

Special Addition



children with special health care needs

fall/winter 2000

A NEWSLETTER FOR ILLINOIS FAMILIES

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Federal Viewpoint

Achieving success for all children with special health care needs by 2010: creating a 10-year action plan

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 Agency

A new century has arrived and, with it, exciting new opportunities to renew our commitment to achieving success for all children with special health care needs.

During the past 20 years, a new model of care for special-needs children has emerged. Much of the credit is due to partnerships among federal and state governments, communities, families, providers, and professional and voluntary organizations. In this country, as well as in many others, this model—comprehensive, community-based, family-centered, culturally competent, and coordinated care—is recognized as the one that serves children and families best.

Over the past two decades, working together, we have developed

and fine-tuned this model. We have shown that it produces much better outcomes for children and families and we have begun to put it in place in many communities. But now it is

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Illinois News

The universal newborn hearing screening program

by Faye Manaster Eldar

The state of Illinois has recently passed a new law, the Hearing Screening for Newborns Act. This law requires that all babies born in hospitals in Illinois by December 1, 2002 will be screened for a possible hearing loss before they go home from the hospital, in addition to other medical screening tests that have been required for a long time. New equipment is available today that allows hospitals to easily and quickly screen newborn babies to see if they

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time to make it a reality. It is time to see that all children with special health care needs, all their families, all their communities are part of our success story. *Together we can do it.*

Our shared history

Before we move forward, it might be helpful to remember where we have been. Thirty years ago, the term “children with special health care needs” was not part of our vocabulary. Instead, states had “Crippled Children’s” programs, and the children they served were seen for diagnosis and correction of defects.

Low expectations led to low achievement. Children with special health care needs often did not live long enough to become adults. Even smaller numbers were able to finish school, find jobs, and go on to lead happy, fulfilling lives.

Families struggled to find services

for their children. Caregivers and policy makers overlooked the fact that families often knew the most about caring for their children. Many families felt ignored and powerless. Families learned to support each other, but had a hard time finding the support they needed.

The 1982 Surgeon General’s Workshop on Children with Handicaps and their Families began to change our national vision of what could be possible. Parents and other family



members, health professionals, financing experts, partners in school and social service agencies, and local, state, and federal government came together to develop a national agenda for children with special health care needs. Families and more than 70 professional associations signed on to this agenda.

In 1989, new language for Title V of the Social Security Act directed the states to “provide and...promote family-centered, community based, coordinated care...for children with special health care needs and... facilitate the development of community-based systems of services for such children and their families.” In 1990, the federal government put forward *Healthy People 2000*, which called for all states to put these comprehensive systems in place by the year 2000.

What we’ve accomplished— together

Since 1990, much progress has been made. For example:

■ **Family Voices**, which began as a



small organization of families of children with special health care needs, now provides support and education to both families and providers in

every state. Through its leadership, families are now active participants in everything we undertake at the federal level.

■ **Medical home**, a concept developed with the American Academy of Pediatrics and the Maternal and Child Health Bureau of the Health Resources and Services Administration (HRSA), is designed to make sure that each child with special health care needs has a regular health care provider in his or her community.

The medical home helps identify all the child’s needs early, provides ongoing primary care, and coordinates this care with the specialty care and community services needed. Parents, providers, and policy makers across the nation are being trained and supported in their efforts to create medical homes for all our children.

■ **Communities CAN** is a program that has brought national recognition to communities that have comprehensive, coordinated systems of care for children. The program also builds leadership, and provides models that other communities can use.

There have been many other important accomplishments for children with special health care needs over the past 20 years:

A new, broad definition of children with special health care needs has been developed and is now widely

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may have a hearing problem. Sixty-five hospitals now have this equipment with the assistance of state allocated money. More work still needs to be done in getting the other 120 birthing hospitals equipped and able to report accurate results to the state. Equipment needs to be purchased for 100 more hospitals, in order that the screening will be universal. In addition, the follow-up activities need to be improved because currently two-thirds of the babies whose screening results say they need to go for a complete hearing evaluation within 3 months of their hearing screening, are either not having this done, or no one is keeping records of what happens to them.

The advantages of newborn hearing screening for the babies and their families are very significant. Early diagnosis of hearing problems means that services to help the baby and family develop communication skills can start as early as possible.

Research has shown that the earlier children with hearing impairments get help, the greater the

likelihood that they will develop good communication skills and do well in school later on. This early help includes getting hearing aids, when needed, speech therapy, sign language instructions, audiological services, and education for the family to help them help their babies as much as possible.

As part of this program, the Department of Human Services Office of Family Health has also established a statewide advisory committee. I am one of the parent representatives on this committee, and will be happy to hear from you and to share your opinions and concerns. You can reach me at 847-677-3796 (Voice), 847-677-3808 (Fax) or (E-mail): familyvoicesillinois@yahoo.com

I am the parent of Maya Eldar, a student in the deaf education program at Hersey High School. Maya, who is deafblind and has cerebral palsy, has received services since the age of 5 months. □

DSCC Family advisory council

In an effort to demonstrate its commitment to the families it serves, Division of Specialized Care for Children (DSCC) had its first Family Advisory Council (FAC) meeting on June 10, 1999 in Springfield. The FAC members will represent each of the 13 DSCC regions. The purpose of the FAC is to:

- Review and comment on DSCC activities, including but not limited to: policies, rules and regulations.
- Expand DSCC access to family input, to assure family-centered values and priorities.
- Review and comment on strategies, programs and services to improve family participation and access to quality services.

- Assist in the development of informational materials for DSCC families.

The FAC will meet formally 2-3 times per year, but all members will have the opportunity to assist on various projects that the FAC identifies throughout the entire year. Members' expenses are reimbursed for attending.

If you are interested in obtaining additional information about the Family Advisory Council or you would like to participate, contact Bob Cook, Family Liaison Specialist at DSCC, 2815 West Washington Suite 300, P.O. Box 19481, Springfield, Illinois 62794-9481, call (800) 322-DSCC (3722) or e-mail rjcook@uic.edu. □

Director's column

by Dr. Charles Onufer

Parents, you are invited...to become more involved in DSCC-related family activities. Advocating for children with special health care needs (CSHCN) and understanding family-centered, community-based health care systems are major challenges for any family.

Last year on July 1, 1999, Bob Cook from Taylorville was hired as the Family Liaison Specialist for DSCC. As part of Bob's job he will:

- Serve as the coordinator of the DSCC Family Advisory Council.
- Serve as the editor of this family newsletter (Special Addition).
- Develop and coordinate parent-to-parent linkages.
- Assist in the development of statewide staff/family training.
- Assist families served by DSCC.

DSCC established a Family Advisory Council (FAC) last year with 13 members and alternates representing the areas served by each of the DSCC Regional Offices. The FAC reviews DSCC policies, family information brochures, yearly Block Grant Report and Application plus other general information issues. Contact the FAC representative in your area or Bob Cook, the DSCC Family Liaison at 1-800-322-DSCC (3722) and ask how you can become involved with the many projects that have been started.

The FAC will be introducing an exciting new group this fall that involves families and CSHCN advocates called "Friends of DSCC." Members can join for a small nominal fee and receive a "Friends of DSCC" lapel pin. All fund raising events organized through this group will be used exclusively to support parent and family activities. These activities may include reimbursement for attending Family Conferences or

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providing stipends to do family training plus other activities determined by the membership. If you are interested in promoting "Friends of DSCC" in your community, contact Bob Cook.

DSCC has several projects that the FAC membership are working on and will gladly accept your help. A family friendly Handbook of DSCC Services is still in the draft stages and your comments and suggestions are welcome. Volunteer to be a member of a support group that specifically involves your child's medical condition. Share your experiences with other parents who have children with similar conditions. Your reassurance and personal experiences will make deep impressions on other families experiencing what you and your family went through when your child was first diagnosed. Help us make the Family Section of the DSCC website more friendly, and provide you with the information that you feel is helpful, such as keeping you current on the health-related bills that your legislators are working on. Write letters or contact their offices to let them know your views on issues that affect you and your family. A good example is the Family Opportunity Act. Your congressmen need to know your views on this important bill. See our website or contact your local FAC representative or Bob Cook to learn more about this bill and how you can make a difference.

The DSCC Family Advisory Council is planning to organize 13 regional support groups that will meet in the future every month for about 5-7 sessions. Each session will address a different topic such as: accessing health care, insurance issues, transition to adulthood, Medical Home concept, care coordination, etc. All families who want to become stronger advocates for their children and also share experiences with other families, are invited to attend. Contact

Bob Cook at 1-800-322-DSCC (3722) for more up to date details. Dates, times, and locations will also be posted on the Family Section of the DSCC website, www.uic.edu/hsc/dsc/.

Parents, you have a wonderful opportunity to make a difference for your child, your family and the special needs children of other families—volunteer to become involved in one of the many DSCC family activities—you can make a difference! ♥ ☐

Join . . .



and help families with special needs children become stronger advocates and better informed.

Children's pen pal program

Children's Hopes & Dreams Wish Fulfillment Foundation's Pen Pal Program is now in its sixth year of matching children with chronic illness or disabilities from around the world to become pen pals. This free program, now in 53 countries, recently enrolled its 10,000th pen pal. Children in this program are matched by age (5-17), gender and illness category. Enrollment cards are available by calling 973-361-7366, or by writing to: Children's Hopes & Dreams Wish Fulfillment Foundation, 280 Rte. 46, Dover, NJ 07801 or visit the website at www.childrenswishes.org. ☐



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
PO Box 769
Algodones, New Mexico 87001
1-888-835-5669
(505) 867-2368
(505) 867-6517 FAX
kidshealth@familyvoices.org
www.familyvoices.org

FAMILY VOICES OF ILLINOIS

*Speaking on behalf of children with
special health care needs*

Is Proud to Announce

New toll-free bilingual hotline!
for Illinois families of children with
special health care needs

For more information, please call:

888-950-8683

(English and Spanish, toll-free in Illinois)

Where you can find answers for
children with special health care
needs because . . .

- families are the key to what is best for their children
- families need good information in order to make good decisions for their children
- families must learn how to survive in our changing health care environments
- and families can learn best from other families who have “been there”

Run by and for families in Illinois, the center will provide support and assistance to families who have children with special health care needs and focus on their children’s health by . . .

- assisting families by sharing information as they navigate the public and private health care

- system in their state and their communities
- helping families understand options for health insurance
- educating families about ways to make appropriate choices of health care providers and resources
- listening to families as they describe their experiences with the health care system and informing them about possible options
- working with government agencies to gather information, monitor health care, and identify ways to improve public and private health systems
- and facilitating communication between families, managed care programs, providers and agencies □

Family opportunity act allows Medicaid buy-in

Have you given up a raise, refused overtime, or turned down a better job just so you can stay in the income bracket that keeps your child on Medicaid? According to a recent survey, 64% of families with special needs children have done this.

“Too often, to obtain needed health services for their children under Medicaid, families are forced to become poor, stay poor, put their children in institutions, or give up custody of their children entirely,” says Senator Kennedy (D-MA). “No parent should be faced with that unacceptable choice.”

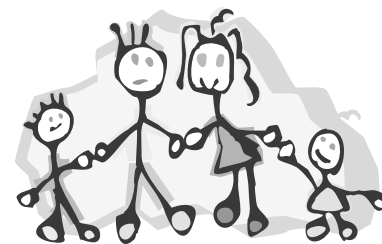
To address this problem, Kennedy introduced the **Family Opportunity Act of 2000** along with Senators Grassley (R-IA), Jeffords (R-VT), Harkin (D-IA), Reed (D-RI), and Moynihan (D-NY).

The bill gives middle-income

families with special needs children the option to buy into Medicaid. Under the plan, families take their employer’s family coverage (if available), then add on Medicaid insurance. The price for Medicaid insurance would be based on family income. The bill covers children receiving hospital, psychiatric services and children with potentially severe disabilities.

Additionally, the bill provides funds for states to create family-to-family health information centers. These centers, staffed by both parents of children with special needs and professionals, would provide information to families on available programs, resources, and services.

Contact Family Voices for further information about this bill (1-888-835-5669), or visit their website at www.familyvoices.org. □



“Nothing in the world can take the place of persistence. Talent will not; nothing is more common than unsuccessful men with talent. Genius will not; unrewarded genius is almost a proverb. Education alone will not; the world is full of educated derelicts. Persistence and determination alone are omnipotent.”

Calvin Coolidge

We want KidCare and Medicaid to work for families!

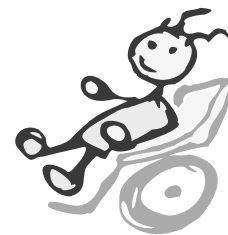
Working together, we have an opportunity for affecting policy in KidCare and Medicaid for children with special health care needs! Two grant-funded projects under the Campaign for Better Health Care (CBHC) are working on seeing that the KidCare and Medicaid programs become more responsive to special needs families' concerns. CBHC is proud to have DSCC as an ongoing partner on these projects.

One project, funded through the Illinois Council on Developmental Disabilities (ICDD), is aimed at direct outreach to families for enrolling into KidCare, strategizing policy for expansion of the program to cover more CSHCN, and developing policies for regulatory changes to improve access to quality care for special needs kids. The second project, funded by the Nathan Cummings Foundation, is joining with the first in pursuing our access and quality improvements over the next two years.

We need your involvement! No one knows better what is needed than families of kids with special needs--this project needs your direction to be a real success. There are a number of ways to be involved: We have a working group that meets bi-monthly in Springfield to pursue these goals--in person and by phone conferencing. We plan to present at conferences throughout the state, including training sessions and outreach workshops. We need recommendatons of who to approach as allies in pursuing these goals. We need your input on what needs to be addressed. In short, we need your assistance for all kids of all levels!

To share suggestions, make recommendations, or get involved to any degree, please contact Andrea Rundell at arundell@cbhconline.org, Jeanne Gerrietts at jgerrietts@cbhconline.org, Amy Stolzmann at astolzmann@cbhconline.org or call any of us in CBHC's main office at 217-352-5600 or (toll-free at 888-511-0290). □

Thanks! We look forward to hearing from you!



DSCC coordinated care record!

Developed by DSCC families & staff for families being served by DSCC, the record is available on the DSCC website at www.uic.edu/hsc/dsc.

This record supplies families with a framework to help organize information and coordinate care for their child.

SECTIONS IN THE RECORD LEAVE SPACE FOR ORGANIZING INFORMATION ABOUT:

1. Diagnosis/Medications/Hospitalizations, Medical History, Home Medical Guide Record,
2. Funding (Private Insurance/Public Insurance, Other Resources)
3. Education/Vocation
4. Parent & Patient's Rights

If you do not have access to the Internet and want a copy, contact Bob Cook at 1-800-322-3722. □

IRS allows deduction for medical conferences

Have you ever wanted to attend a medical meeting that talks about your child's special health care needs, but couldn't due to cost?

Well, thanks to Congressman Miller (D-CA), the Internal Revenue Service (IRS) will now allow you to deduct travel and admission costs associated with attending a medical conference related to your child's special health care needs.

"Virtually everyone else attending meetings can deduct the cost: physicians, vendors, salespeople," said Miller. "I thought that the parents of the patient should get a little help, too, and I am delighted the IRS has agreed."

Miller said he will work with various children's health and advocacy organizations to make sure parents have access to the new ruling for the 2000 tax year. □

VISIT THE DSCC WEBSITE

www.uic.edu/hsc/dsc/



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



“It is time to see that all children with special health care needs, their families, and their communities are part of our success story.”



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accepted: “Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”

It is a definition that focuses on the services our children need, not on the conditions they have. We want to make sure that the needs of all of these children are met.

A national survey of children with special health care needs is being supported by the HRSA and carried out by the National Center for Health Statistics (NCHS). By 2002, for the first time, we will know how many children with special health care needs are in each state and in the nation.

The survey will also tell us a great deal about what services these children need and are using, how well their care is being coordinated, how well they are covered by health insurance, and how satisfied their families are with the care their children are getting. The information we receive from this survey and others will help us better understand how well we are doing and what gaps remain. It will also help us advocate for better services and systems for our children.

Measuring success

How will we know when we have created the kind of system of care our children deserve? We believe that these six things must happen before we have been successful:

- All children with special health care needs will receive 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;
- Services for children with special health care needs and their families will be organized in ways that families can use them easily;
- Families of children with special health care needs will participate in decision-making at all levels and will be satisfied with the services they receive; and
- All youth with special health care needs will receive the services necessary to make appropriate transitions to all aspects of adult life, including adult health care, work, and independence.

State Title V programs are now required to report their progress toward these six outcomes every year. At the Federal level, through our grants and contracts, we are developing models, materials, expert workshops, and other activities to support state and local efforts.

Achieving success: a 10-year action plan

While we want to measure success, **achieving** success is much more important to us. Late last year, the Federal government rolled out *Healthy People 2010*. Once again, as in *Healthy People 2000*, states and territories were given the task of putting in place service systems for all children with special health care needs.

In partnership with the March of Dimes, we at HRSA’s Maternal and Child Health Bureau have begun a major effort to develop a 10-year action plan for creating a nationwide system of services for all children with special health care needs. The action plan should be finished by October 2000. A national meeting on

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October 2000. A national meeting on children with special health care needs is planned for 2001.

Six workgroups were formed to create these plans. Each includes members from State Title V programs, families, professional groups, providers, and communities. Each is focusing on one of the six outcomes above, and each is developing an action plan to achieve that outcome.

This summer and fall, those six action plans are being pulled together into one 10-year Action Plan for Children with Special Health Care Needs. That plan will be the basis for a monograph to go along with

Healthy People 2010. It will guide our work at the Maternal and Child Health Bureau around children with special health care needs and work of partners for the next ten years. It will have practical steps for putting into place and **keeping** in place the services and supports children with special health care needs and their families need to succeed.

Creating a 10-year plan is an important step, but moving it from paper to action is much more important, and much more difficult. We need all of you to work with us, to support us, to bring your partners along on this next stage of our

journey together. With our eye on the prize-our children's future-we can do it...and we will do it!

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

Do you know about KidCare health insurance in Illinois?

KidCare is an affordable health insurance plan for children 18 years and younger. Review and compare the benefits (below) provided by KidCare and DSCC to understand what each program can provide for your child.

■ Why Do You Need KidCare?

- ✓Prenatal care
- ✓Well-child and well-baby visits
- ✓Immunizations and prescription medicines

✓Physician visits (both routine and specialty), hospitalizations, and emergency services

✓Vision, dental, mental health, substance abuse, physical/occupational/speech therapies, and other specialty medical services including medical equipment and supplies

■ Why Do You Need DSCC?

- ✓KidCare may not pay for some specific medical items
- ✓Care Coordination Services for all medically-eligible children with special health care needs regardless of income status that:

✓Helps families arrange medical care with qualified health care providers

✓Helps families access other community programs

✓Helps families best use the benefits from their KidCare or other private insurance plans

✓Care Coordination that is family-centered, community-based and culturally sensitive

For additional information on applying for KidCare, call 1-800-322-DSCC (3722)

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www.uic.edu/hsc/dscc/

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