

Transition to Adulthood: The Important Role of the Pediatrician

Donna Gore Olsen, BA*, and Nancy L. Swigonski, MD, MPH‡

ABSTRACT. This article, written by a parent of 2 youths with special health care needs and a pediatrician, builds on the Medical Home framework to give concrete examples of what physicians and families can and should do to prepare families for transition(s). The article consists of 3 parts. The first part is an introduction giving an overview of the importance of transition. "Developing a Life (not Illness) Plan: Begin With the End in Mind," emphasizes that no matter how challenging the disability or compromising the chronic illness, we owe it to our children to take the risk of thinking about the future and beginning to help them to develop a life (not illness) plan. The third part, "With a Little Help from My Friends," looks at how linking families with other parents, young adults, and adults living with disabilities and serious chronic illness can be a source of information to both families and physicians as they plan for the future. *Pediatrics* 2004;113:e159–e162. URL: <http://www.pediatrics.org/cgi/content/full/113/3/e159>; *transition, children with special health care needs, physician role.*

ABBREVIATIONS. CYSHCN, children and youths with special health care needs; CF, cystic fibrosis.

Advances in medical science and technology have improved outcomes for many children with special health care needs. Families and physicians who, historically, had focused on getting a child through one health crisis after another now face a different challenge—that of transitioning the growing child into the world. Transition is a continuum of changes that may include the move from hospital to home, from home to school, from school to work, from home to community, and from pediatric to adult health care. Children and youths with special health care needs (CYSHCN) are less likely than their peers without disabilities to succeed at some transitions. They are less likely than their peers without disabilities to graduate from high school, attend college, work in competitive employment, or live independently.^{1,2} Preliminary findings of studies conducted in the adolescent transition projects funded by the federal bureau of Maternal and Child Health indicate that many youths with special health

care needs "have little or no experience in managing their own health care, making medical appointments, or discussing their medical conditions."³ The studies also indicate that although youths may want an education and a job in the community, the adults in their lives often have low expectations regarding their future employment and independence.⁴ Like their families, youths have trouble getting timely information about community resources, struggle with ineffective systems of communication, and experience poor care coordination of their health care.

Each transition is an opportunity to help families of CYSHCN develop skills and strategies for making the next transition. The American Academy of Pediatrics Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs⁵ uses the Medical Home as its vision of health care and health care transition for CYSHCN. The Medical Home,⁶ ie, care that is family centered, community based, and coordinated, also serves as a framework for developing transition-related competencies. In a Medical Home, physicians, practices, and families partner together to provide accessible, coordinated, compassionate, comprehensive, and culturally effective care. Families look to pediatricians as a source of information and support, approached with mutual respect, when planning for the future. We believe that there are 3 transition competencies that pediatricians and residents should develop: 1) planning for the future with families, 2) linking families (including youths and young adults) to share information and experiences, and 3) developing practices that encourage the child/youth/young adult to accept responsibility for his or her own health care. To start, physicians and families need to develop a life (not illness) plan that begins with the end in mind.

DEVELOPING A LIFE (NOT ILLNESS) PLAN: BEGINNING WITH THE END IN MIND

"To begin with the end in mind means to start with a clear understanding of your destination. It means to know where you're going so that you better understand where you are now and so that the steps you take are always in the right direction."

Stephen R. Covey

When our son was 3 months old, he was diagnosed with cystic fibrosis (CF), a progressive, genetic condition that primarily affects breathing and digestion. Soon after his diagnosis, his physician, in his typically family-centered approach, asked me where I wanted my son to be in 20 years. I can remember

From *The Indiana Parent Information Network, Inc, Indianapolis, Indiana; and ‡Children's Health Services Research, Indiana University School of Medicine, Indianapolis, Indiana.

Received for publication Jul 17, 2003; accepted Oct 23, 2003.

Reprint requests to (N.L.S.) Children's Health Services Research, Indiana University School of Medicine, 699 West Dr, Rm 344, Indianapolis, IN 46202-5119. E-mail: nswigons@iupui.edu

PEDIATRICS (ISSN 0031 4005). Copyright © 2004 by the American Academy of Pediatrics.

being a little confused by his question. I was still very focused on getting through each day and really did not have much energy to think beyond taking 1 day at a time. He persisted. Where did I want my son to be in 20 years? What had I wanted for him before he was diagnosed? Forced to think about it, I finally said that we were hoping that all of our children would be able to go to college. His response was very positive and explained that because CF would mean physical limitations, it would be wise to think of ways that our son could make a living using his mind. He said that planning for college was one way to begin thinking about the future. For him to go away to school, we would also need to begin to think of ways to help him gradually assume more responsibility for his own health care.

To make his point about planning for the future, the physician told me about a young man who had been diagnosed with CF when he was 6 years old. His family had been told to take him home and love him for as long as they would have him. Expecting that their son might die anytime, the young man and his family did not plan for the future. By the time he was 17, he had dropped out of school because he saw no purpose in continuing his education. He then spent his time watching television and waiting to die. The tragedy was not that the young man had cystic fibrosis, the tragedy was that a life seemed to have been wasted. Given no hope, it is easy to understand why the family did not think about the future—it was too painful. With the twists and turns that CF sometimes takes, I, too, was unsure of what the future had in store for my son. However, with the story of the 17-year-old in mind, I knew that we needed to take the risk of beginning to plan for the future and to help our son plan for his own future. At less than 6 months of age, I knew I had some time—I just did not know how quickly the time would pass.

No matter how challenging the disability or compromising the chronic illness, we owe it to our children to take the risk of thinking about the future and beginning to help them develop a plan. Another important concept in the development of life plans is the idea of “not going around closing doors.” My son always wanted to be an airline pilot (an unlikely career for someone with CF). Rather than squelching his dreams, we allowed him to take flying lessons, and (although not as a pilot) after he graduated from college, he went on to work for an airline. Families frequently make decisions about their child with special needs on the basis of their fears of what might or might not happen rather than the interests, talents, and capabilities of their child. Rather than forcing themselves to consider the opportunities, families can become immobilized with their fears of failure or their refusal to take any risks where their child with special needs is concerned. My son’s pediatrician frequently reminded me not to go around closing doors before it was necessary and to trust that I would know when it was absolutely necessary. As my son was growing up, there were numerous times when I remembered his words. Some of the risks were small, but there were also times when I wanted not only to close a door but also to lock it and throw

away the key. Although it was hard to let go, I have no regrets and believe that my pediatricians’ encouraging words forced me to think before I was tempted to close a door unnecessarily.

Developing a clear understanding of a destination with a child with special needs is not easy. Building on the experiences of other families, talking with young adults and adults with disabilities and serious chronic illness, looking for options, and working with other knowledgeable professionals all are ways to get started in the right direction. A family-centered approach using some of the following strategies may be helpful:

- Begin by asking families questions that help them begin to think about the future (“Have you thought about what your toddler might do after he finishes high school?” “What are your child’s interests and talents?” “Is there something that he or she loves to do?” “Does your child have a special interest or talent that can be a starting place for thinking about future work or a career?”). When families are asked these questions, many will relate their child’s special interest in fire stations, airplanes, trains, or animals. Other families report their child’s special talent for meeting people, a fondness for infants and young children, or a love of music. Each of these may lead to a possible career path or open a different door in their life plan.
- Educate yourself about options for the future, including asking families of older CYSHCN what they have done or are doing to prepare their children for the future.
- Set a positive “can do” attitude with families by encouraging families to allow children to attempt new things, especially activities that are developmentally appropriate for a typically developing child of the same age. Look for opportunities to discuss what the child can do rather than focusing only on the challenges. Use “people first” language that emphasizes that a child with special needs is a child first (ie, child with Down syndrome rather than a Down syndrome child).
- Encourage families to include their child with special needs in programs and activities with typically developing children, including but not limited to regular classrooms in school, recreational programs that include children with a variety of abilities, community preschool programs, church camps, and other community programs designed for all children.

It is important to remember that helping families think about the future and maintain positive attitudes about the possibilities happens only over time and through consistent, thoughtful interactions that focus on the positive and the world of possibilities that are available to youths and young adults with special needs. By providing a Medical Home with a focus on family-centered and community-based care, physicians can be instrumental in helping families plan for the future where expectations are held high, developmentally appropriate decision making and

responsibility are encouraged, and “life plans” are continuously reviewed.

WITH A LITTLE HELP FROM MY FRIENDS: LINKING FAMILIES IN A PLAN FOR THE FUTURE

“There are only two lasting bequests we can hope to give our children. One of these is roots—the other, wings.”

Hodding Carter

Building a life plan for children with special needs is easier when physicians and families connect with families of older children with disabilities or serious chronic illness. A friend who has a son with Down syndrome reported that when her son was only a toddler, she got to know some families who had older children with developmental disabilities. She learned about resources and opportunities as these older children were prepared for jobs in the community through high school. She also, however, observed and learned from the pitfalls—ie, when these youths with developmental disabilities transitioned into jobs after graduation, many could not keep a job. There were reports that the young people took longer breaks than they should, did not get along with supervisors or peers, and did not take pride in doing a good job, whatever it was. It occurred to her that although some of these young people had been trained in specific job skills, they had never been given the opportunity to develop a work ethic. Learning from the experiences of other families, my friend developed a life plan for her son that included, among other things, a job delivering newspapers when her son was 10. His older brother was his job coach, and he was responsible for delivering those newspapers regardless of the weather, his attitude, or any other reason. He was taught that his customers depended on him and that being developmentally disabled was not an excuse for not doing a good job. At 27 years of age, this young man with Down syndrome has held the same job for the past 5 years with employment benefits including health insurance and a 401(k) plan.

My first opportunity to meet young adults with CF was at an annual family conference for children with CF. At the conference, we heard a presentation by young adults who talked about the successes and challenges of growing up and living with a chronic illness. I have to admit that meeting older adults with CF was sometimes difficult, particularly when the adult was having a lot of problems with his or her disease. For me, it was worth the risks. I learned a great deal from those folks, and I will always be grateful for their willingness to share their life and stories with me. I especially remember a young man who seemed to have such a positive attitude about his life and his disease. Although he was working full time, it was very clear that he also had a part-time job just keeping his body healthy. I will never forget the conversation that came up at the conference about how many courses a student with CF should take as a freshman in college. There were lots of different opinions about what was best for whom. It did not matter that each family had a different opinion. What was important was that through our

conversations, we each had a better idea about the issues and the possibilities.

As previously stated, building life plans and developing a clear understanding of a destination with a child with special needs is not easy. Relating the experiences of other families, talking with young adults and adults with disabilities and serious chronic illness can help not only families but professionals as well to get started in the right direction. Some of the following strategies may be helpful in building transition competencies:

- Introduce families to one another. As you work with families, ask them whether they would like to talk to other families who have a child with a similar condition—permission to release their name and telephone number to another family can be documented easily with the parent’s signature in the chart.
- Use formal support and information organizations. Both condition-specific (Down syndrome, attention-deficit/hyperactivity disorder, etc) and broader organizations exist. Our Family Voices affiliate, The Indiana Parent Information Network, Inc, helps parents of children with a wide variety of special health care needs to link with other parents around specific disabilities or issues. At Indiana Parent Information Network, disability groups for families are intentionally called Information and Support Groups.
- Recognize that for both pediatricians and families, other families may be a perfect resource for getting practical information that may not be written down anywhere. For example, who has the largest size diapers in stock? To whom do you talk about accommodations when signing up your son for summer league baseball? Which methods work best in supervising reminder systems for your child to take his or her own medication?

Through contacts with other families and with adults who are living with disabilities, families have a wonderful resource of information for developing a vision for the future. Remember that each family and child is unique. We come from different communities and different cultures and have different strengths, hopes, and needs. The purpose of connecting with others is to help families think about the possibilities, including the successes and the challenges. Pediatricians, working through a Medical Home, can foster and partner with families and individuals with disabilities to develop life plans that give our children with special health care needs not only “roots” but also “wings.”

ACKNOWLEDGMENTS

Supported in part by Health Resources and Services Administration, Maternal and Child Health Bureau CFD #93.110.

REFERENCES

1. West M, Kregel J, Getzel EE, Zhu M, Ipsen SM, Martin ED. Beyond Section 504: satisfaction and empowerment of students with disabilities in higher education. *Except Child*. 1993;59:456–467
2. Louis Harris and Associates. The N.O.D./Harris survey program on

- participation and attitudes: survey of Americans with disabilities. New York, NY: Louis Harris and Associates; 2000. Available at: www.nod.org/content.cfm?id=130. Accessed June 20, 2003
3. Integrated Services Branch, Division of Services for Children with Special Health Care Needs, Maternal and Child Health Bureau. *Healthy and Ready to Work (HRTW) National Center Cooperative Agreement*, Washington, DC: Health Resources and Services Administration, US Public Health Service, Department of Health and Human Services; 2001. Available at www.hrsa.gov/redesign/mchb/Marty/html/grantext/readytowork.htm. Accessed June 20, 2003
 4. Betz CL, Redcay G. Lessons learned from providing transition services to adolescents with special health care needs. *Issues Compr Pediatr Nurs*. 2002;25:129-149
 5. American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians-American Society of Internal Medicine. A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics*. 2002;110:1304-1306
 6. Medical Home Initiatives for Children With Special Needs Project Advisory Committee. American Academy of Pediatrics. The medical home. *Pediatrics*. 2002;110:184-186

Transition to Adulthood: The Important Role of the Pediatrician

Donna Gore Olsen and Nancy L. Swigonski

Pediatrics 2004;113:e159

DOI: 10.1542/peds.113.3.e159

Updated Information & Services

including high resolution figures, can be found at:
<http://pediatrics.aappublications.org/content/113/3/e159>

References

This article cites 4 articles, 1 of which you can access for free at:
<http://pediatrics.aappublications.org/content/113/3/e159#BIBL>

Subspecialty Collections

This article, along with others on similar topics, appears in the following collection(s):
Adolescent Health/Medicine
http://www.aappublications.org/cgi/collection/adolescent_health:medicine_sub

Permissions & Licensing

Information about reproducing this article in parts (figures, tables) or in its entirety can be found online at:
<http://www.aappublications.org/site/misc/Permissions.xhtml>

Reprints

Information about ordering reprints can be found online:
<http://www.aappublications.org/site/misc/reprints.xhtml>

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN®



PEDIATRICS[®]

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

Transition to Adulthood: The Important Role of the Pediatrician

Donna Gore Olsen and Nancy L. Swigonski

Pediatrics 2004;113;e159

DOI: 10.1542/peds.113.3.e159

The online version of this article, along with updated information and services, is located on the World Wide Web at:

<http://pediatrics.aappublications.org/content/113/3/e159>

Pediatrics is the official journal of the American Academy of Pediatrics. A monthly publication, it has been published continuously since 1948. Pediatrics is owned, published, and trademarked by the American Academy of Pediatrics, 345 Park Avenue, Itasca, Illinois, 60143. Copyright © 2004 by the American Academy of Pediatrics. All rights reserved. Print ISSN: 1073-0397.

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN[®]

