

# Special Addition



children with special health care needs

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## DSCC Family Advisory Council

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## Federal Viewpoint

### Family participation and satisfaction: DELIVERING ON THE PROMISE

by Diana Denboba, Public Health Analyst, Division of Services for Children with Special Health Needs, Maternal and Child Health Bureau, Health Resources and Services Administration

Families of children and youth with special health care needs. Youth with special needs. Communities. Partnering organizations, like the American Academy of Pediatrics, Family Voices, and March of Dimes. State Children with Special Health Care Needs (CSHCN) programs. All have been working with the Division of Services for Children with Special Health Needs (DSCSHN) to create and implement a new model for serving children with special health care needs. The model is community-based, family-centered,

and culturally competent. It is coordinated care, delivered within comprehensive and integrated systems of services. To be successful, this model must include the following core outcomes:

- family participation and satisfaction,
- access to a medical home,
- access to affordable insurance,
- early and continuous screening,
- easy-to-access, community-based service systems,
- services necessary to make the transition to adulthood.

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## Local Viewpoint

### The Illinois Early Learning Council

by Claudia Fabián, DSCC Family Advisory Council Chairperson

Did you know that Governor Blagojevich created the Illinois Early

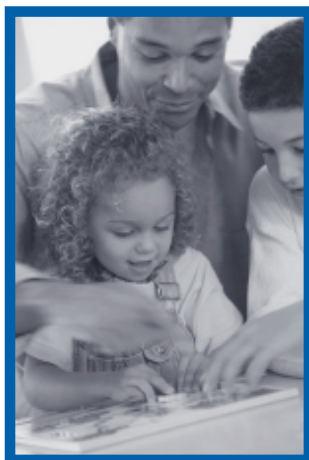
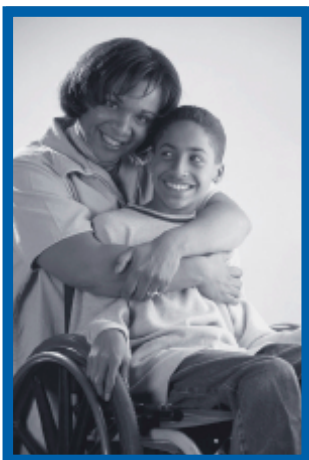
Learning Council to build on recent and ongoing childhood planning efforts and initiatives as well as lessons learned and input from parents and local communities?

The long-term outcome is that all children in Illinois are safe, healthy, eager to learn and ready to succeed by the time they enter school. By **all**, they mean all children from birth to

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*"I've learned - that it's a lot easier to react than it is to think"*

# DELIVERING ON THE PROMISE



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This new model of care serves as a way to achieve the *Healthy People 2010 (HP 2010)* objective of increasing the proportion of states and territories that have service systems for children with special health care needs. *HP 2010* provides an opportu-

*Delivering on the Promise*, the Health and Human Services self-evaluation to promote community living for people with disabilities, was de-

veloped in response to the President's New Freedom Initiative, which reduces barriers to community services and independent living. It charges the Maternal and Child Health Bureau (MCHB) with taking the lead to develop and implement a plan to achieve appropriate community-based service systems for children and youth with special health care needs and their families.

The model (including the above core outcomes) developed by DSCSHN and partners serves as the basis for this New Freedom Initiative plan. The implementation activities for the core outcome, family participation and satisfaction, address the following goal: to recognize that families are the ultimate decision-makers for their children and to encourage them to participate in making informed decisions. This goal is also part of a national effort to have this new model of a service system in communities by 2010.

A medical home is an approach to providing access to quality health care services in a cost-effective manner in a primary health care setting. Families and providers act as partners to identify and access all the medical and nonmedical services needed to help children and their families achieve their maximum potential.

## Family-centered care

The DSCSHN and our partners know that families have been struggling for many years to find services for their children with special health care needs. Their expertise is often overlooked or ignored. Moreover, families often require additional family support and information on community services, such as transportation, respite care, care coordination, translation and interpretation services, and financial support for services. But,

such information has often been hard to obtain, hindering families' ability to make informed decisions with providers about the health and related needs of their children.

For years, DSCSHN has promoted family-centered care and family-professional partnerships. Family-centered care is based on the recognition that most children, including children with special health care needs, live within the context of families, which may include biological, foster, and adoptive parents, grandparents, other family caregivers, and siblings. Family-centered care ensures that (1) the organization and delivery of health care and support services meet the emotional, social, and developmental needs of children; and (2) the strengths and priorities of families are integrated into all aspects of the health care plan.

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five years of age, including those with special health care needs, disabilities, living in poverty, growing up in families whose primary language is not English and the children of incarcerated parents.

The main goal in creating this Council was to receive input from Illinois citizens representing the public and private sector and the regional, cultural and racial diversity in Illinois to ensure the development of actions and recommendations related to:

**Quality:** How can Illinois enhance the quality of existing early childhood programs and design a high-quality, voluntary, universal pre-school model for all three-and four-year olds?

"We know that children have an immense capacity for learning very early in life, and those who have the opportunity to start the education process early have much better chances of succeeding in school and later in life. Now that we know these things, it's our responsibility to extend the chance to get an early start for as many kids as possible."  
 Governor Rod Blagojevich,  
 July 24, 2003

**Accountability:** How can Illinois ensure programs are providing quality early learning opportunities and are appropriately assessing and supporting children's readiness to succeed in school?

**Expansion:** How can Illinois expand access to high-quality preschool for all children?  
**Linkage and integration:** How can Illinois improve coordination and integration across early childhood programs and systems?  
**Workforce development:** How can Illinois develop a statewide training and workforce development system?

As a proud appointed member to the Council, I will represent our children with special health care needs and disabilities, and I will report to you as the Council begins its important work. If you have any questions or suggestions, please feel free to contact me at 217-524-5848.

## IEPs here we come

by Alicia Becker, DSCC

In the spring, the saying, "April showers bring May flowers" is often heard. For children and youth with special health care needs, spring is usually Annual Review time for IEPs (Individual Educational Plans); and with these meetings sometimes come frustrations and tears. However, by taking information in and learning to discuss needs and desires through a team approach, the team might begin to look forward to the "May flowers" and see the budding growth in your child.



- Keep ongoing home/school communication with your child's teacher.
- Make sure you have a copy of the latest edition of the Parent's Rights blue book from the Illinois State Board of Education.
  - Bring someone with you to the meeting for support.
  - If both parents are attending the meeting, decide who will be doing the majority of the talking.
- Before the meeting, write down questions, concerns, needs, goals, health status and current functioning of your child.
- If professionals come to the meeting with written goals and objectives, these are to be draft goals and objectives only.
- If professionals use language you do not understand, ask them to put it into clearer language.



- You may ask for the meeting to end if the situation is getting frustrating. Make sure you set a new date for the next meeting before leaving.
- You always have the right to disagree with any part of the IEP and can ask for another meeting to discuss changes.
- Get a copy of the IEP before you leave the meeting.
- Remember to be assertive, but positive in your requests.

If you need further assistance during the IEP season, your DSCC Care Coordinator may be able to help you, and remember, "When you plant lettuce, if it does not grow well, you don't blame the lettuce. You look for reasons it is not doing well. It may need fertilizer, or more water, or less sun." (Thich Nhat Hanh) □

# SUMMER SAFETY TIPS



## Heat stress in exercising children

- At the beginning of a strenuous exercise program or after traveling to a warmer climate, the intensity and duration of exercise should be limited initially and then increased gradually during a period of 10 to 14 days to accomplish acclimatization to the heat.



- Before prolonged physical activity, the child should be well-hydrated. During the activity, periodic drinking should be enforced, e.g., each 20 minutes 5 ounces of cold tap water or a flavored sports drink for a child weighing 88 pounds and 9 ounces for an adolescent weighing 132 pounds, even if the child does not feel thirsty.
- Clothing should be light-colored and lightweight, and limited to one layer of absorbent material to facilitate evaporation of sweat. Sweat-saturated garments should be replaced by dry garments. □



## Pool safety

- Never leave children alone in or near the pool, even for a moment.
- Install a fence at least four feet high around all four sides of the pool.
- Make sure pool gates self-close and self-latch at a height children can't reach.
- Keep rescue equipment (a shepherd's hook - a long pole with a hook on the end - and life preserver) and a portable telephone near the pool.
- Avoid inflatable swimming aid/aides such as "floaties." They are not a substitute for approved life vests and can give children a false sense of security.
- Children are not developmentally ready for swim lessons until after their fourth birthday. Swim programs for children under four should not be seen as a way to decrease the risk of drowning.
- Whenever infants or toddlers are in or around water, an adult should be within arm's length, providing "touch supervision." □



## Boat safety

- Your children should wear life jackets at all times when on boats or near bodies of water.
- Make sure the life jacket is the right size for your child. The jacket should not be loose. It should always be worn as instructed with all straps belted.
- Blow-up water wings, toys, rafts, and air mattresses should never be used as life jackets or life preservers.
- Adults should wear life jackets for their own protection and to set a good example. □



## University of Illinois Summer Sports Camps

**T**op wheelchair athletes and coaches will be teaching track and wheelchair basketball camps at the world renowned University of Illinois. Each day provides fundamental skills for anyone interested in developing their game.

Camps are open to males and females aged 10 and up for the track camp and 20 and under for the basketball camp.

Contact the U of I at the below information to receive a registration form.



Track Camp  
June 10 - 24

Elite Basketball (invite only)  
July 10 - 15

Team Camp  
July 15 - 19

Basketball Ages 15 - 19  
July 19 - 24

Basketball Ages 10 - 14  
July 24 - 29

Phone: (217) 333-4606 or  
Email: [sportscamp@uiuc.edu](mailto:sportscamp@uiuc.edu)  
Website: [www.rehab.uiuc.edu](http://www.rehab.uiuc.edu)

## FAMILY VOICES

Family Voices of Illinois - Speaking on behalf of  
children with special health care needs  
2800 W. Jerome - Chicago, IL 60645  
773-274-8683 (voice) 773-274-8685 (fax)  
[familyvoicesillinois@yahoo.com](mailto:familyvoicesillinois@yahoo.com)

**F**amily Voices of Illinois, part of the Family Voices National Network, is run by two parent volunteers, Faye Manaster and Joanne Carbonell-Rodriguez. Faye has been volunteering for Family Voices for over 12 years, and Joanne for more than ten years.

Together, we volunteer to operate a toll-free, bilingual English and Spanish hotline for Illinois families, 888-950-8683. Our mission is to share information with other families about health care for children with special needs in our state. Calls are generally returned on evenings and weekends, and we ask callers to leave a message saying when is a good time to reach them.

Our email address is [familyvoicesillinois@yahoo.com](mailto:familyvoicesillinois@yahoo.com) and

we welcome emails from families and friends.

We also have an electronic mailing list, and often share alerts and announcements from other groups related to children with special needs and health care.

We use our own personal resources to support the telephone hotline, and email access. We are also involved with health care advocacy on the state level, and collaborate with DSCC and the Illinois Chapter, American Academy of Pediatrics, Committee on Children with Disabilities, in addition to other parent groups and disability organizations.

We are dedicated to sharing information with other families and look forward to hearing from you. ☐

## Thank you from friends of DSCC honor roll of giving

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

SBC Employees (through United Way contributions) - \$956.28

DSCC Employees - \$1,389.10

Kingsley Jr. High School - \$156.63

Private Donations - \$1,016.12

Friends of DSCC is a resource to help families of children with special health care needs. The Division of Specialized Care for Children (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.

DSCC will use these funds for purposes that 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 e-mail at [rjcook@uic.edu](mailto:rjcook@uic.edu). ☐

*"Never doubt that a small group of thoughtful committed people can change the world: indeed it's the only thing that ever has!"*

*Margaret Meade*

# Understanding one's disability can lead to success for youth seeking jobs

by Deborah Leuchovius and Sue Fager

The idea that parents are “the experts” about their children is a cornerstone of the special education system. It is helpful, however, to remind ourselves that the goal of the system is to prepare our sons and daughters for success after they have completed school. Both parents and professionals therefore have responsibility for helping students with disabilities to become “experts” about themselves. An understanding of oneself, one's strengths, and one's needs is key to becoming an effective self advocate and essential to postsecondary education and employment success.

One reason it is so important for youth to become knowledgeable about the kinds of accommodations they need and to feel comfortable talking about their disabilities is that persons who do not disclose a disability to an employer have no protection from discriminatory practices under the Americans with Disabilities Act (ADA).

Youth with obvious disabilities generally have less of a decision to face when it comes to disclosing the fact that they have a disability, but they still should be able to request and articulate the kind of job accommodations they need. (A job accommodation is any modification or adjustment to a job or the work environment that will enable a qualified applicant or employee with a disability to participate in the application process or to perform essential job functions.)

For those with hidden disabilities—such as mental health issues, learning differences, or health impairments—the question of whether or not to disclose a disability to an employer can be a difficult one. Persons with less obvious disabilities need to

consider if, when, and to whom he or she will disclose their disability. They must balance the need for employment accommodations against potential discrimination and negative perceptions. A key factor in the decision to disclose is whether or not a job accommodation will be needed at any point in the employment process. If an accommodation is necessary, disclosure of the disability will be necessary. Individuals can choose not to disclose their disability if an accommodation is not needed and if their disability creates no safety issues for themselves or their co-workers.

It should be acknowledged that disclosing one's disability can be particularly daunting for young adults who want more than anything else to fit in with peers and do not want to highlight anything about themselves that makes them different.

What can parents do to promote self awareness? The skills necessary to confidently disclose a disability and discuss accommodation needs are developed over time and can be included in a student's transition individualized education program (IEP) goals. Parents can also advocate that schools incorporate self-determination training into school programs, for student-led IEPs, and for person-centered transition planning.

There are also things parents can do at home. Parents can try to share as much of their hard-won insight with a young person as they can. This includes helping youth understand their disability, how it affects them, and helping them understand the accommodations that help them be successful. Parents can work to create an atmosphere at home where youth feel comfortable talking

openly about their disability.

Mothers and fathers should also be aware that young adults may need someone to talk about their disability outside of their family members. Parents can help youth find opportunities to meet with other young adults with disabilities or with adult role models with disabilities. These kinds of connections can be important to establishing a positive self-identity and make it easier for a young person to talk about their disability in other settings.

Fully understanding the impact of their disability may be a lifelong process, but children and young adults will have a head start on success if they are comfortable with publicly identifying themselves as having a disability and are able to articulate the supports and accommodations they need to be successful at work or school. Individuals who can confidently discuss their disability and accommodation needs have greater control over their lives.

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**VISIT THE DSCC WEBSITE**

[www.uic.edu/hsc/dscc/](http://www.uic.edu/hsc/dscc/)



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

# DELIVERING ON THE PROMISE

## MCHB funded F2F centers

\*Last year's funding total  
(Including Family Voices): \$3,028,016

Organization	Contact
Support for Families of Children with Disabilities; San Francisco, CA	Juno Duenas/ Linda Vossler-Swan (415) 282-7494 ext 15
Parent to Parent of VT; Williston, VT	Julie Arel, (802) 764-5920 ext 28
Parent Advocacy Coalition for Educational Rights, (PACER), Inc.; Minneapolis, MN	Carolyn J. Allshouse, (952) 838-9000
Maine Parent Federation; Augusta, ME	Beverly J. Baker/ Janice LaChance (207) 623-2145
Family Voices of Tennessee at the Tennessee Disability Coalition; Nashville, TN	Dara Howe (615) 383-9442
Florida Institute for Family Involvement (FIFI); Crawfordville, FL	Conni Wells (850) 926-3514
Family Voices of Iowa at Access for Special Kids (ASK) Resource Center	Paula Connolly (515) 223-6714

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## Family/professional partnerships

Active partnerships between families, youth, and professionals are the cornerstone of family-centered care. These partnerships support families in being integral partners with their children's medical home and in systems and policy development at the community, state, and federal level. This is critical if we are to improve services and supports to children and youth with special health care needs. For this reason, DSCSHN began funding activities that support "families as partners in decision-making at all levels and being satisfied with services they receive." The Integrated Services Branch of DSCSHN has had the program, "Family/Professional Partnerships," for many years.

This program supports the development of partnerships between

families and providers to better (1) organize mechanisms to educate, inform, and serve families with children with special health care needs; (2) assist family members with informed decision-making about the health and well-being of their own children and as partners in policy making for service systems; and (3) infuse cultural competence policies, practices, and values in health care.

The newest funded effort of this program is the Family-

To-Family Health Information and Education (F2F) Centers. Instrumental in this effort has been Family Voices, which has been using family/professional partnerships to assist in developing F2F centers in every state.

## Why F2F centers?

A national survey conducted by Brandeis University and Family Voices in 1999 showed that, although families want to be informed decision makers for their children, many times they can not consistently access accurate and quality information in a timely manner. Families also indicated that other families are often the most helpful in assisting them in obtaining and understanding information, particularly if it is a sustained state-level effort, formally organized and staffed with paid parents. Also, literature indicates that networks of informed families having similar

issues and backgrounds (such as families with similar cultural, ethnic, and linguistic backgrounds) impact health behaviors of other families.

The F2F grants fund statewide, family-run centers that (1) develop and disseminate needed health care information to families and providers and respond to information gaps identified by both; (2) provide education and training opportunities for families; (3) integrate the philosophy and practices of family-centered care, family/professional partnerships, and cultural competence; and (4) collect and analyze data related to the core outcomes.

## MCHB F2F center accomplishments

All of the F2F centers have devised ways to serve families statewide, from having statewide regional coordinators or liaisons with donated office space in community-based organizations, to coordinating networks of family-run organizations. Newsletters, information about trainings, and other materials are disseminated through these statewide structures. These centers provide individualized assistance to families and professionals by phone and visits, and conduct trainings and workshops for families and professionals on topics such as insurance changes, disabilities, and the medical home.

Most centers have trained and assisted families in becoming members of community and state advisory groups. Two centers use grant funding for a part-time social worker and a health care financial coordinator because of intense needs in these areas. Some of the centers

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have an additional focus of reaching out to families who might be underserved. These include families in rural and isolated areas or large urban areas, and families of diverse cultural and ethnic backgrounds, some with English as a second language. Two centers have materials in up to ten languages, and one has a cultural competence advisory group.

Curricula have been developed to train parent staff and volunteers so that information provided to families and data collected are uniform. Data are collected on family needs, trends, and gaps in services and how families across the state are using the centers. All centers are attempting to collect the same data, particularly how changes in Medicaid and other health care financing services in states are impacting families.

The cooperative agreement with Family Voices provides technical assistance, particularly in developing a uniform database and a way of reporting data across centers so this information can be provided to state and federal partners for policy decisions. Family stories, putting a human face on statistics, are used with data to document needs for system changes and enhance state information obtained from the National Survey for Children with Special Health Care Needs.

The demand for center services has been tremendous. For example, in a three-month period:

#### For additional information . . .

- about this article, contact Diana Denboba, Maternal and Child Health Bureau, DDenboba@hrsa.gov, (301) 443-2370.
- about the President's Freedom Initiative, go to: <http://www.hhs.gov/newfreedom/final/hhsfull.html#intro>.
- about Family Voices, contact Jennifer Cernoch, Executive Director, or Cindy White, Director of Fiscal Operations, (505) 872-4774 or [kidshealth@familyvoices.org](mailto:kidshealth@familyvoices.org); website: [www.familyvoices.org](http://www.familyvoices.org).
- about the National Survey for Children with Special Health Care Needs, see <http://www.cdc.gov/nchs/slairs.htm> or try the new MCHB funded Data Resource Center up in mid-March at <http://www.schcnodata.org>.

■ Seven centers received more than 11,000 requests for assistance from families (36%) and professionals (64%);

■ Six Centers reported participating in over 400 meetings in which close to 5,600 people participated;

■ Five F2F centers produced newsletters reaching more than 150,000 people and had over half a million website hits; and

■ Four F2F centers reported distributing about 30,000 pieces of material to families and professionals (Draft 3rd Quarter 2003 Data Summary from Family Voices).

All of these activities are designed to enhance informed decision-making and partnerships at all levels and to increase family satisfaction with services.

#### Partner F2F centers

In 2003, our partner agency, The Centers for Medicare and Medicaid Services (CMS), in collaboration with MCHB also funded F2F Centers as a

component of their Real Choice Systems Grants. These statewide centers will (1) provide education and training opportunities for families with children with special health care needs; (2) develop and disseminate needed health care and home and community-based services (HCBS) information to families and providers; (3) collaborate with the MCHB F2F centers to benefit children with special health care needs; and (4) promote the philosophy of individual and family-directed supports.

Although these are still in their first year, we expect to see benefits to families and providers in the grantee states of Alaska, Colorado, Indiana, Maryland, Montana, Nevada, New Jersey, South Dakota, and Wisconsin. For details, see [www.cms.hhs.gov/newfreedom/rcc93003.pdf](http://www.cms.hhs.gov/newfreedom/rcc93003.pdf). □

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