

Special Addition



children with special health care needs

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A NEWSLETTER FOR ILLINOIS FAMILIES

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In this Issue

- 3 From The Heart. . .
- 3 DSCC Support Group
- 3 New FamilyCare Program
- 3 Internet Connection
- 4 Youth and Family Perspectives on Transitioning to Adult Health Care
- 5 Friends of DSCC
- 6 Family Voices
- 6 Check out the New DSCC Family Page

Federal Viewpoint

Making the transition from youth to adult medical care

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 President's New Freedom Initiative calls for removing barriers that prevent people with disabilities from living in their communities. In the New Freedom Initiative report, *Delivering on the Promise* (dated March 25, 2002), the Health Resources and Services Administration (HRSA), is acknowledged as the federal agency with pro-



gram responsibility for addressing the barriers to children and youth with special health care needs.

HRSA is charged with developing a plan aimed at eliminating those barriers. The report identifies the following target areas:

please see page 2

Local Viewpoint

Youth and young adults want control...

by Alicia Becker, DSCC

When reading those words, many emotions and visualizations might come to a parent's mind. Parents may be nodding yes and thinking; teens want

control of the wallet, the car keys, the curfew and their own identity.

Additionally, youth with special health care needs (YSHCN) also want to be in control of their own health care.

In order to address this unique issue for youth with special health care needs, DSCC has intensified its

please see page 4

continued from page 1

- comprehensive, family-centered care;
- affordable insurance;
- early and continuous screening for special health care needs;
- transition services to adulthood.

The report also notes the following issues for families of children with special health care needs:

- need for family satisfaction, and
- complexity and organization of services resulting from fragmentation and multiple funding streams.

As states look at the health and welfare of its citizens and build community systems of care, youth with special health care needs should be considered carefully. The fact that more children with special health care needs are living to adulthood is wonderful and remarkable. Improved medical science, technology, and outstanding care may allow many to progress with

their adult lives barely impacted. For others, however, adulthood may present challenges to attaining the milestones that most take for granted—education, employment, and independence.

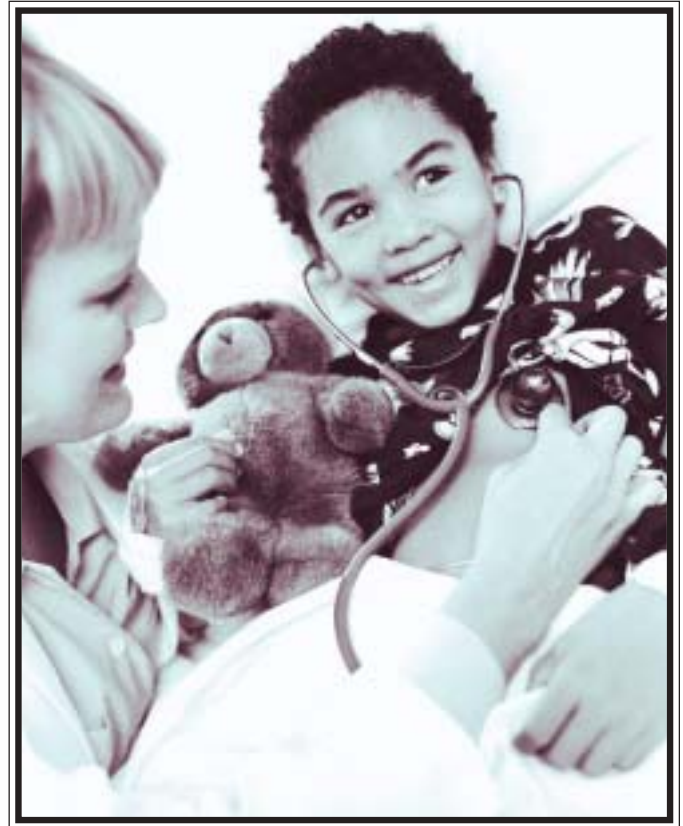
Medical Insurance

According to the Social Security Administration, there are nearly one million children under age 18 receiving Supplemental Security Income (SSI) payments based on disability. Another 500,000 adult recipients first became eligible as children.

Many more enter the SSI system as “adults” at age 18, when parents’ income and resources are no longer considered, even though their medical condition would have qualified them at an earlier age.

The actuarial projections are that a recipient who first starts receiving SSI as a child will collect payments for almost 30 years. This represents a significant dependence on federal and state funds. Even those who are able to graduate from high school and college are often unable to make the transition to employment and leave the SSI rolls. While there are probably a number of reasons for this, access to and utilization of health care seem to figure prominently.

The older the children are, the less likely it is they will have health insurance. For those receiving SSI and Medicaid, many lose that coverage at adulthood. For those who continue, however, once they age out of the Early



Many youth and parents express strong ties to their pediatricians.

and Periodic Screening, Diagnosis, and Treatment (EPSDT) Program, covered items and services drop significantly.

On the private insurance side, coverage under the plan of a parent usually has an age limit. While the age limit may or may not be extended if the youth has special health care needs, often the plan is either too expensive or inadequate to cover all of the youth’s needs.

If a youth is working, part-time and entry-level service jobs do not typically provide health insurance coverage. All of this adds up to the potential decreased access to and utilization of health care at the time the youth is making the transition to adulthood.

From child to adult medical care

The actual transition from pediatric to adult medical care can be a difficult process for youth with special health

please see page 7

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From the heart. . .



CURTIS GETS CALL TO THE BIG LEAGUE

Curtis is a young adult with a diagnosis of Cerebral Palsy. He has always been interested in sports, especially St. Louis Cardinals Baseball. Having CP left him unable to participate in regular contact sports. During his summers off from school, he would have major surgeries that would keep him homebound, but he would keep busy watching the Cardinals. When he was offered a wish, Curtis knew immediately what he would like — to make the “opening” pitch at a Cardinal game.

Through the help and generosity of the Make-A-Wish Foundation in Metro St. Louis and the regional

Collinsville office, Curtis' wish became a reality. On July 17th, 2002, Curtis got called up to make his famous pitch prior to the Cardinal/San Francisco Giant game. Curtis had Steve Kline, Cardinal left-handed relief pitcher noted for his “dirty” hat, catch the pitch. Curtis had his moment in the sun, his name in lights, and his left-handed delivery on the giant TV Tron. Curtis was also treated to another game the next day, and went to the Cardinal dugout where he met Cardinal players like Jim Edmonds, Tino Martinez, and even Manager Tony LaRussa. Curtis received an autographed ball from the team. If the Cardinals ever make it through post-season play and the World Series, Curtis' wish will continue to just get bigger and better. □

DSCC support groups

DSCC is developing regional support groups for families of children with disabilities or chronic health conditions. A DSCC-trained family member facilitates meetings and coordinates the support groups. The meetings are held in community accessible locations on weekday evenings. Currently, groups meet in Greenville, Olney, Peoria, Palos Hills and Chicago. DSCC hopes to increase the number of groups, with the goal of having at least one support group per region. If you would like to participate or want additional information, please contact Bob Cook at (800) 322-3722. □

New FamilyCare program

Will provide health insurance to low-income parents in Illinois

Illinois will extend its KidCare program to provide medical coverage to low-income parents under the new FamilyCare program. In September 2002, the U.S. Department of Health and Human Services granted Illinois' request for a waiver to create the parent coverage component. The initial phase-in of FamilyCare will extend health insurance coverage to 30,000 parents and caregivers of children covered by the KidCare program. Parents with annual incomes at or below 49% of the federal poverty level, or \$739 per month for a family of four, will be eligible. FamilyCare will be structured similarly to KidCare, and will cover a range of medical services, including physician visits, hospitalization, prescription drugs and eyeglasses.

“We know that children are more likely to get the medical care they need, especially preventive care such as check-ups and immunizations, when their parents also have medical coverage,” former Governor Ryan said.

To enroll in FamilyCare or to receive additional information, contact the KidCare hotline: 1-866-4-OUR-KIDS (1-866-468-7543) (TTY: 1-877-204-1012). □



Internet connection

In each issue of Special Addition we will include a website which can assist families of Children with Special Health Care Needs (CSHCN). In this issue, we are highlighting www.DisabilityInfo.gov. This website has a comprehensive list of disability-related government resources. This collaborative effort is the latest step toward a citizen-centered federal government. DisabilityInfo.gov is a comprehensive online resource designed to provide people with disabilities with the information they need to know quickly. With just a few clicks, the portal provides access to disability-related information and programs available across the government on numerous subjects including civil rights, education, employment, housing, health, income support, technology, transportation, and community life. □



continued from page 1

efforts in emphasizing the necessity of 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.* Along with this definition, it is believed that a successful transition from adolescence into adulthood, regardless of medical conditions, requires looking at the young adult as a whole person with needs and desires to be addressed.

Through concentrated efforts and training, DSCC Care Coordinators and other staff have received materials, guidelines, tools, activities and web site resource information. These resources and materials were developed for the purpose of educating and emphasizing to the youth and their families the importance of building independence skills in health care management, preparing for the future and raising expectations of abilities for young adults with significant impairments.

As the DSCC Medical Transition effort expands, it is DSCC's hope that the future caption for the newsletter article will read "Youth are in Control of their Health Care Management and are Prepared for the Future."

Youth and family perspectives on transitioning to adult health care

by Rosalind German, Family Supports Specialist, in *The Cultural Competence Exchange*, Fall/Winter 2001, Issue 4.

The Division of Services for Children With Special Health Care Needs, MCHB, has established six indicators to *Measuring Success* for children with special health needs and their families. These outcomes/

performance measures are articulated in the Division's goals for Healthy People 2010. *Measuring Success* addresses two critical issues for families and youth with special health care needs or disabilities who are transitioning to adult health care.

■ 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.

■ All families of children with special health care needs will have adequate private and/or public insurance to pay for the services they need.

As youth with special health needs begin to transition to the next phase in their lives, they must contend with their independence. This includes employment, housing, personal finances, recreation and many other areas we all face as adults. Planning for the future needs of a young person is an arduous process. Some areas of transition are addressed by school systems through the requirements of the Individuals With Disabilities Education Act (P.L. 105-17). There is however, no systematic approach required by legislation that governs transition to adult health care and insurance coverage for youth with special health needs or disabilities.

Transitioning to adult health care can be a frightening and sometimes overwhelming process for both parents and youth. This article is based on interviews with parents and young adults with special health needs or disabilities. It provides perspectives on transitioning from pediatric/adolescent care to adult health care systems.

Scarcity of knowledgeable health care providers

First and foremost, parents, family members and young adults with

special health needs or disabilities expressed fear in changing from pediatric/adolescent care to adult care because they were unable to identify health care practitioners who were familiar with their unique needs. One young person described a particular concern. "My pediatrician and I had a good rapport about my health needs. When I had shunt problems at age twenty, she was able to immediately identify the issue just by looking into my eyes and assessing a few other symptoms. I don't know if that will be possible with my new doctor because she doesn't know me that well and I'm her first patient with Spina Bifida." This is typical of the kinds of concerns also expressed by parents on behalf of their children.

Developing rapport, trust and confidence with adult health care providers

Developing rapport, trust and confidence with a new health care provider was a concern voiced by all young people interviewed. They were concerned about how long it would take to develop a relationship and how receptive the health care provider would be to their needs.

Adapting to new service delivery approaches

Parents were concerned that the manner in which services would be delivered would be quite different in many respects. Pediatric/adolescent care actively involves the parent and/or other family members. This is not typically the case with adult care, which tends to focus only on the patients with the assumption that they can manage their health care independently.

Changes in health care coverage & insurance

Parents expressed concerns about the impact of changes in health care

please see page 5

continued from page 4

coverage for young adults with chronic illness or disabilities. Under some insurance plans, a variety of conditions must be met in order to maintain coverage. In some cases, families found it necessary to access Medicaid because their children no longer met the age or dependent status criteria of their private insurance. One parent shared an experience in which transition took place very abruptly for her son with special health needs. The insurer's policy limited the health care practitioner's ability to serve patients to those 21 years and younger, although the practitioner and family thought the ceiling was 25 years. This resulted in an interruption of care for her son. Additionally, because her son had complex needs, there was inadequate time to prepare with a new health care practitioner.

Things To Do To Prepare for Transition

What parents/families can do

As parents begin the process of transitioning their young adults from pediatric/adolescent care to adult health care, these considerations may be helpful in supporting your child through this process.

1. Find out the policies regarding the age and service policy limits for your child's pediatric/adolescent practice.
 2. Find out your health care insurer's policy regarding the age limit of services under pediatric/adolescent care.
 3. Begin discussing transition at 14-15 years of age with both your child and the health care provider.
 4. Foster the development of an independent relationship between your child and his/her health care practitioner. This provides a foundation for developing future relationships with adult health care providers.
5. Request that your pediatric/adolescent health care practitioner recommend an adult provider who is sensitive and knowledgeable of special health care needs and disabilities.
 6. Find out how your insurer handles referrals and consultations for transition to adult health care.
 7. Explore your state's legal requirements about the need for limited guardianship based on your child's unique needs.

What youth can do ...

There are a number of things you may consider as a young person preparing for or transitioning to adult health care.

1. Make a list of questions to ask your prospective health care practitioner such as:
 - Have you ever had a patient with special health care needs?
 - Are you willing to spend time with my pediatrician/adolescent health care provider to gain an understanding of my unique health issues?
 - Do office visits include a time for me to talk to you about my concerns?
 - Can I talk with you directly if I call you on the phone? Do you respond to patient e-mail inquiries?
2. Find out how your health insurance coverage works.
3. Keep a notebook or journal of current medications, specialists and other information that is relevant to your care.
4. Remember that your parents and family members are there to support you, and inform them when issues are too difficult for you to handle alone. □

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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.

Aurora Foods (Steven Keihler) - Gold level - \$1,000

Olga J. Walker (Emeraldhill Publications) - Silver level - \$500

Illinois Academy of Family Physicians - \$200

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. □



VISIT THE DSCC WEBSITE

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.

Why Was Family Voices Formed?

Many groups focus on particular childhood illnesses or populations. Others represent children and adults, or concentrate on specific reform proposals. Until Family Voices was formed, there was no national organization that spoke for all children with special health needs.

Family Voices believes that children with special health needs face common problems caused by fundamental inadequacies in our health care system. Family Voices does not support any specific health care reform plan. Instead, the role of Family Voices is to advocate for the inclusion of a set of basic principles in every health care reform proposal.

What Family Voices Does

Family Voices is a national, grassroots clearinghouse for



information and education concerning the health care of children with special health needs. There are almost 40,000 Family Voices members - families of children with special health needs and friends and professionals who know and love our children.

How to contact Family Voices

National Office

3411 Candelaria NE, Suite M
Albuquerque, NM 87107

1-888-835-5669

(505) 872-4774

(505) 872-4780 (fax)

E-mail: kidshealth@familyvoices.org

Web: <http://www.familyvoices.org>

How to Join Family Voices

Although Family Voices does not charge membership fees, they do accept donations and promise to put them to good use. Family Voices State Coordinators mail members in their states information from other states and our national office bi-monthly without charge.

If you would like to receive the same information directly from Family Voices' national office, please include \$25 for postage and handling. If you want to be part of a grassroots movement to make sure that children with special health care needs receive the health services they need and deserve, please send your name, mailing address, e-mail address and telephone number to:

Family Voices

3411 Candelaria NE, Suite M
Albuquerque, NM 87107

Check out the new DSCC family page!

To meet the ongoing influx of materials to assist families with children with special health care needs, DSCC has revised its family website, <http://internet.dsc.uic.edu/dscroot/parents/parents.asp>

On the main families page you will see a new section called:

New Online information library for Families

- ☐ Applications for DSCC Programs (English and Spanish versions)
- ☐ DSCC Coordinated Care Record
 - Workbooks to help families of children with special health care needs record and organize information on their children.
- ☐ DSCC Brochures
 - DSCC Family Handbook with the most common questions families ask about DSCC services. (English & Spanish version)

☐ DSCC Family Newsletter "Special Addition"

- Published twice per year, the Family Newsletter provides national updates and information for families. (English & Spanish version)

☐ Every Child Deserves a Medical Home

- This section provides basic information and materials about the concept of "Medical Home," which enhances the family and professional partnership in medical care.

☐ Health Insurance Materials

- "Choosing and Getting the Most from your Managed Care Plan"
- "Insurance Terminology for Families"
- "Understanding Health Insurance"

☐ Illinois Providers for Children with Disabilities

- A Statewide resource for locating pediatric health care

in Illinois and surrounding border states.

☐ Medical Documents of Interest

- Links to the National Library of Medicine and Medline.

☐ Preparing for Adulthood (Transition)

- Materials on preparing for transitions from pediatrics to adult care. Many new materials will be added after January 2003.

☐ Questions and answers about DSCC

Additional information is also provided about

- ☐ Family Support Groups
 - Regional support groups that meet at least 6 times per year to inform families about various topics of concern to families with special health care needs.
- ☐ Family Advisory Council
 - A Statewide group of DSCC parents who meet three times per year to provide guidance and direction to DSCC. ☐



Moving from pediatric

continued from page 2

care needs. Many youth and parents express strong ties to devoted pediatricians who have provided treatment for long periods of time—if not entire lifetimes. Thoughts of changing providers can be frightening, especially if the idea is unexpected. Furthermore, many pediatricians are reluctant to turn over care of a patient with special health care needs to another provider who may not be as familiar with the specific condition or need.

On the other hand, many individuals say that their pediatric providers have not addressed adult issues. They report feeling embarrassed and demeaned as young adults who are in their 20s or even 30s, and are still seen in pediatric offices, clinics, and hospitals. Pediatric-trained providers can sometimes miss signs and symptoms that would be recognized by adult-focused providers.

The transition to adult care would seem to be most effective and most easily achieved if it was anticipated and planned for from the earliest point in the child's treatment. So that youth and families do not feel forced to change providers or do not feel trepidation over the quality of care to be received in the

future, the transition should be expected, well thought out, and managed to minimize any negative impact. It should be one more informed choice made by the patient, family, and health care provider. That is the course taken in the HRSA's National Healthy and Ready to Work (HRTW) initiative.

HRTW projects

The six state implementation grant projects (Arizona, Iowa, Kentucky, Maine, Mississippi, and Wisconsin), currently running in Phase II of the HRTW initiative, are all looking at the

The Life Maps are designed to both elicit information about the child's status and progress and to give age-appropriate advice for ways the family can help prepare the child for future transition. Information is put into a database, and it is then available for future contacts with the child and family. This gives the commission staff a focused way to track the child's progress, identify specific family needs, and match with, or refer to, available resources. It also provides management information data for this population of children and youth.



.to adult medical care.

issues involved with transition from pediatric to adult health care.

The Kentucky TEACH project has changed the way the Kentucky Commission for Children with Special Health Care Needs interacts with the children and families. Through the use of "Life Maps" and introduction of a computerized tracking system, the Kentucky commission now focuses on transition at every point of contact with the child and family.

This change in focus at the commission was achieved, in part, by changing the job descriptions and performance plans of staff to reflect transition as a required element. That signaled to the staff the importance and value of transition as part of the services provided by the commission to the citizens of Kentucky.

please see page 8

continued from page 7

Using the medical home

In addition to the issues that youth, families and pediatric providers face, finding adult providers who are willing and able to accept youth with special health care needs into their care can be a challenge in certain parts of the country. A number of the HRTW projects are approaching this issue as a part of the medical home concept.

The thinking is that comprehensive and coordinated care in the medical home would include planning for a transition to an appropriate adult provider. The grant project in Arizona, for example, has recruited adult providers who work with the various health plans and are willing to accept youth with special health care needs as patients. Linking those providers with the medical home will hopefully ease the entire transition process. It is already clear that a training need exists and the HRTW initiative will be focusing on how to address that need with the adult provider community.

Also, the HRTW initiative and the state implementation grant projects are looking at ways to address the insur-

For more information about the New Freedom Initiative, visit www.hhs.gov/newfreedom
For more information about the SSI program, visit www.ssa.gov
For more information on the HRTW initiative, go to www.mchbhrw.org

ance issue. In general, lack of information is a major factor. It seems that many youth and families would benefit from the assistance of a transition coordinator or facilitator who would help them explore the various options and find access to needed care, services, and insurance.

Cultural issues

Furthermore, there are cultural competency issues that impact access to and utilization of health care. Some minority populations are historically underserved as stated above. The situation worsens as these youth move into adulthood. Some cultures have different values about health and health care that may impact issues, such as if, or when, treatment is sought, whether or not medications or invasive proce-

dures will be used, and at what age youth will begin to exercise control over medical decisions. When providers are culturally competent, care improves and families express increased satisfaction. The HRTW National Center is working with the National Center on Cultural Competency to further identify and address the needs of minority youth in transition.

By providing youth and families with as much information as possible and building a system of care that encompasses the medical home concept, including planning for and facilitating the transition to adult health care, the HRTW initiative aims to enable youth and families in making choices that allow for a full, rewarding, and independent life in their community. □

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