

Special Addition



children with special health care needs

spring/summer 2002

A NEWSLETTER FOR ILLINOIS FAMILIES

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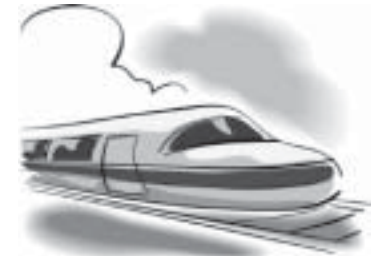
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Federal Viewpoint

ALL ABOARD the 2010 express

by Merle McPherson, MD, Director, and Gloria Weissman, Deputy Director, Division of Services for Children with Special Health Needs, Maternal and Child Health Bureau, Health Resources and Services Administration

The 2010 Express officially took off at the National Summit in Washington, DC, December 12th and 13th, 2001. More than 600 people, including many families, attended the summit. More than 150 volunteer, professional, and con-



sumer organizations co-sponsored the meeting, organized by the Health Resources and Services Administration (HRSA), Family Voices, the American Academy of Pediatrics (AAP), and the March of Dimes.

Claude Allen, JD, Deputy Secretary of the US Department of Health and Human Services addressed the group. He was introduced by HRSA's Acting

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Illinois News

Illinois assistive technology project (IATP) equipment loan center

Automobile salespeople believe that if they can get you to take a car on a test drive, half of their job is done. Why? Because they know that a test drive is asking to "try it on for size." While you're driving, you might imagine the car full of your friends or children. You'll see yourself taking it on vacation, or to visit family.

You'll want to check out its features, tune the radio to your favorite station to see how the speakers work or roll up the windows to see how quietly it runs at 60 M.P.H. You'll check to make sure it's within your price range. But when you test drive a car the main thing you decide is if it "fits" you. And if it does, the salesperson's job just got easier.

Technology designed for people with disabilities works the same way. The device must fit the user's needs, wants/desires, personal preferences and his/her pocketbook. The difference between technology for people with disabilities and a car is that car lots dot many corners in town, disability technology does not.

(IATP) please see page 10

"Listen to the calling of your heart and the true riches of life will follow."

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Administrator, Elizabeth Duke, PhD. Allen stated that the 2010 Express would “build upon work done over the past decades and represent the consensus of organizations and individuals throughout the country about how best to serve children and youth with special health care needs.” Mr. Allen presented data from the first National Survey on Children with Special Health Care Needs. The data indicates the following:

- about one-fifth of US households with children have at least one child with special health care needs.

- 15% to 16% of school age children have a special health care need.

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■ 16% to 20% of special needs children had an unmet need for a health-related service in the past year.

Polly Arango, co-founder of Family Voices and, until last year, its Executive Director, was the other opening speaker. She presented the six goals of the 10-year action plan, which is still undergoing formal approval, by using the stories of six families of children with special health care needs.

Commitments to the 10-year action plan were given by leaders of the meeting's four major sponsors: Louis Cooper, MD, AAP President; Jennifer Howse, PhD, President of the March of Dimes; Peter Van Dyck, MD, Associate Administrator for HRSA's Maternal and Child Health Bureau; and Jennifer Cernoch, PhD, Executive Director of Family Voices.

Other sessions at the summit focused on successful strategies for community and statewide implementation of the action plan. Representatives from a number of federal agencies, including the Department of Education, the Substance Abuse and Mental Health Services Administration, and the Centers for Medicare and Medicaid Services, agreed to help HRSA put community-based systems of services in place for all children with special health care needs.

Award-winning storyteller Odds Bodkin provided inspiration and motivation to summit participants. Smaller workshop sessions gave participants a chance to learn and exchange new information, models, tools, and skills for undertaking successful activities around the action plan's six major goals. In other small group sessions, communities of excellence from the US and abroad highlighted their strategies for building coordinated, family-friendly systems of care for children and youth with special health care needs.

The meeting was closed by a panel of youth with special health care needs who, through their inspiring stories, left participants with an exciting vision of what the future can

You can hear many of the summit's sessions by going to www.mchcom.com and clicking on "All Aboard the 2010 Express." A list of resources, which were available to meeting participants at the summit's cyber cafe, can be obtained at www.mchb.hrsa.gov. First click on "Links" on the sidebar, then "Children with Special Health Care Needs," and finally "CSHCN Helpful Links."

hold for all children with special health care needs.

Moving to statewide implementation

Now that the summit is over, the focus shifts to implementation at the state and community level. HRSA and its partners on the Summit Steering Committee—Family Voices, AAP, and the March of Dimes—are developing coordinated, complementary strategies to support families, professionals, state leadership, and state-level representatives of the other 150 summit co-sponsors in their efforts. The development of statewide coalitions and state action plans is an important goal for the next year. Identifying and engaging new partners in states and communities—from both the private and public sectors—will be critical.

The Division of Services for Children with Special Health Care Needs in HRSA's Maternal and Child Health Bureau has developed a national program around each of the six goals. Its efforts around one of these, the medical home, is described on page 7. Similar programs around the other goals will be described in future issues. □



DSCC family support groups

DSCC has started regional support groups around the state. The purpose of the support groups is to provide a structure for a group of people with a common life situation or set of challenges. They meet together to help themselves by sharing their experiences, ideas, frustrations, accomplishments and hopes. Each support group is open to all families and individuals with disabilities, not just DSCC families.

Currently, four regional groups have been developed:

Greenville, Illinois, serving families in our East St. Louis Office

Naperville, Illinois, serving families in our DuPage Office

Palos Hills, Illinois, serving families in our Metro South Office

Peoria, Illinois, serving families in our Peoria Office

Each group has a parent coordinator who is responsible for arranging the meetings. Topics from the groups have included: special education rights, family stress, medical home, transition and many more.

If you would like to participate in an existing group contact Bob Cook, Family Liaison at 1-800-322-3722 or rjcook@uic.edu. □

From the Heart...

Stories & Comments from DSCC Families



Well, the jaybird did it! He had his first day of school. He loved it. They sit around in a circle, sing songs, hit switch toys to say GOOD MORNING, JAY IS HERE TODAY!

He slept a little in the morning, but they had a b-day party for him, I brought cupcakes to schmooze the teachers a little! The teacher said

he enjoyed it. He came home on the bus, that was so funny, I am so happy he likes it. The therapists are good & are working with him. I just kept thinking I was going to get a call saying to come get jaybird, he is screaming!

It's so funny, I kept looking around the house for him, then I kept thinking I would forget the time he comes home! I told the teachers, if they think the cupcakes



Jay Krieter

are good, wait till next week - KRI SPY KREMES!!!

Oh well, I was talking about this for so long I just wanted everyone to know it went well, and the program there is wonderful! I will get pictures when he gets his "ENGER" school wear! Linda (mother)

submitted by Marcia Brueggemeyer
DSCC - Metro North Regional Office

Oral Health: It's more than just clean teeth

by Campaign for Better Health Care: The Voice of Illinois Consumers

As Americans look for ways to improve their health, it is essential to recognize the importance of good oral health. Good oral health starts at home and in the schools, with regular brushing and flossing as well as high quality oral health education. High quality, comprehensive oral health services need to be available. This includes preventative services such as regular cleanings, sealants, dental exams and x-rays, as well as restorative services including reconstructive and surgical procedures.



The Surgeon General's "Oral Health 2000" Report paints a serious picture of our oral health problems. In America, 50% of our population does not receive adequate preventative dental care, mostly due to problems getting services. In Illinois, this is particularly a problem for children, the elderly, rural Illinoisans, people with disabilities, racial and ethnic minorities, and working families. That is a lot of Illinoisans! In 1995, the American Academy of Pediatrics ranked Illinois last of all fifty states for Medicaid-enrolled children with a dental visit: only 1%.

The Campaign for Better Health Care, a statewide grassroots coalition dedicated to improving health care services in Illinois, has developed a Dental Access Working Group to advocate for high quality accessible oral health services for low-income children. This group is reviewing oral health policies in Illinois and is creating a set of recommendations to present to the Illinois Department of Public Aid. Everyone who is interested in improving oral health services for children in Illinois is encouraged to join and become a member of the Dental Access Working Group. The Dental Access Working Group meets quarterly in Bloomington, Illinois and runs an ongoing online discussion group. To join or to get more information, or share your story, call or e-mail Andrea Rundell at the Campaign for Better Health Care at 1-888-511-0290, arundell@cbhconline.org.

Oral health disease is 99% preventable. Poor oral health leads to needless suffering and poor overall health, especially for children. Get involved in advocating for quality oral health services for children, because every child should be proud of their smile. □

Visit Our Home on the Web

www.familyvoices.org

What can you find on the Family Voices WebSite?

Our Weekly Alert "Friday's Child"
Our bi-monthly newsletter, "Voices"
Position Papers
Fact Sheets
Family Voices Projects
State Specific Information

We are families from throughout the United States who have children with special health needs.



We are also caregivers, professionals and friends whose lives have been touched by these children and their families.

We are a diverse group, representing a wide variety of children, health conditions, families and communities.

Our concern for children brought us together.

Family Voices

Family & Friends Speaking on Behalf of Children with Special Health Care Needs

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People first language

by Kathy Snow

A handicap has been defined as an obstacle which society imposes on a person with a disability, i.e., inaccessible transportation or buildings, no signage, etc. Handicapped is not a term to describe human beings. A disability has been defined as a body function that operates differently. It's that simple! It's just a body function that operates differently. People First Language seeks to put the person first and the disability second! People with disabilities are people, first and foremost.

The disability rights movement had a slow start in the 1970s, but the momentum has continued to accelerate, especially in the past few years. Using People First Language is part of the disability rights movement.

In 1990, the Senate Subcommittee on the Handicapped became the Senate Sub-committee on Disability Policy.

On July 26, 1990, the Americans with Disabilities Act, P.L. 103-336, was enacted, prohibiting discrimination based on disability in employment, public service, public accommodations, and telecommunications for the more than 43 million adults and children with disabilities in the U.S.

Notice it was not called the Handicapped Americans Act!

In late 1990, P.L. 94-142, the Education of All Handicapped Children Act, was reauthorized and renamed by Congress to become P.L. 103-476, the Individuals with Disabilities Education Act (IDEA).

Isn't it all great? But we still have a long way to go. For government cannot legislate morality, values, or feelings. Persons with disabilities must be perceived as valuable, participating members of society because they are. Since our language reflects our values, our language must change.

Remember the Civil Rights Movement? The Civil Rights

Act was passed long ago in 1964. But it took years before the law really seemed to have an effect. During that time, a long-used, degrading term finally became Negro, then Black, and now African-American.

Ditto the Women's Movement . . . "honey" and "girl" gave way to "Ms." No legislation was ever passed for this movement, but our society has, nevertheless, changed a great deal in this area.

A person is not handicapped.

A person is not disabled.

A person has a disability.

Now it's our turn . . . time to change the language used to describe children and adults with disabilities. No more labels! Labels degrade. Labels evoke negative pictures in our heads. Labels don't address individuality - they lump people together and focus on the disability, not on a person and his/her abilities. Society will not change its language unless we insist on the change. We have the right to do so.

Have you ever wondered where the word "handicap" came from? The dictionary has one definition

from an old Gaelic term, which referred to a person with disability who had to stand on the street corner begging with his "cap in

hand." Is this a term that should be applied to anyone with a disability???

Persons with disabilities want the same things all Americans want: dignity, respect, and the opportunity to participate fully in American life.

Those achievements are hard to attain when one's whole being is defined by a label: handicapped, disabled, mentally retarded, crippled, autistic, blind, deaf, etc. Traditionally,

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"Imitation of another is limitation on oneself."

What families need to know about a medical home

by Dr. Charles Onufer, Director of DSCC



Illinois governor George Ryan has proclaimed “2002, The Year of the Medical Home.” In this issue of “Special Addition” we have articles explaining the various aspects of a medical home. The medical home isn’t a place but a concept that enhances the family-professional partnership in medical care for children. Please feel free to contact us at DSCC regarding this partnership.

When a family brings their child to DSCC and they’re asked whether they want to participate in a medical home, what does that mean? Will I now have to receive my child’s health care at a medical home? Does it cost more money? Do I have to fill out a long application? What am I expected to do? What will DSCC do? Will it affect my health insurance benefits? Will I need to change doctors? The questions can be endless, but let me try to explain medical home.

Medical home is not a place, a house, or a building. It is not a place where you can go. Medical home is a special relationship that you have with health care professionals and how they provide health care for your child. There are no additional applications to fill out; every family whose child is eligible for DSCC services can participate in a medical home. There are no special fees you have to pay. A medical home does not change your health insurance coverage. Then you might say, “tell me what a medical home will do for my child and family.”

Medical home is a relationship among the health care professionals who take care of your child. We call this a “family-professional partnership.” In this partnership all the health care professionals respect the parents’ understanding of their child’s needs and the priorities the family has for meeting those needs. A “care coordination plan” to meet your child’s needs and good communication between the health care professionals caring for your child are additional important elements in a medical home.

this “family-professional” partnership.

The next professional to become involved in this “family-professional partnership” is your child’s “primary care provider.” A family physician or a pediatrician are the two most common primary care providers for children. They take care of your child for such common problems as head colds and earaches; and they give immunizations and advice on routine health care problems. Your child’s “primary care provider” will work with you, your child, and the DSCC

care coordinator to add the “medical details” to your child’s “care coordination plan.” In other words, for each health care need you identified for your child, the “primary care provider” will suggest how that need can be met. For example, you may be concerned that your child has a “seizure problem” and needs help. Your child’s seizures may be causing learning problems in school, school absence, and behavior problems at home. The

“primary care provider” may order some blood tests, a brain wave test and refer your child to a pediatric specialist, called a pediatric neurologist, and a behavior specialist, called a psychologist.

The “family-professional partnership” is growing and now includes a pediatric neurologist and a psychologist. All the people making up the “family-professional partnership” can also be called the

How closely does this describe the health care situation your child has now?

A child should have at least one personal doctor or nurse who can be depended upon:

- To know your child’s health history
- To treat your child with compassion and understanding
- And to be available in a timely way when your child needs care

You should be able to trust this same doctor or nurse to:

- Listen to your concerns
- Involve you in decisions concerning your child and, when necessary
- Help you to arrange for other health care or services needed by your child

—This Is a Medical Home!

In the 13 Regional Offices throughout the state, the DSCC staff who serve your child are called “care coordinators.” They will help you develop a “care coordination plan” for your child. This plan is based on what you explain are the “needs” of your child and the “priorities” you feel need to be addressed. In other words, what needs to be worked on first, then second, and so on. You and your child, plus the DSCC care coordinator, create the beginning of

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“medical home team” for your child. These two additional “team members” will add their areas of expertise to the “care coordination plan.” Your DSCC “care coordinator” can help you understand who the members of your child’s “medical home team” might be.

The degree to which all members of the “team” provide a medical home can be called “medical homeness.” Let’s look at what adds to “medical homeness.”

- A primary care provider (your child’s pediatrician or family physician) is available 24 hours a day, 7 days a week. That means you may call your doctor and arrangements can be made for your child to be seen or questions answered 24 hours a day, 7 days a week.
- You have a trusting and good working relationship with all members of the “team.” You feel comfortable sharing your concerns about your child and

know that the team members respect you.

- The “care coordination plan” that is developed by the DSCC care coordinator with all other team members is comprehensive; the “plan” includes all your child’s needs and how they are going to be taken care of.
- Your child’s “care coordination plan” should contain a timeline so that immediate needs are addressed as well as future needs, like transition to adulthood. You may need to think about things like health insurance, employment, education (college or vocation), living in the community (by themselves, in your home, etc.) and community recreation.
- Communication occurs among all members of the “team.” Here is where the DSCC care coordinators can help to make sure that all reports and other information from “team

members” are shared with your permission.

- All members of the “team” show compassion for your child’s problems and are sensitive to your individual cultural background.
- Health care providers (your pediatrician or family physician and pediatric specialists like the psychologist and pediatric neurologist) have offices that are accessible by wheelchair, have office staff who are aware of your child’s special needs, and give you appointments that allow enough time for you to express your concerns and have your questions answered.

All of the above make up a medical home. The degree to which they are practiced determine the amount of “medical homeness” that you and your child experience. DSCC wants to work with the professionals who make up your child’s “medical home team” so that you experience the maximum “medical homeness” in a medical home. □

How can families help in a Medical Home?

*By Dr. Merle McPherson, Director of the Division of Services for Children With Special Health Care Needs in the Maternal and Child Health Bureau,
U.S. Department of Health and Human Services. Washington, D.C.*



“Families are key to promoting medical homes at the practice, policy, and practical level and accomplishing our goal of a medical home for every child. Families are best able to communicate with other families about the benefits of a medical home and most effective in advocating for the needs of their children. They also have an important role to play in educating healthcare professionals around the changes in attitude, behaviors, practices, and procedures that are needed to truly implement medical homes.” In order to ensure that all families feel welcome and comfortable in medical homes, a diversity of families need to be involved in this effort.



*Excerpt from “Parents as partners in the medical home, Part 4”
Exceptional Parent Magazine December 2000*

The National Medical Home Implementation Program

by Merle McPherson, MD, Gloria Weissman, and Bonnie Strickland, Ph.D., Chief, Integrated Services Branch

Since the early 1990's, the "medical home" concept of coordinated care (originally championed by Dr. Cal Sia of the Hawaii Medical Foundation), has become a model of care for children with special health care needs. The medical home is an ongoing source of routine health care that provides preventive, primary, and acute care. It is coordinated with other aspects of health and medical care, such as subspecialty care, and with other community services, such as audiology and early intervention. And it supports inclusion and full participation for the child and family in the community.

In a 2002 policy statement, the American Academy of Pediatrics (AAP) defined the medical home as "the collaborative effort between primary care providers and children with special health care needs and their families to ensure that care is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and delivered in a culturally competent environment."

Here and abroad, the medical home model has been recognized as the one that serves children and families best. Research supports the concept, and now "medical home" is an important measure of quality care.

Yet, we know that many children with special health care needs do not

receive adequate primary care. Coordination between primary and specialty care is often lacking for these children, and health care is not well coordinated with other community services.

For these reasons, over the past decade, the Maternal and Child Health Bureau (MCHB) has been playing a national leadership role in promoting the medical home concept and supporting the development of medical homes for all children with special health care needs.

Demonstration projects

MCHB's Medical Home Initiative began in 1997 with the funding of demonstration projects by the Division of Services for Children with Special Health Care Needs. These projects were located in Alaska, Arizona, California, Connecticut, Hawaii, Indiana, Massachusetts, New Hampshire, New York and Virginia. From them we learned that partnering with state organizations, families and private organizations, including payers and insurers, was the most effective strategy to promote the medical home concept at the state level.

Medical Home National Center

At the same time, MCHB realized that, in order to bring about medical homes for all children with special health care needs, it was important to provide national leadership to help health care professionals put the medical home concept to work in their medical practice settings.

The bureau has partnered with AAP to create a national center for medical home resources and training. Along with Shriners Hospitals for Children, the AAP conducts up to 12

Medical Home Trainings a year. There is an extensive handbook and curriculum for these trainings that can be tailored to cover local concerns, while still addressing all components of the medical home.

Training participants learn how to develop strategies for better coordi-



nation between primary and specialty care and how to establish mechanisms for coordination between the medical home and other community services. Training teams include families, in order to both teach and model the family-professional partnership-so crucial to a successful medical home.

With MCHB support, the AAP also spearheads the medical home Mentorship Network, which takes a "train the trainer" approach. Outstanding state teams host other states at different stages of medical home implementation. This year there are 15 funded states, including Illinois in the Mentorship Network. Several additional states are providing leadership on statewide implementation of the medical home.

Measuring the medical home

One key to developing medical homes for all children with special health care needs is finding ways of measuring the additional services and costs this type of care entails so that pediatric and family physicians can be appropriately reimbursed. Preliminary work is underway around practice-level costs of

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The AAP has a medical home website (www.medicalhomeinfo.org). Descriptions of past and current projects, available resources, and other technical assistance are provided at the site. Scheduled medical home trainings are listed well in advance of training dates.

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implementing the medical home.

Additionally, a practice-level medical home measurement tool, the Medical Home Index, has been developed under a MCHB grant by Dr. Carl Cooley in New Hampshire. This tool, to be used over various time intervals, allows a practice to find out how well it is accomplishing the core components of the medical home and to improve its work in each area. This has become a key component of the Mentorship Network's technical assistance program.

The MCHB is also looking at how to measure the extent to which medical homes are in place for children with special health care needs at both the state and national levels. Through a contract with the Foundation for Accountability (FACCT), we have put together a medical home measurement advisory committee, which is

developing a common approach to measurement of medical home across national surveys, including the National Survey on Children with Special Health Care Needs, and at the state level.



Statewide implementation

In 2001, MCHB began to support a different kind of medical home project—one that was focused on bringing all the necessary partners together to implement medical homes for children with special health care needs throughout a state.

These projects build upon the knowledge gained from the demonstration projects, but are focused on full implementation of the medical home concept in a state. State Title V program involvement is the key.

Seven grants were funded the first year—in Massachusetts, New Hampshire, New Mexico, Oregon, Pennsylvania, Utah, and Washington. In late March 2002, an additional eight states were funded for medical home implementation.

Statewide medical home projects are as varied as each state. Different approaches are used for rural versus urban locations, multicultural and multilingual locations, and demographically varied populations. However, all have the same goal: to work with families, providers, and other partners to provide the best possible comprehensive coordinated care for all children with special health care needs through a medical home. □

7 principles of family/professional collaboration

Family/professional collaboration:

1. Promotes a relationship in which family members and professionals work together to ensure the best services for the child and the family;
2. Recognizes and respects the knowledge, skills and experience that families and professionals bring to the relationship;
3. Acknowledges that the development of trust is an integral part of the collaborative relationship;
4. Facilitates open communication so that families and professionals feel free to express themselves;
5. Creates an atmosphere in which cultural traditions, values and
6. diversity of families are acknowledged and honored;
6. Recognizes that negotiation is essential in a collaborative relationship; and
7. Brings to the relationship the mutual commitment of families, professionals, and communities to meet the needs of children and their families.

What is Trust?

- Trust means having a firm belief or confidence in the honesty, integrity, and reliability of one another.
- Trust validates each person in the collaborative relationship and implies a shared belief that everyone is interested in providing the best services for the child and the family.

Trust Involves Risk:

For Families: It means entrusting the care of their child to others in the belief that they will be sensitive to the family's goals and wishes.

For Professionals: It means that they may not meet the expectations of the child and the family.

For Both: It can mean exposing vulnerability. Trust must be earned. Once it is achieved, trust creates an atmosphere in which the dynamics of the relationship can flourish. □

These principles were obtained from "Family/Professional Collaboration for children with Special Health Needs and their families" by Kathleen Bishop

Upcoming events for families

Abilities Expo

August 16-18, 2002

Donald E. Stephens Convention Center, Rosemont, Illinois

Abilities Expo, the one show dedicated to educating and improving the lives of people with disabilities, senior citizens, their families & caregivers, as well as healthcare and education professionals, allows you to discover new products and services - from computers to athletic equipment and mobility products to daily living aids - all conveniently displayed for you to see, test and compare. For information go to www.abilitiesexpo.com Chicago location.

Statewide Parent Advocacy Conference: "2002 Advocacy Odyssey"

September 14 & 15

Holiday Inn, Decatur, Illinois

Sponsored by the Soyland Access to Independent Living (SAIL), one of the Illinois Centers for Independent Living, this two day event will bring together families with children and individuals with disabilities from across the State to learn and share stories and ideas. Topics will include:

- Using the law to advocate for your child.
- How to form and sustain parent groups.
- Working with your schools.
- Plus many, many more.

The conference committee is looking for parent volunteers to help both on the committee and during the conference. For further information contact Emily Dobson, Family Advocate for SAIL at 1-800-358-8080 or e-mail Emily at edobson@hotmail.com. □

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our society has not expected much from a person with a label. This is changing now, for people with disabilities are more like people without disabilities than they are different! A disability is simply only one aspect of the sum total of a unique individual.

No more labels! Instead, People First Language (PFL)! What is it? It focuses on the person first, the disability last. How do you know what it is? It describes what the person HAS, not what he/she IS. It's easy, just use your imagination:

- people with disabilities
- a child with cerebral palsy
- my sister has a cognitive impairment
- my father has a visual impairment
- my daughter has a hearing impairment
- my child has a developmental delay
- my brother has autism
- I have an orthopedic disability

And no one "suffers from," "is afflicted with," or "is a victim of" anything! Nor is anyone wheelchair-bound. There are people who use wheelchairs, nothing else. My son is not "bound" by his wheelchair; he is free to go where he wants!

In addition, children are not born with birth defects. They are born with congenital disabilities; they are not defective - toasters might be, babies aren't. And, we don't say that typical kids are in regular ed, so why do we say kids with disabilities are in special ed? Instead, children with disabilities receive special ed services.

When a label comes from the mouth of a doctor, a teacher, a therapist, an employer, a rehabilitation counselor, a TV reporter, a newspaper writer, or a friend, gently correct them . . . "I prefer the term 'people with disabilities' (or whatever)." Then explain why it's important to use

People First Language. Would they like to be labeled; to be defined by only one aspect of who they really are? What it really comes down to is good manners and the old Golden Rule . . . treat others as you would like to be treated.

- As our society's language changes, as we talk about people first, perceptions will change, and
- attitudes will change, and
- society's acceptance and respect for people with disabilities will increase, and
- an inclusive society will become a reality.

History tells us it takes at least one generation between the time an idea is born and the time it is actually incorporated into our society. Perhaps we'll change that truism. We have no time to waste. I hope that when my now 8-year-old son is an adult, labels will be as extinct as dinosaurs!

We're advocating on behalf of many people - millions who currently have disabilities, as well as those who may have disabilities in the future! Advocacy means change and change creates tension. Don't be dismayed if you encounter resistance or if you have to correct the same people many times. Old habits die hard; they do go away when they're replaced by good habits. Change your habits first, then work on others.

People First Language is right and the time for it is now. Just do it! □

VISIT THE DSCC WEBSITE

www.uic.edu/hsc/dscc/



This newsletter is available on-line and in alternate format in English and Spanish upon request by calling (800) 322-3722.

continued from page 1 (IATP)

However, TechConnect is working to make it easier to try devices on for size.

The Illinois Assistive Technology Project (IATP) located in Springfield has a new and improved demonstration and loan center open for business. They have expanded their services and added more technology and more features.

Loan devices from the project are available in the following areas:

- Activities of Daily Living
- Communication Devices
- Sensory Devices (Vision/Hearing)
- Toys, Books and Educational Materials
- Computer Access/Office Technology
- Switches

Loan Policy

TechConnect loans devices on a first-come, first-serve basis to individuals or organizations in Illinois. The sole purpose of the loan is to let the borrower try it out. TechConnect always retains ownership of the device. Borrowers must fill out and sign an Equipment Loan Form. By signing the form the borrower agrees to assume responsibility for the device and any accessories that may accompany the device. Accessories include, but are not limited to: batteries, overlays, adapters, attachments, carrying cases, cables, manuals, directions, etc. TechConnect will list all accessories on the loan form.

Borrowers must also agree to these statements:

- They are a resident of Illinois.
- TechConnect loans devices for two weeks only.
- We allow two mailing days from our office and two mailing days back to TechConnect for a total loan period of 18 days. The borrower assumes responsibility for returning the

device within the allotted time.

- TechConnect pays for shipping to the borrower. The borrower must cover the return postage or personally return the device to the office.
- The borrower is responsible for charging and replacing the batteries as needed.
- The borrower is responsible for the care and maintenance of the device on loan.
- The borrower could be responsible for repairing or replacing the device if it is lost or irreparably damaged through carelessness.

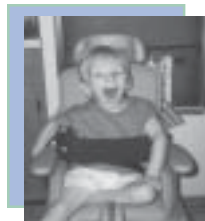
To borrow a device call 800-852-5110 v/tty, Monday through Friday between 8:00 a.m. and 4:30 p.m. TechConnect will follow-up to learn how the user felt about the device and any action he/she took in obtaining a device. □

From the Heart...

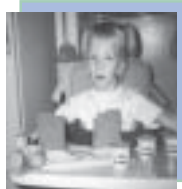
Stories & Comments from DSCC Families



In August, DSCC helped purchase a new feeder seat for Francis "Frankie" Coley.



Frankie's mother sent pictures of his 6th birthday party to care coordinator Marcia Brueggemeyer, Metro North Regional Office, along with this note, "This is the little boy you help so much. Thank you for everything you have done for us this past year - highly appreciated." Frankie's new tray has proved useful for both feeding and for playtime, illustrated by the pictures mom sent of Frankie with his toys spread out on the tray in front of him. "He loves it," she says, "and so do I."



Thank you from Friends of DSCC honor roll of giving

Friends of DSCC would like to thank the following individuals and organizations for their recent contributions.

\$200

Illinois Chapter of the American Association of Healthcare Administrative Management (AAHAM)

Under \$50

Lisa S. Thornton, MD
Gregory & Diane McClure
Jeri Karkos & David Ellington
Lisa Hill

Friends of DSCC is a resource to help families of children with special health care needs. The DSCC Family Advisory Council and the University of Illinois Alumni Association have worked together to establish an avenue for businesses and individuals to assist these families through tax deductible donation.

DSCC will use these funds for purposes which further the broad mission of the agency, including assisting families to meet unique, non-recurring needs of the child and/or family and educational needs which cannot be met through the established DSCC program. If you want to make a donation or have any questions or comments about *Friends of DSCC*, please contact the DSCC Family Liaison Specialist, Bob Cook, toll-free at 1-800-322-DSCC (3722) or email at rjcook@uic.edu. □



Management of the child with spasticity

by Deborah Gaebler-Spira, M.D.

There are many options for management of spasticity in the growing child. Spasticity is a resistance to movement imposed on a limb, such as arms or legs. The decision to treat spasticity is based on the severity of tone abnormality and the impact it has on the child's comfort and function. Generally high tone or spasticity is treated if it interferes with mobility, such as crawling, standing or walking, activities of daily living such as feeding, dressing or bathing or orthopedic alignment. It is important to assess the extent of the spasticity. It should be determined if spasticity interferes all over the body or if it is localized to one or more limbs. If the spasticity is local or just involving an arm or leg, frequently botulinum toxins are utilized to reduce this type of focal tone. Botulinum toxins act only at the site of the injection and last 3-4 months. The effect is temporary but can change the balance of muscle forces in dynamic or non-fixed contractures. Typically, this management is used prior to orthopedic surgery in a younger child. There are many studies to support the reduction of muscle tone following injections. It is important to use botulinum toxins in conjunction with physical therapy and occupational therapy to get the most out of the reduced muscle tone. If the spasticity is global or all over the body, there are medications that may reduce the muscle tone sufficiently to improve the movement of the limbs. There are side effects to all medications



however; a trial of oral medications is warranted in the child with severe to moderate tone.

The surgical options for spasticity are selective posterior rhizotomy (SPR) and Intrathecal Baclofen (ITB). Each have their place and advantages. The SPR is utilized for the child with pure spasticity, no other tone abnormality. This surgery cuts the posterior rootlets of the nerves coming into the spinal cord. These nerves are the ones that carry sensory input into the spinal cord. The child does not lose any ability to move but the stretch reflexes are reduced. This has been very effective in reducing spasticity. This procedure has been utilized in the United States as early as 1987. The child that benefits from this surgery is generally a younger child, 3-8 years of age, who will most likely be able to walk in the future before any orthopedic problems manifest. The child should be free of major orthopedic contractures and able to have strength enough to support their weight. Strength may be reduced after SPR. Rehabilitation is critical post surgery. Careful follow-up must continue for orthopedic concerns. SPR is a permanent procedure and is destructive to the nerve rootlets.

The use of Intrathecal Baclofen is another neurosurgical operation that introduces Baclofen into the spinal area. This is a very effective and profound way to reduce spasticity. The dose of Baclofen is controlled by a computer in the pump that is implanted into the abdomen.

The dose can be changed depending on the child's need. This has been utilized in spasticity associated with cerebral palsy since 1996 with good results. The children who benefit from it are those with moderate to severe spasticity who have been

unable to tolerate oral meds. The child should be at least 30 pounds to tolerate the pump implant. The ITB pump needs to be refilled every 3 months as an outpatient office procedure. There are risks and complications for ITB as well. The family needs to be able to communicate with the physicians and be able to make all appointments so that the pump does not run out of medication. The battery life is 5 years. This procedure though is reversible.

If the effects are not appropriate, or if the child does not benefit, the pump may be removed.

In a growing child, contractures form as the muscles become tight. Orthopedic surgery is the mainstay of management of contractures. Neurosurgical or spasticity management does not rid the child of orthopedic surgery completely. All children should be carefully screened for contractures that limit the progression of mobility and activities of daily living (ADLs). The trend for orthopedic surgery is to wait until it is clear how each joint impacts on the child's ability to stand, sit and walk. The multilevel approach to orthopedic surgery is favored over what used to be a one-surgery-at-a-time approach. This minimizes the number of hospitalizations for the child. Also immobilization after surgery has been reduced so rehabilitation may begin earlier than when casts were left on for long periods of time. This has reduced the muscle atrophy and weakness seen after surgery. In most children with cerebral palsy or other conditions, well-timed management of muscle tone and attention to alignment problems are necessary. By integrating orthopedic management with spasticity control, children with spasticity maximize their function and comfort. □



Are you planning for transition?



Transition means change. All of us go through transitions in our life, from infancy, to school, to adolescence, to adulthood. Children and families experience many transitions, large and small, over the years. The journey from childhood to adulthood is often filled with joys and challenges. This journey becomes even more challenging for children with special health care needs. At the time of diagnosis, the journey begins with hurdles to cross and paths to choose. When children grow older, navigating through the journey may seem easier, yet always filled with obstacles to face. When moments come and you have a chance to think about the future, it may be helpful to be aware of those transitions and obstacles you may face. Transition involve changes: adding new expectations, responsibilities, resources and letting go of others.

Transition is a process, not a one-time event, consisting of a series of planned steps to provide learning opportunities for building skills, preparing to meet new expectations,



and taking on new responsibilities to become more independent. It should occur gradually. Parents, youths, DSCC care coordinators and healthcare providers need to work collaboratively to plan for transition, keeping the needs and desires of the youth at the center of the plan. Young adults should take charge of their lives, including their health care, while parents and health care providers gradually let go and provide support through this process.

DSCC care coordinators have expertise in coordinating medical services, advocating for children and youth with special health care needs (CYSHCN) and assisting CYSHCN through the transition process utilizing their expertise in medical transition. Medical transition has been defined as the purposeful planned movement of adolescents

and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems.

To help CYSHCN achieve independence in their own health care and other areas of their lives, it is necessary to consider the child's/youth's developmental age and physical, emotional, social and intellectual abilities. Guidelines, suggested

activities and tools have been developed to assist in promoting successful transitions for CYSHCN. To

find out more, discuss transition with your DSCC care coordinator and soon DSCC will be adding transition information to the DSCC web site. You may also want to visit the following web sites: <http://depts.washington.edu/healthtr/>; <http://hctransitions.ichp.edu/>; <http://www.mchbhrw.org/>.



PLANNING FOR THE FUTURE

"The future is not something we enter. The future is something we create and creating that future requires us to make choices and decisions...that all begins with a dream."

Leonard L. Sweet

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