze and report on the result of the surveys. A brief summary of the survey results follows.

### Community Health Access

Choosing from a list of services (i.e. dental, prescription medications, hospital care, etc.) families were asked: what services their child or youth needed, and whether those services were used or not used. Families were also asked about travel times required to access the services they used. For DSCC families, the three most common services reported as needed but not used were dental care, respite care and specialty dental care. For SSI families, the top three services needed but not used were respite, speech therapy and dental care. DSCC families most commonly reported traveling over an hour to use respite care, specialty care and genetic testing. SSI families reported that they traveled over an hour to use specialty care, genetic testing and hospital care.

### Care Coordination

In this section of the questionnaire families selected from a list of care coordination needs such as: help finding specialty care for treatment of your child’s condition, talk

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ing to your child's medical providers, etc. Overall, the most common assistance requested by families was working with education/school and medical providers. The three most common care coordination requests by DSCC families were meeting with the school to help teachers plan, helping their

pay. When families were asked if they had gone without necessities because of healthcare costs, one in five families reported that they had gone without necessities.

## Service Barriers

The questionnaire asked families what got in the way of getting services for their child or youth. Almost two-thirds of DSCC fami-

a medical home. These include: My child's personal doctor or nurse knows my child's health history; treats my child with compassion and understanding; is available in a timely way when my child needs care; involves me in decisions concerning my child; and helps me arrange for other healthcare services needed by my child. About 60% of families strongly agreed with each of these statements. Over 70% of families reported that their main provider usually or always made them feel like a partner in care.

## Transition Services

Families with a youth 14 years or older answered additional questions about transition needs, the availability of a transition plan to become independent, who helped develop the plan and how well that plan met their youth's needs. Over one third of DSCC families indicated that they have a plan or are developing a plan. Two-thirds of families report that school is assisting them with their child's plan. Over four in ten families said that their transition plan is serving their child extremely or very well. Over two-thirds of DSCC families reported health care transition planning needs including: accessing primary medical care, helping manage medical needs, accessing adult specialty care and paying for health care. 🌸



"We want to thank everyone who responded to the DSCC Family Survey, because your thoughtful responses help us to focus our program on addressing those barriers that prevent you from building better lives for your children."

child get special services at school and talking to medical providers. For SSI families, their most common care coordination needs were understanding the medical treatment plan, understanding changes in their child's medical condition, and talking to medical providers.

## Paying for Healthcare

Almost 93% of DSCC families and 87% of SSI families reported that they have a source to pay for medical care. For DSCC and SSI families, less than one family in five reported that the cost of care was a major deciding factor in whether their child received care. About one in twenty DSCC and SSI families reported that they were denied healthcare because of inability to

lies listed at least one barrier. Three-quarters of SSI families listed at least one barrier and were more likely to have more than one barrier. The three most common barriers reported by DSCC families were: needed services are too far from home, care is not covered by insurance, and waiting time in the doctor's office is too long. For SSI families, the three most common barriers were: transportation is not available or too costly, waiting time in the doctor's office is too long, and needed services are too far from my home.

## Primary Care Services

Families were asked how strongly they agreed or disagreed with six statements that are components of

## School nurse: your child's health assurance

**A**dam's needs are complicated. Born with multiple medical issues, he has daily medications, tube feeding and other care to stay healthy enough to be in school. He requires much of that care at school.

He is not alone. Some 13 million children in this country require some kind of medical attention during their school day. Their needs may be as simple as taking an antihistamine or as complicated as having their trachea tube suctioned. The child may already have a Section 504 Plan under the federal Rehabilitation Act or an Individualized Education Program (IEP).

It is the school nurse who makes sure the health care is delivered properly at school. If you have a child with health needs, knowing how to develop a strong working relationship with the nurse is a vital skill.



"The school nurse can be the linchpin in helping a child succeed in school," says Carolyn Allshouse, coordinator of PACER's Health Information and Advocacy Center. Cindy Hiltz, president of the School Nurses Organization of Minnesota, agrees. "School nurses can help problem solve," she says, noting that positive things can happen when the nurse and parents work together as a team.

Building a working relationship with the school nurse can take time, but it's worth the effort. Allshouse and Hiltz offer the following tips. Just remember ICE: Include, Communicate, Educate.

### Include

Teamwork and collaboration can go a long way toward providing the care your child needs in school. Many people may be part of the team, but parents should always be at the center of discussions. "They bring a unique and valuable expertise," Allshouse says.

- The parents and the child's doctor should work together to decide what orders should be written so the child can receive the needed services at school.
- Request that the school nurse be invited to your child's IEP meeting or set up a separate meeting with him or her to discuss your child's diagnosis and needs.
- Invite your child's doctor to join the IEP meeting in person or by conference call to answer questions from the nurse or staff.
- Involve your child as appropriate. Doing so establishes a closer relationship between your child and the nurse. It also builds independence, self-advocacy, and self-care skills.

### Communicate

You, the IEP team and perhaps your child's doctor, will be involved in meeting your child's health needs at school. To keep lines of communication open and avoid power struggles:

- Keep the focus on the child and your goals.
- Make sure your doctor puts in writing a list of all your child's health needs at school.
- Understand the nurse's perspective. A nurse may be responsible for 500 students—or 3,000. In addition, he or she

may need special training to work with your child's needs.

- Let the nurse know your child has a medical condition—even if it isn't currently active. You and the nurse can put a plan in place so school staff know what to do should a problem arise.
- Update the nurse when your child's medications, status or diagnoses change.
- Provide multiple contact numbers so the nurse can reach parents easily and quickly.
- Make sure you are speaking with the nurse when you call the health office.
- Have a plan for making sure medications and other supplies are on hand.

### Educate

Learn what the school district needs from you.

- The nurse may need more information on your child's particular condition or illness and how it affects your child. When you share pertinent information, the nurse begins to know your child and can provide better care and solutions.
- Bring information from the doctor as needed by the school district. This may include a doctor's written orders for medication or other medical procedures.

Above all, Allshouse says, keep a positive attitude and look for creative solutions. "They're out there," she says with a knowing smile. For information on school health plans, visit [www.pacer.org](http://www.pacer.org). 🌸

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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 Administration (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 statewide 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

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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 ev-

erything that will be needed, conveniently located with well-marked signs to guide them on their journey.

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 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

### 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.

to help more individuals with TBI, like Jeneesia and Brian (see box above), and their families. Just as important, because of these programs, the public will have a heightened awareness of TBI, which could ultimately result in measur- 

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

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