

Special Addition



children with special health care needs

spring/summer 2001

A NEWSLETTER FOR ILLINOIS FAMILIES

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Federal Viewpoint

A 10-year action plan for children with special health care needs and their families

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

In partnership with Family Voices, the American Academy of Pediatrics, and the March of Dimes, the Maternal and Child Health Bureau of the Health Resources and Service Administration (HRSA) has released a draft of *A 10-Year Action Plan: Achieving Success for Children with Special Health Care Needs and their Families*.

This plan is the work of six workgroups that met in 2000. The groups included members from state Title V programs, families, professional groups, providers and communities. Each group focused on one of the six core goals, which are listed on page 2, for implementing community-based systems of care.

The 10-Year Plan contains practical action steps and strategies for accomplishing each of these goals, and putting in place—for good—the

services and supports that our children and youth with special health care needs deserve. The plan will be the centerpiece of a monograph that accompanies *Healthy People 2010*. Most important, it will provide a roadmap for our work at the Maternal and Child Health Bureau on behalf of children and youth with

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Illinois News

What does the term medical home mean?

Over the next year DSCC will be expanding care coordination to include the components of the concept *medical home* for children with special health care needs.

A *medical home* is not a building, house, or hospital, but rather an approach to providing health care services in a high-quality and cost-effective manner. Children and their families who have a *medical home* receive their primary care from a pediatrician or family physician they trust. Pediatricians/family physicians and parents act as partners in a *medical home* to identify and access all the medical and non-medical services

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special health care needs and their families for the next decade. We are working hard with partners, including families, providers, states and communities, national and local organizations, foundations, insurers and businesses, to build the plan into the ongoing efforts for children and families.

The draft of the 10-Year Action Plan is available on the web at <http://cshcnleaders.ichp.edu/measuresachievingsuccess.htm>. We are interested in your reaction to the draft, which will be revised in late summer. Please read it, and share it with others in your community. Any comments should be addressed to Gloria Weissman, who can be reached by phone at 301-443-8999 or by e-mail at gweissman@hrsa.gov.

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Heading for a national summit

Formal roll-out of the 2010 monograph and the 10-Year Action Plan will take place at a *National Summit on Children with Special Health Care Needs* scheduled for December 12th and 13th, 2001 in Washington, DC. The meeting will be sponsored by HRSA, Family Voices, the American Academy of Pediatrics, the March of Dimes and many other organizations. Save the date, and stay tuned for future details!

We are expecting about 1,500

“The plan will provide a roadmap for our work at the Maternal and Child Health Bureau for the next decade.”

participants at the meeting—families; health professionals; federal, state, and local officials in health, education, childcare, and social services; and representatives from the business and foundation communities. All are welcome! The summit will present the action plan and encourage participants to help each other achieve its goals. It will showcase community and state successes, models and best practices. It will provide opportunities for families of children with special health care needs from throughout the nation to come together and work in partnership with others from their states and communities.

A planning committee is busy trying to make this an exciting and

Core goals for community-based systems of care

- All children with special health care needs will receive coordinated ongoing comprehensive care within a medical home.
- All families of children with special health care needs will have adequate private and/or public insurance to pay for the services they need.
- All children will be screened early and continuously for special health care needs.
- Families of children with special health care needs will partner in decision making at all levels and will be satisfied with the services they receive.
- Community-based service systems will be organized so families can use them easily.
- All youth with special health care needs will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work and independence.

valuable summit. Please contact Gloria Weissman if you have ideas for meeting sessions or speakers. We are developing materials that can be used to get the word out about the meeting. These materials will include a “Save the Date” notice, as well as a fact sheet about the 2010

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needed to help their children and families achieve the maximum potential.

All children should have a *medical home* where care is accessible, family-centered, continuous, comprehensive, coordinated, compassionate and culturally competent. Examples of these elements include:

■ **Accessible** - Care provided in the child's community. All insurance, including Medicaid and KidCare, is accepted and changes are accommodated.

■ **Family-Centered** - Recognition that the family is the principal caregiver and the center of strength and support for children. Unbiased and complete information is shared on an ongoing basis.

■ **Continuous** - Same primary pediatric health care professionals are available from infancy through adolescence. Assistance with transitions (to home, school, adult services) is provided.

■ **Comprehensive** - Health care is available 24 hours a day, 7 days a week. Preventive, primary and tertiary care needs are addressed.

■ **Coordinated** - Families are linked to support, educational and community-based services. Information is centralized.

■ **Compassionate** - Concern for the well-being of the child and family is expressed and demonstrated.

■ **Culturally-Competent** - Family's cultural background is recognized, valued and respected.

The ideal source of a child's *medical home* is a primary care physician working in partnership with the child's parents. For children with special needs, it may be best for a pediatric subspecialist to coordinate care with the child's primary care physician and parents to provide a *medical home*. □

Consumer stipend project

The Illinois Early Childhood Intervention Clearinghouse distributes money provided by the Illinois Council on Developmental Disabilities to enable people with disabilities and their families to attend conferences of their choice related to disability issues.

Who Can Apply?

- Illinois resident
- A person with a developmental disability
- A parent of a person with a developmental disability
- An immediate family member of a person with a developmental disability
- A guardian/foster parent of a person with a developmental disability

How Much Can I Apply For?

There are limits on how much money the Project can provide. The limit is \$400 per person or \$600 per family, one time every two years. Individuals must provide receipts for

all costs incurred to attend the conference.

How Do I Apply?

Stipends are granted on a first-come, first-served basis with Project funds evenly distributed over four quarters during the year. The application form must be completed and returned with a complete copy of a registration form from the conference/workshop the applicant plans to attend. It should be filled out in the name of the person(s) attending the conference. All applications and conference registration forms must be received prior to the date of the conference/workshop (no exceptions). Conference or workshop topics must be specifically related to disability issues. □

Where Do I Apply?

ILLINOIS ECI CLEARINGHOUSE
830 South Spring Street
Springfield, IL 62704
Phone: 800-852-4302 (in Illinois)
Fax: 217-524-5339 (24 hours)

Lekotek play centers and toy lending libraries

Lekotek Play Centers and Toy Lending Libraries, located throughout the state, provide services to children with any disability, special need or chronic illness and their families.

Lekotek Centers are dedicated to making play - and the learning that results from it - accessible to children with disabilities and other special needs. Lekotek Centers focus on play because it is the vehicle for learning during early childhood.

There are many Lekotek Centers located around the state. Although services and types of toys can vary from one center to another, they all have the same goals of providing:

- family play sessions and play groups;

- adapted and specialty toys for lending;
- facilitated computer play using assistive equipment and adapted software; and
- parent support and referral to additional resources.

For more information, or to find the Lekotek in your area, contact the National Lekotek Center at (847) 328-0001 (voice) or (800) 573-4446 (TTY). The Toy Resource Hotline number is (800) 366-PLAY.

The website, www.lekotek.org, includes a listing of all the centers located around Illinois and the United States.

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.

\$500 - Dellia Robbia Club Silver level
Gary and Susan Kritzberg

\$250 - Dellia Robbia Club Bronze level
Orthotic & Prosthetic Lab

\$100
Associated Dental Specialists of Long Grove
Caring Health Equipment
Deniman Services, Inc
Research Design, Inc
Marilyn Miller, MD
United Access
In memory of Mike Seibel
In memory of Desmond Kernahan

\$50
Chris and Sally Eickhorst
Total Access, Inc
Nancy Young, MD
In honor of all the children Susan Kirchgessner has served thru DSCC

Under \$50
Nancy and Nik Bradley
Thomas and Constance Butler
Daniel B. Hier, MD
Doc's Drugs of Pontiac
Rose Keller
Keokuk Area Medical Equipment & Supply, Inc
Mark Rosenberg, MD
Eugene Schitzler, MD
Lisa Thornton, MD
In honor of Social Workers and Families of Children with Chronic Illness
In memory of Tomika Holmes
In memory of Shelia Newcom
In memory of Betty Rawls
In memory of Mike Seibel

Friends of DSCC is a new 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 a tax deductible donation.

This donation helps families access resources to better understand the special needs of their children, attend family conferences, plus be involved in other educational and advocacy opportunities. 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. □

Internet connection

In each issue of Special Addition we will include a website which can assist families of children with special health care needs. We are highlighting in this issue *Children with Disabilities*.

Children with Disabilities, www.childrenwithdisabilities.ncjrs.org, offers families, service providers and other interested individuals information about advocacy, education, employment, health, housing, recreation, technical assistance and transportation covering a broad array of developmental, physical and emotional disabilities.

Children with Disabilities online guide is an initiative by the Coordinating Council on Juvenile Justice and Delinquency Prevention, (the Council), as part of their effort to promote a national agenda for children and foster positive youth development.

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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

National Office
3411 Candelaria NE, Suite M
Albuquerque, New Mexico 87107
1-888-835-5669 Toll-Free
(505) 872-4774 Phone
(505) 872-4780 Fax
kidshealth@familyvoices.org
www.familyvoices.org

The little league challenger division

Little League's fastest growing division—The Challenger Division—provides boys and girls with disabilities the opportunity to experience the emotional development and the fun of playing Little League Baseball. This groundbreaking program enables every child to have the opportunity to participate in a structured athletic program—regardless of their ability.

The Challenger Division also helps to establish strong bonds of friendship and understanding between Little Leaguers from other



programs or at Challenger games, “buddies” help their challenged partners by acting as guides for blind children or pushing wheelchair-bound children around the base paths. This interaction has proven to be a positive experience for all the children involved, as Challenger players enjoy the thrill of participation and their “buddies” experience first-hand, the challenges these children face in their daily lives.

The Challenger Division is the Little League's way of providing new opportunities for children with disabilities so that everyone can get



into the game. To sign-up your child for participation in Challenger Baseball, or to volunteer as a “buddy,” call the Little League Regional Office nearest you. To start a Challenger Division in your community, call your local

Little League President or a member of your league's Board of Directors. All kids deserve to have fun. □

To learn more you can go to the National Little League website: <http://www.littleleague.org>



What is a Center for Independent Living (CIL)?

The Office of Rehabilitation Services (ORS) helps fund a network of 24 Centers for Independent Living (CIL's) statewide. Centers for Independent Living serve people with disabilities. Centers for Independent Living are community based, not-for-profit, non-residential organizations which serve persons of

any age with **any type of disability**. CIL's are controlled by people with disabilities (consumers). This control is maintained through various means such as: People with disabilities constitute at least 51% of the board of directors. At least 51% of all staff, and 51% of management staff are people with disabilities.

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.

INDEPENDENT LIVING CENTERS' PROVIDE

*Advocacy
Peer Counseling
Independent Living Skills Training
Information & Referral*

To locate the Center nearest you, call the ORS Independent Living Unit at:

217-782-9689 (Voice/TTY); 524-7549 (Fax) in Springfield

312-814-4037 (Voice/TTY); 814-4351 (Fax) in Chicago

Did you know...

The (United States Golf Association) USGA Resource Center for Individuals with Disabilities provides information for people with disabilities who are looking for opportunities to learn about or continue to play the game of golf. The Center also provides information regarding topics within the arena of golf for course owners, operators and practitioners. Information may be obtained via phone, e-mail and the Internet site located on the Resource Center homepage at http://www.usga.org/resource_center.



Listening to families is important to us

DSCC believes that it is important to listen to families. To help us build a way to regularly hear concerns of families and seek their advice, DSCC has some additional resources for families of Children with Special Health Care Needs (CSHCN).

Family Liaison Specialist

In July 1999, Bob Cook was hired to enhance family involvement in the agency. Bob serves as the coordinator of the Family Advisory Council and the editor of this family newsletter (Special Addition) in addition to other family related responsibilities.

Family Advisory Council (FAC)

The council represents families of CSHCN in all regions of the state and meets 3 times a year. The FAC reviews and comments on DSCC activities, including but not limited to policies, rules and regulations. They assist in the development of informational materials for DSCC families, for example, the newly published DSCC Family Handbook which can be downloaded from the DSCC website.

Family News on our Web Site

The DSCC website, www.uic.edu/hsc/dsc, has a family section with diverse information including resources such as the DSCC Coordinated Care Record and editions of the family newsletter, Special Addition.

Special Addition

All families eligible for DSCC services will receive Special Addition, a newsletter devoted to issues of concern to families of CSHCN. Articles focus on CSHCN issues at the state and national levels.

If you have any questions or comments please contact Bob Cook, at 1-800-322-DSCC (3722) or by e-mail at rjcook@uic.edu. □

What parents expect from their doctor

Adapted from The Parent-Professional Partnership,
Children's Hospital of Pittsburgh

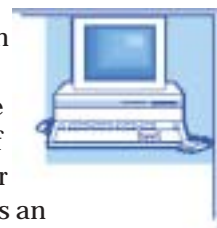
- The more I know, the less fearful I am about my child's condition—I can then be able to make more informed decisions about my child's care.
- Give me information that will help me understand my child's condition, diagnosis and treatment.
- Answer my questions in terms I can understand. Be willing to say "I don't know, but I will try to find that information for you"—and I will respect you for your integrity.
- Listen to my ideas/concerns. I have observed my child and know him/her better than anyone else. Don't feel threatened if I question your knowledge or authority. I'm just trying to provide my child with the best care.
- Talk **TO** me—not **AT** me. I want to be an equal partner with you in providing the best services for my child.
- Realize that although my child has a disability, he/she is part of a family who enjoys outside interests and activities. Help me to incorporate your suggestions into our family's life.
- Remember that our family is unique. We are different from other families—with different needs, abilities, styles, personalities and values.

**THANK YOU FOR BEING AN EQUAL PARTNER
IN THE CARE OF MY CHILD**

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The Council's nine participating Federal agencies and offices have joined forces to create this website to provide children with disabilities and their parents access to a wide range of Federal, State, local and national resources. The eight areas addressed by the online guide are: Federal Resources; State/Local Resources; National Resources; Calendar of Events; Grants and Funding; Research and Statistics; Youth to Youth; and Highlights.

The identification of this resource does not constitute an endorsement of that organization or group. Neither does an omission signify disapproval. The use of any information is entirely the responsibility of the reader. You are the ultimate judge in deciding whether the resource is appropriate to your needs. □





The national survey

Being able to tell our story well is an important element in moving forward with our 10-Year Action Plan. Our national communication strategy will help to get us there, but we also need better data—and we will soon have it.

Since October of 2000, HRSA's Maternal and Child Health Bureau, along with the National Center for Health Statistics, has been conducting a national telephone survey of families of children with special health care needs. Approximately 750 families from each state are being included in the study. Some of you may have received calls; others may be receiving them in the next few months.

The survey will, for the first time, give us reliable estimates of the number of children with special health care needs in each state, and the nation as a whole. It will tell us what these children and their families need and how well those needs are being met. And, since the survey will be repeated every four years, it will

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We're in this together!

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initiative and some paragraphs that can be dropped into organizations' newsletters, list serves, etc. If you have mailing lists that you are willing to share with us, please let Gloria know.

Building momentum— we need your help

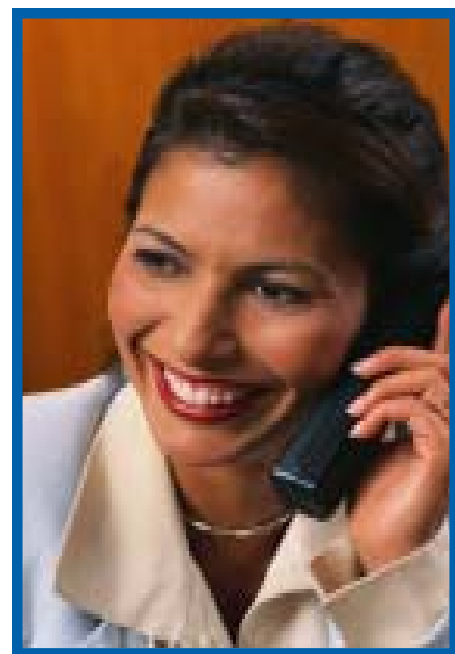
As we prepare to launch the 10-Year Action Plan and convene the national summit, we are working hard to bring partners—old and new—into our *Healthy People 2010* initiative. We are doing some of that work at the national level by distributing the draft plan; making presentations at meetings and conferences; and convening groups of families, primary and specialty care physicians, nurses and allied health professionals, and public officials in a variety of service sectors. But much of this work must be done at the state and community level.

To help you in spreading the message, we are working on a national communication strategy.

Within the next few months, we will develop attractive, easy-to-understand materials that can be used with many different kinds of groups as we try to engage them with us in the 10-Year Action Plan.

National Child Health Day

Many of those materials will be distributed for National Child Health Day, scheduled for October 1, 2001. We are delighted that children with special health care needs and the 10-Year Action Plan will be the focus of National Child Health Day this year. It will provide a wonderful opportunity for all of us to tell our stories and to listen to others. We can educate our friends, colleagues, and communities about our children. Youth with special health care needs can tell their own stories. And, it will give visibility to our plan, and identify new partners.



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give useful information on how well we are doing with our 10-Year Action Plan-and where we need to focus our efforts. We will be using this newsletter and many other vehicles to inform you about survey results, as they become available in early 2002. Preliminary data from the survey will be presented at the national summit in December. See you there! □

KASA - Kids As Self Advocates

Dear Families—

When I was in school as a youth with a disability, I was very isolated. I did not know my rights to equality as a person with a disability. I knew nothing of a Disability Rights Movement or other youth fighting for their rights in a school system. I was entirely ignorant and wrong.

I encourage you and your children to check out KASA, Kids As Self Advocates. KASA is important because it is formed by youth with disabilities to make us all aware of each other. It includes all youth with disabilities to support and learn from each other to erase isolationism and pigeonholing. It creates a national group for youth to understand all of our differences to work together and

simply change the world. It happens with youth. Youth is the heart of any movement.

If I would have had access to KASA as a youth, I would have known about Centers for Independent Living, my equal rights and laws that ensure my freedom, other youth who felt as I did, and how important it is to accept all people with varying disabilities (including myself). At an earlier age, my ignorance would have been knowledge and my wrongs would have become rights.

*Marlin Thomas
KASA Board Member, Alton, IL*

Join KASA! We are a national, cross-disability and cross-chronic

Save these dates!

October 1, 2001-

National Child Health Day

December 12th-13th, 2001-

National Summit on Children with Special Health Care Needs

Future articles will provide updates on this national initiative. For additional information, please contact Gloria Weissman at 301-443-8999 or by e-mail at gweissman@hrsa.gov.

conditions project, run by youth themselves, ready to assist their peers with special health care needs become leaders. KASA provides young people with the tools they

need to become their own advocates, to mentor other young people with disabilities, to talk with one another via the Internet, to receive leadership training, and to be available as skilled and well-spoken representatives of youth with disabilities and chronic health

conditions, ready to speak out on issues that affect them. For information or to join, visit our website, www.fvkasa.org or call Julie (Keys) Sipchen, Project Director, 773-465-3200, Julie@fvkasa.org. □



On Tuesday, April 3, 2001, KASA member Liz MacDonald, 11 years old, greeted President George W. Bush as he landed in Delaware.

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800-322-DSCC (3722)
www.uic.edu/hsc/dscc/

October 1, 2001... National Child Health Day
launches 10-Year Action Plan!

PRESORTED
STANDARD
U.S. POSTAGE
PAID
SPRINGFIELD IL
PERMIT NO. 500