



## Promising Practices in Health Care Transition: A Research Fact Sheet for Consumers

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 to adulthood. However, these medical successes have created a new challenge: to successfully transition these young adults with disabilities and SHCN from pediatric to adult medical services.

Health care transition (HCT), in simplest terms, is the process that youth and young adults with SHCNs and chronic medical conditions go through as they move from child-centered (pediatric) to adult oriented health care.

A well planned and successful transition to adult medical care services is critical to assuring the long term health, quality of life, and productivity of youth with chronic health conditions and disabilities. However, despite the importance of HCT, little information on this topic is available to youth and their families.

### Promising Practices in Health Care Transition

To help fill this information gap, we initiated the "Promising Practices in HCT" project which is designed to address the following 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?

To answer these questions we conducted 34 focus groups and interviews with youth and young adults, family members and health care providers. The 143 focus group participants were drawn from more than 20 states, represented 30 different medical conditions and had a variety of backgrounds and ethnicities.

Through our analysis of the focus groups data we learned that many young people and their families found their journey from pediatric to adult health care to be a difficult one. We also learned that these individuals had many valuable ideas about how youth, families and professionals could be better prepared for HCT, and how the process of HCT could be improved. In this brief we present some of these promising practices and recommendations. After each section there is a series of highlighted questions designed to help you begin to think about HCT.

### Envisioning a Future

Parents and providers felt that, just like non-disabled children, children with a disability or SHCN need to have goals for the future. Having hopes, goals and aspirations was seen as critical because they give direction and meaning to the process of health care transition. Participants often mentioned higher education, employment and community living as meaningful goals for the future. Focusing on the future also included being aware of the probable changes in health status, health care services and insurance coverage. Having a vision for the future serves to focus and promote the actions needed to accomplish important goals. Participants also cited numerous examples of young people and their families who did not have goals for the future. Many of these individuals were said to have failed to: make arrangements for continuing medical care, develop skills for independent living skills, or continue their

*"We need to help families think long term and [see] the big picture and prepare our children to be responsible for their own health care and be their own advocate. We're teaching parents how to be advocates for their children but we need to teach the children to be advocates for themselves."*

PARENT PARTICIPANT

education. These examples were given as a warning of what will happen if youth do not have concrete goals for themselves.

As you begin to think about your child's future, you might ask yourself the following questions:

- ◆ **What does my child want to be when he or she grows up?**
- ◆ **Where does my child want to live?**
- ◆ **Am I encouraging behaviors and activities today that will serve as stepping stones toward the future?**
- ◆ **What could my family do now to help accomplish these dreams for tomorrow?**

## Start Early

Families who reported the most success in health care transition said that they began to give their children the opportunity to actively participate in their medical care and encouraged independence at a very early age. These families suggested that all parents should help the child to be knowledgeable about their own health condition, and play an active role during medical visits. They suggested that the child be encouraged to be the first to answer questions posed by health care providers. Additionally, the child should be given increasing levels of responsibility for taking medication, knowing doses and effects, ordering medication from pharmacies and making medical appointments. Families reported including their child as early as two years of age in their health care, and most felt it important that children develop positive medical habits and responsibilities before the beginning of adolescence.

*"He (pediatric physician) was a firm believer in children taking responsibility for their own health care. And so when Jim was 2 to 2 1/2 years old he started answering his own questions when we came to clinic and as a family we started rehearsing those questions and answers on the way to clinic."*

PARENT PARTICIPANT

As you begin to think about your child's health care transition, you might ask yourself the following questions:

- ◆ **What medical or personal care responsibilities does my child have now?**
- ◆ **What health care tasks would I like my child to carry out more independently?**
- ◆ **What is standing in the way?**

## Planning for the Future

Several focus group members recommended that all families develop a detailed plan for addressing the inevitable changes in their child's health insurance eligibility and coverage (due to age or change in dependency status). They also felt it was important to plan carefully for the time when their child, as a young adult, would assume primary responsibility for managing their own medical care (for example when the young person goes away to college). Families said that their plans were not always successful but believed that, by planning, they were better able to overcome many of the barriers to successful transition.

*"This is an issue that we need to be talking to the families [about], from the time those kids hit 12, [or] 14. This [pediatric health care] is a finite service and it isn't going to be here forever and you need to make sure you have a plan."*

NURSE PARTICIPANT

As you begin to plan for the future, you might ask yourself the following questions:

- ◆ **What changes will occur in my child's health insurance coverage when he/she reaches age 18? age 21? age 23?**
- ◆ **Does my child have the skills, knowledge, and experience to supervise personal care aides?**
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## Medical Journal

Most children with a disability or SHCN have extensive medical histories that may need to be shared every time a new health care provider is seen. Families suggested that parents keep a medical journal that presents a concise summary of current medical treatments, medications and providers as well as significant past medical treatments. This journal can document previous treatments, medications and allergies, etc. Some families suggested that youth be given increasing levels of responsibility for the medical journal. They felt that maintaining and updating the journal builds a young person's working knowledge of their disability and treatment, and reinforces their independence. It was suggested that young adults, when meeting with new health care professionals, can also use the journal, as an aid in providing information about their

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condition, medical history, medications, and response to treatments. Medical journals are available for purchase, and examples of the content and structure of a medical journal are available on the Web. See [mchneighborhood.ichp.edu/ CARENotebook/care-notebook.htm](http://mchneighborhood.ichp.edu/CARENnotebook/care-notebook.htm) and <http://www.finonline.org/>

*“Some of the kids have a hard time. We had one kid who’d made a poem up ‘cause he would never remember what he had or medicines that he took so he made this whole rhyme. Then he would try and recite it to the physicians in the emergency room...”*

PEDIATRIC PHYSICIAN PARTICIPANT

As you think about your child’s medical history, you might ask yourself the following questions:

- ◆ **Can my child list their medications and dosages?**
- ◆ **Does my child know or can she/ he quickly find the name and contact information for their health providers?**
- ◆ **Can my child provide necessary information about their health condition or disability to professionals in an emergency or during routine medical visits?**
- ◆ **What tools and strategies can be employed for my child to communicate information about health needs?**

## Education/Training

Families and health care providers agreed that it is critical for children and youth to receive ongoing education and training about their condition or disability so that they are prepared for the transition to the adult health care system. Suggested topics for training included: what to expect from adult health care providers, programs and facilities; how to describe your disability or SHCN and your needs; how to be assertive with providers; and how to negotiate with health insurance companies and managed care organizations. Families suggested that education and training be provided through peer teaching, role models and support groups. It was also noted that adult providers need training in the care of young adults with childhood onset medical conditions.

*“[I ask my patients questions like] what’s the nature of your heart disease? What was fixed? Here’s a picture, show me what happened?... they [may] go to an adult physician who may not understand their heart disease. If they understand that they’re better off.”*

PEDIATRIC PHYSICIAN

This issue of provider education will be addressed in a future brief.

As you think about what your child needs to know in order to be able to manage their disability or SHCN, you might ask yourself the following questions:

- ◆ **What more do my child and I need to learn about health care transition?**
- ◆ **What youth self-advocacy training programs are available to my child?**
- ◆ **Do these programs address health care transition?**
- ◆ **Where can I get more information about health care transition?**

The final section of this brief contains a list of additional resources on the topic of HCT.

## Conclusions

By sharing their transition experiences the participants in our study helped to identify some important steps that all families can take to foster a successful health care transition. We have highlighted four areas in this brief:

- ◆ Envisioning a future
- ◆ Starting early
- ◆ Keeping a medical journal
- ◆ Providing education/training

In this brief, we have included some ideas and suggestions that were made by study participants. What worked for them will not work for every family because of the strengths and needs unique to each family. However the results of our study do show that it is important for all families of children with disabilities and special health care needs to find their own answers to the following HCT questions:

- ◆ **Who will provide health care to my child when she/he is an adult?**
- ◆ **How will these services be paid for?**
- ◆ **How will the medical needs of my adult child such as primary care, specialty care, and reproductive health be addressed?**

We hope that the information we have gathered through our research will help you start, today, to answer these important health care transition questions.

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## Additional Resources

For additional resources on health care transition we invite you to join our Transition list serve. The list's 1300+ members share ideas, ask questions and provide support and information to fellow members. To join the HCT listserv send a blank email message to [transition-join@mchenet.ichp.edu](mailto:transition-join@mchenet.ichp.edu) or go to the list web site at: <http://mchenet.ichp.edu/scripts/lyris.pl?enter=transition>

We also invite you to visit the project's Health Care Transition web site. This site brings together many HCT-related resources in one location. The web site provides access to our annotated bibliography of the HCT literature, and a variety of other HCT-related information and training resources and Web sites. On this site, you can also view "Jim's Story" a 10 minute informational video about one family's transition experience.

To visit this site, go to:  
<http://www.consortiumnrrtc.org/nlinks.html> or  
<http://hctransitions.ichp.edu/>

*This is the first of a series of consumer/family member briefs that cover critical topics for children and youth with disabilities and special health care needs. The research and training activities conducted by the Consortium focus on access to pediatric rehabilitation issues, health plan utilization, best practices in health care transition, the use of telehealth in rural settings, as well as assistive technology services.*

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