

HIPAA - What is it and why am I asked to sign all of these forms?

By now all of you have received many privacy notices from your doctor's office, local pharmacy, insurance companies and yes, from us, DSCC. These privacy notices are in response to HIPAA, the new Federal law on the privacy of health related information. HIPAA is the acronym for the Health Insurance Portability and Accountability Act of

1996. DSCC's vision, as we implement HIPAA, is to improve our attention to the privacy issues of families with children having special health care needs by keeping their protected health information secure.

By April 14, 2003, all health care providers and health insurance plans began offering and posting notices to their clients on how any health care information about them will be used.

You can expect to be asked to sign an "Authorization to Release Health Information" form whenever sharing of protected health information is needed for DSCC to coordinate your child's services. This may occur

frequently. Your signature on this form allows your health care provider, including DSCC, to share information with other providers, a school or another program. DSCC may ask some families to sign many Authorization to Release Health Information forms at one time. Understand that DSCC is trying to coordinate your child's health services with many providers and this law requires your informed consent through signed permission.

If you have any questions about how DSCC is dealing with the HIPAA law regarding your child's protected health information, contact your DSCC care coordinator. ☐

Parent training and information centers

Parent Training and Information Centers (PTIs) in each state provide training and information to parents of infants, toddlers, children, and youth with disabilities and to professionals who work with children. This assistance helps parents to participate more effectively with professionals in meeting the educational needs of children and youth with disabilities. The Parent Centers work to improve educational outcomes for children and youth with all disabilities (emotional, learning, mental and physical). The PTIs in Illinois are:

Designs for Change

29 East Madison, Suite 950
Chicago, IL 60602
312-236-7252 voice
312-857-1013 TDD
312-236-7927 FAX
E-mail: markse@designsforchange.org
Web Site: www.designsforchange.org

Family Matters (ARC Community Support System)

2502 South Veterans Drive
Effingham, IL 62401
217-347-5428 voice
217-347-5119 FAX
866-436-7842 Toll-Free
E-mail: info@fmptic.org or deinhorn@arc-css.org
Web Site: www.fmptic.org
Serving: Statewide except Chicago

Family Resource Center on Disabilities

20 E. Jackson Blvd., Room 300
Chicago, IL 60604
312-939-3513 voice/312-939-3519 TTY/TDY
312-939-7297 FAX
1-800-952-4199 IL only
E-mail: frcdptiil@ameritech.net
Web Site: www.frcd.org ☐

Division of Specialized Care For Children
2815 West Washington, Suite 300
P.O. Box 19481
Springfield, Illinois 62794-9481
800-322-DSCC (3722)
www.uic.edu/hsc/dsccl



Special Addition



children with special health care needs

A NEWSLETTER FOR ILLINOIS FAMILIES

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Director: Charles N. Onufer, M.D.
Editor: Bob Cook

DSCC Family Advisory Council

Claudia Fabian	Mary Fitzsimmons
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Dee Pratscher	Linda Prewitt
Julie Stover	Sherri White

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Federal Viewpoint

Achieving community-based service systems for children and youth with special health care needs and their families

by Lynda Honberg. From AboutFace. Reprinted with permission.

When my daughter Sarah was born 10 years ago, I often struggled with what to call her condition. Crouzon's Syndrome was far too clinical and cranial-facial condition or facial difference just didn't roll off my tongue very easily. And I absolutely hated the word birth defect - because she is definitely not defective in any way.



Sarah proudly shares a winning moment with her coach (and mom), Lynda. Sarah's soccer team won their division championship.

My dilemma was solved when I heard the phrase "children with special health care needs," because Sarah is so special and she does have many health care needs.

A new definition

Children with special health care needs are those who have or who are at increased risk for a chronic physical, developmental, behavioral, or

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Local Viewpoint

DSCC youth/young adults surveyed

by Alicia Becker & Darcy Contri, DSCC

In an effort to develop some baseline data on knowledge, available services and skills of youth/young adults regarding transition issues, DSCC surveyed a random selection of 386 youth/young adults, ages 14-21 living throughout

"Laughing deeply is living deeply."

the state of Illinois, enrolled in the DSCC core program. They were asked to respond to questions in the following areas: medical transition, student status, employment status, self-care information, independent living plans, social/recreational involvement, knowledge of laws and the type of assistance provided by DSCC, assistance from other agencies/programs and transition materials.

With a response rate of 21%, demographic information revealed 39% of the respondents were

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Sarah is a natural at mothering. Here she is thrilled to hold the newest member of her family, cousin Sarina.

emotional condition, and who also require health and related services of a type or amount beyond that required by children generally.

This definition was developed under the leadership of the federal Maternal and Child Health Bureau (MCHB) and has now been accepted by child health experts nationwide, including the American Academy of Pediatrics.

In the past, categorizing children by their diagnosis led to a proliferation of disease-specific programs and a

fragmentation of services. An assumption was also made that the need for services was limited to children with disabilities that restricted their daily functioning or activity. This new definition recognizes that there is a broader group of children who have ongoing needs for health services.

Despite the vast array of diagnoses and conditions, children with special health care needs and their families all share the same need for a comprehensive system of care that allows them to live, to be educated, to play, and to build relationships in their community.

It is estimated that 13% of our nation's children have a special health care need. While the nature, scope, and intensity of services vary, adopting this definition shifts the focus to developing systems of care that meet the needs of all these children, regardless of the specific diagnosis or category.

The needs of families

Seven years after I heard this phrase, "children with special health care needs," I accepted a position with the MCHB/Department of Health and Human Services. As I frequently speak with families of children with special health care needs across the

country, including families referred to me by *AboutFace*, the same issues are universally brought up: Families want to have access to a physician who will be compassionate

and provide coordinated, ongoing, and comprehensive care. They are tired of trying to organize the vast array of services their child needs, especially coordinating school and medical services.

Families often feel their voices and concerns are not heard, and they are

not always satisfied with the care their child is receiving. Not enough is being done to assure their son or daughter can make the transition to adulthood. And more than anything, families want health insurance that pays for the services their child needs and includes their child's providers.

Improving systems of service

In response to this need, the Social Security Act was amended in 1989 and mandated Title V Maternal and Child Health Programs for Children with Special Health Care Needs to "facilitate the development of community-based systems of services for such children and their families."

This focus on improving service systems for these children is also reflected in both Healthy People 2000 and Healthy People 2010, the nationwide agenda developed by the U.S. Surgeon General to improve the health of all the people in the United States. Healthy People 2010 includes an objective to "increase in the proportion of territories and states that have service systems for children with special health care needs."

Under the leadership of the MCHB, six performance outcomes were developed as a way to measure progress in meeting the Healthy People

objective and our mandate under the Social Security Act. These outcomes—our promises for all children with special health care needs—are listed in the box on page 7.

Our goal to achieve community-based systems of care is also part of the President's New Freedom Initiative, a major activity across federal agencies to increase community integration for people of all ages with disabilities.

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Sarah loves music. She particularly enjoys playing guitar. Music has helped Sarah cope through her 21 surgeries.

In *Delivering on the Promise*, a report to implement this initiative, the MCHB was given the responsibility of developing and implementing a plan to achieve appropriate community-based systems for children and youth with special health care needs and their families. We are in the process of working with many partners - families; providers; health insurers; public agencies at the federal, state and local levels; businesses; and voluntary organizations to develop practical action steps and strategies to develop this plan.

Results of the national survey

Another exciting development is the completion of the first National Survey on Children with Special Health Care Needs. The survey interviewed 750 families who have a child with special health care needs in each state and the District of Columbia.

For the first time, we are able to assess the prevalence of special health care needs among children and explore the extent to which these children have medical homes, adequate health insurance, and access to needed services.

Results of the survey, along with the products of other initiatives, will provide us with a national database to perform needs assessments, measure quality of care, and promote and

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implement the services needed by children with special health care needs. For more up-to-date information, go to the MCHB website at www.mchb.gov.

Moving ahead

I have worked in both the private and public sector, and I have to say in all honesty, I have never been part of a more strategic, forward-thinking program. Yes, our goals are ambitious, and given budget and resource

limitations, we face huge obstacles. But I am convinced by 2010, we will make progress in assuring that all children with special health care needs have access to the system of care they deserve.

I will keep you abreast of our progress in the years to come. If you are interested in getting more information or in learning about specific initiatives in your state, feel free to e-mail me at LHonberg@hrsa.gov. □

Core Outcomes

1. 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.
2. Children with special health care needs will receive coordinated, ongoing, comprehensive care within a medical home.
3. Families of children with special health care needs will have adequate private and/or public insurance to pay for the services they need.
4. All children will be screened continuously for special health care needs.
5. Community-based service systems will be organized so families can use them easily.
6. 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.

US Department of Transportation

Establishes Toll-Free Hotline to Assist Air Travelers with Disabilities

The hotline will provide general information to consumers about the rights of air travelers with disabilities, respond to requests for printed consumer information, and assist air travelers with time-sensitive disability-related issues that need to be addressed in "real time." The line is staffed from 7 a.m. to 11 p.m. Eastern time, seven days a week. Air travelers who experience disability-related air travel service problems may call the hotline at 1-800-778-4838 (voice) or 1-800-455-9880 (TTY) to obtain assistance. □

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State News Editor

Bob Cook
2815 West Washington, Suite 300
Springfield, IL 62794-9481
(217) 793-2350
rjcook@uic.edu

State Director (DSCC)

Charles N. Onufer, MD
2815 West Washington, Suite 300
Springfield, IL 62794-9481
(217) 793-2340
cnoufer@uic.edu

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Family Voices, (FV), is a national, grassroots clearinghouse for information and education concerning the health care of children with special health needs. FV stays on top of public and private sector health care changes that affect our children and families through the collective efforts of our families: a volunteer coordinator in every state; 10 regional coordinators; and a small staff working in several locations around the country. Together, FV shares the expertise and experiences

FAMILY VOICES



of families from around the country with state and national policymakers, the media, health professionals, and

other families. 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.

For additional information contact
Family Voices:

National Office
3411 Candelaria NE, Suite M
Albuquerque, NM 87107
1-888-835-5669

E-mail: kidshealth@familyvoices.org
Web: <http://www.familyvoices.org>

DSCC family support groups

DSCC has developed 3 regional support groups for families of children with disabilities. A DSCC trained family member facilitates each of the meetings. Support groups in Chicago, Peoria and Olney will meet six times between July 1, 2003, and June 30, 2004.

If you would like to participate or want additional information please contact Bob Cook at (800) 322-3722. □

Internet Resources

Consumer Guide to Handling Disputes with Your Employer or Private Health Plan, from Kaiser Family Foundation, provides clear and useful information, including click-on maps of state and federal rules and resources. Focusing first on understanding health coverage and then moving to disputes, the specifics involved in appealing decisions about what will be provided or paid for, followed by independent and external reviews. Go to: www.kff.org/consumerguide/



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.

Bookshelf

Looking for books, videos or other resources for individuals with disabilities? www.DisABILITIESBooks.com It's a new website with materials that provide information regarding information and products for people with disabilities.

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.

Illinois Academy of Family Physicians

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 deduction 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. □

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between the ages of 14-17 and 61% were between the ages of 18-21. Eighty-six percent were students. Twenty-four percent indicated they were employed. When asked to identify their main disability, 27% indicated health as their main disability, 25% hearing, 19% mobility, 5% cognitive, 4% learning and 18% other.

In regard to medical transition, youth/young adults were asked to identify the skills and responsibilities that they acquired in independent health care management, as well as the types of information they received to assist them in gaining independence. When asked about responsibilities and skills acquired, 66% indicated they were able to recognize when their condition worsened. Seventy-three percent knew their medications and the reasons for taking them, 27% responded they did not know their medicines and 38% indicated this question did not apply to them. In a cross tabulation of the main disability and knowledge of medicines, 46% of those who answered that the question did not apply categorized themselves with a main disability of hearing. Only 34% of the respondents made calls to refill their own medicines and supplies. Sixty-one percent of the respondents knew the name of their health insurance coverage. When asked about moving from pediatric to adult health care providers, 93% of the respondents were followed by a regular physician, with 75% indicating their doctors treated adults, leaving only 25% currently being followed by pediatric providers.

Respondents were asked to rate the helpfulness of DSCC assistance, tools and resources provided. Nearly one-half of the respondents did not reply. From those who replied, an overall rating of DSCC's assistance, in regard to transition, indicated 60%

were satisfied. While the percentage of satisfaction appeared above average, the number of respondents to this question was significantly lower than all other responses. This percentage was expected to be lower because materials and staff training had not yet been implemented.

Other areas, such as socialization, knowledge and resources were also assessed. In the area of socialization, results revealed at least half of the respondents participated in one to three activities/clubs. These results demonstrated a possible relationship between the type of disability and the level of participation in community activities/clubs; however, the likelihood of the disability correlating to the level of community integration was not formally tested. When asked if youth/young adults knew about the laws governing their rights, 19% within the 14-17-age category answered "yes" and 52% within the 18-21-age category responded "yes." In the area of resources, overall results indicated youth/young adults found family and friends to be the most helpful resources with medical, school and community resources following respectively.

In reviewing the results, six areas of need were identified. The first two areas were related to developing independence in health care skills and promoting medical transition from pediatric to adult health care providers. To encourage independent skill building and a shift of responsibility for health care management to youth/young adults, the dissemination of DSCC materials and coordination of resources/services are very helpful. Other areas of need are promotion of socialization and participation in the community, as well as promotion of self-determination and self-advocacy by raising the level of awareness and increasing the knowledge of laws pertaining to adults with disabilities.

The final two areas of need identified were strengthening interagency collaboration and providing transition information and coordination of services to the families. DSCC staff will continue to emphasize transition efforts with families, recognizing that youth/young adults turn to their family and friends for guidance more often than any other entity.

DSCC will be able to compare the strengths and weaknesses of future transition efforts to the baseline data that was obtained through this survey questionnaire. It is DSCC's intent to continue emphasizing planning for the future and fostering independence by ongoing dissemination of transition information material, and interagency partnerships. □

A medical home conference for families in Springfield

What is a Medical Home? And what does it mean for you and your child?

OSF - Saint Francis Hospital in Peoria will host an all day conference on Saturday, April 24, 2004 from 8:00 a.m. to 4:00 p.m. Join other health care providers and families discuss the values of family-professional partnerships, transition and care coordination issues and how to access quality health care for children with special health care needs. Learn about the benefits of the Illinois Medical Home Model. Registration forms with the program content are available on the DSCC web site: <http://internet.dscc.uic.edu/forms/medicalhome/SpfldMedHomeTrgConf.pdf> or call 1-800-322-3722 for more information. □

Backpack safety



Look for the following when choosing a backpack:

- Wide, padded shoulder straps - Narrow straps can dig into shoulders. This can cause pain and restrict circulation.
- Padded back - A padded back protects against sharp edges on objects inside the pack and increases comfort.

To prevent injury when using a backpack, do the following:

- Pack light. The backpack should never weigh more than 10 to 20 percent of the student's body weight.
- Always use both shoulder straps. Slung a backpack over one shoulder can strain muscles. Wearing a backpack on one shoulder may increase curvature of the spine.
- Organize the backpack to use all of its compartments. Pack heavier items closest to the center of the back.
- Use a rolling backpack. This type of backpack may be a good choice for students who must tote a heavy load. Remember that rolling backpacks still must be carried upstairs. And they may be difficult to roll in snow.

For additional information:

http://www.aap.org/advocacy/backpack_safety.PDF

TV tips

- Set limits on the amount of TV your child watches. Be firm. Limit children's TV viewing to an hour or two daily.
- Hide the remote. Eliminate channel surfing which encourages passive viewing.
- Keep TV's out of your youngster's bedroom. Children should watch their favorite shows in a central area of the home.
- Whenever possible, videotape programs and watch them later. Fast forwarding through commercials will shave ten minutes off of every hour of TV viewing.
- Discourage repeated viewings of the same video. The graphic language, violence and sexual content of movies rated PG-13 and R can have a cumulative effect on a child if they're watched over and over again.



- Harness the power of television in a positive way. TV can be a valuable tool for learning and expanding one's awareness of the world.
- Make use of ratings systems to know whether or not a program or movie is appropriate for your child.

BACK TO SCHOOL TIPS



School avoidance

If your teen is avoiding school, and has anxiety about returning:

- Talk to your teenager about why he doesn't want to go to school.
- Contact the principal, guidance counselor and school nurse, and make them aware of the situation.
- After you've taken steps to rectify the upsetting circumstances, insist that your teen return to school immediately.
- Severe phobias may require a gradual reentry to school.
- After days of anxiety-related absences from school, it's time to visit your pediatrician.



Before and after school child care

- During middle childhood, youngsters need supervision. A responsible adult should be available to get them ready and off to school in the morning and watch over them after school until you return home from work.
- Children approaching adolescence (the 11 and 12 year olds) should not come home to an empty house in the afternoon unless they show unusual maturity for their age.
- If alternative adult supervision is not available, parents should make special efforts to supervise their children from a distance. Children should have a set time when they are expected to arrive at home and should check in with a neighbor or with a parent by telephone.
- When evaluating child-care options, determine whether other family members can handle these responsibilities. For example, does a grandparent or other relative live nearby, and is he or she available and willing to help?
- If you choose a commercial after-school program, inquire about the training of the staff. There should be a high staff-to-child ratio, and the rooms and the playground should be safe.

School bus safety

Review the basic bus safety rules with your youngster:

- Wait for the bus to stop before approaching it from the curb.
- Do not move around on the bus.
- Check to see that no other traffic is coming before crossing.
- Make sure to always remain in clear view of the bus driver.

