



Promising Practices in Health Care Transition: Project Brief

Advances in health care practices over the last 30 years have made it possible for most children with disabilities and special health care needs (SHCN) to live well into adulthood. However, these medical successes have created a new challenge: transitioning young adults with disabilities and SHCN from pediatric to adult medical services. Newacheck and Halfon (1998) estimate that 1.8 million (6.5%) of our nation's youth, ages 12-17, have a chronic medical condition that, to some degree, limits their functional activity. A planned transition to adult medical care services for these youth is critical to assuring their long term health, quality of life and productivity. However, despite the importance of a successful health care transition, little empirical information is available regarding the nature and process of moving from pediatric to adult-oriented health care services.

Promising Practices in Health Care Transition

To address the need for more information about how to make successful health care transition a reality for all young adults we initiated the "Promising Practices in Health Care Transition" (HCT) project.

This project addresses the following research questions:

- ♦ What is it like for youth, families and professionals to go through the process of HCT? What facilitates HCT?
- ♦ What stands in the way of successful HCT?

The overall goals of the project are to: 1) increase awareness of the importance of HCT; 2) share information about current HCT programs and projects; 3) encourage and support active involvement of consumers in the research; and 4) promote the adoption of promising health care transition practices. The remainder of this brief describes our research, the involvement of consumers, and our information dissemination efforts.

Research

The Promising Practices in HCT research project is being carried out in three phases. During Phase I we conducted 34 focus groups with youth and young adults, family members and pediatric health care providers. The 143 focus group participants were drawn from over 20 states and represented 30 different medical conditions as well as a variety of backgrounds and ethnicities.

Through our analysis of focus group transcripts, we identified three major categories of HCT information: Transition Services (statements about needed transition services, recommendations for change and promising transition practices), Health Care Systems Issues (descriptions of the organization, financing, and delivery of health care and its impact on transition) and Transition Narratives (stories of the interpersonal relationships between young people with disabilities and chronic illnesses, families, and medical providers).

During Phase II, now underway, a second series of focus groups is being conducted with adult oriented health providers in order to better understand transition from their perspective. During Phase III of the project, we will examine HCT within the context of managed care arrangements.

Related Activities

In addition to the research, the Promising Practices in HCT project is carrying out a number of consumer support and information dissemination activities.

♦ HCT Listserve

In the Fall 2001, the Project started an electronic e-mail discussion group (listserv) for

youth, family members and health care professionals with an interest in HCT. Currently the list's 1300+ members share ideas, ask questions, and provide support and information to fellow list members. To join the HCT list send a blank e-mail message to transition-join@mchenet.ichp.edu or go to the list web site at: <http://mchenet.ichp.edu/scripts/lyris.pl?enter=transition>

◆ **Web Site**

The Project's Health Care Transition web site is designed to bring together a variety of HCT-related resources in one location. The web site provides access to our annotated bibliography of the HCT literature, and to a variety of other HCT-related information and training resources and Web sites. HCT programs and projects are invited to submit a description of their activities for inclusion on this web page. Through this site, users can also view "Jim's Story", a 10 minute informational video about one family's transition experience. To visit this site, go to: <http://hctransitions.ichp.edu/> or <http://www.consortiumnrrtc.org>

◆ **PAR Group**

Another important component of the Promising Practices in HCT project is our Participatory Action Research (PAR) group. The group is comprised of consumers (young adults and family members) who are going through or have completed transition to adult care. These individuals meet monthly by phone to discuss project findings and provide guidance and assistance to the project staff. Currently, PAR group members are involved in the development of ways to effectively

communicate and disseminate research findings to youth, young adults and their families. A few openings remain on the PAR group and interested individuals may apply by contacting Robert Gibson at rwg@ichp.edu

◆ **Training, Technical Assistance and Presentations**

Project staff also provide HCT-related consultation, technical assistance, training and presentations to health care facilities, medical and professional associations, and consumer groups. If you are interested in these services or would like to learn more about our research findings and other project activities please contact John G. Reiss at jgr@ichp.edu

References

Newacheck, P. & Halfon, N. (1998). Prevalence and impact of disabling chronic conditions in childhood. *AJPH*: 88, 610-617.

This brief is one in a series that cover disability issues among children and youth with disabilities and special health care needs.

These publications can be obtained directly from the Consortium for Children and Youth with Disabilities and Special Health Care Needs or at our website www.consortiumnrrtc.org. The Consortium is funded by the National Institute on Disability and Rehabilitation Research of the U.S. Department of Education.

For further information on this brief, please contact Robert Gibson, MSOTR/L (rwg@ichp.edu) at the Institute for Child Health Policy, University of Florida.



For further information on The Consortium for Children and Youth with Disabilities and Special Health Care Needs, its partners or projects, please go to the consortium website at: www.consortiumnrrtc.org



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