

Transition Digest 02-09 (June 29, 2009)

Colleagues:

I have not gotten the Transition Blog going, but want to share some of the most interesting transition related resources members have sent, and I have found on the web

#1: Best Practice Guidelines

["The Best Journey to Adult Life" for Youth with Disabilities: An Evidence-based Model and Best Practice Guidelines for the Transition to Adulthood for Youth with Disabilities"](#)

© Debra Stewart, Matt Freeman, Mary Law, Helen Healy, Jan Burke-Gaffney, Mary Forhan, Nancy Young, & Susan Guenther, 2009

Published and distributed by *CanChild* Centre for Childhood Disability Research

<http://transitions.canchild.ca/en/OurResearch/resources/BestPractices.pdf>

The "[Best Journey to Adult Life](#)" is a model that represents the dynamic and ever-changing developmental process of a young person's lifecourse, with the transition to adulthood depicted as an important 'journey'. Best Practice Guidelines for the transition to adulthood for youth with disabilities have been written using the words of youth, parents, community members, service providers, educators and researchers in Ontario, Canada. The Guidelines are organized into six main themes that emerged from comprehensive literature reviews, consensus meetings and focus groups with key stakeholders.

1. Collaborative initiatives and policies are necessary supports for the transition to adult life.
2. Building capacity of people and communities will enhance transition process.
3. The role of the "Navigator" within communities facilitates capacity building.
4. Information and resources are available to all involved in the transition process.
5. Education is a critical component of any transition strategy.
6. Ongoing research and evaluation provides the evidence needed for success.

Within each theme, guidelines are provided for three key phases of the transition process: preparation, the journey itself and the landings in the adult world. Specific guidelines within each phase are written for the key stakeholders involved in the transition process. These [Best Practice Guidelines](#) are generic and can be used and adapted by different communities and services.

For more information see:

<http://transitions.canchild.ca/en/OurResearch/bestpractices.asp>

#2 Dr. Eyal Shemesh at the Children's Hospital of Philadelphia, and Rachel A. Annunziato, Ph.D are interested in putting together a special issue of *Pediatric Transplantation* devoted to transition issues in transplanted children. Prospective authors should contact Dr. Annunziato at rachel.annunziato@mssm.edu with possible manuscript ideas.

#3. In December, 2008, Florida Health Care Transition Services Task Force for Youth and Young Adults with Disabilities completed its report and set of recommendation for assuring successful transition from pediatric to adult care. This report was requested by the Florida Legislature under Senate Bill 988. A copy of this report is available on the Task Force Web site.

See: <http://healthcaretransition.org/>

The work group that was brought together to develop the report and recommendations continues to work on ways to implement Task Force recommendations. To read about the current activities of the work group, see:

<http://healthcaretransition.org/Updates.html>

A list of the transition related documents and resources that were identified and reviewed by the Task Force are available at:

<http://healthcaretransition.org/Documents.html>

#4 A brief video about the transition program at Nationwide Children's Hospital (Columbus, Ohio) for youth with congenital heart disease.

http://www.youtube.com/watch?v=T-j9Bd_dAfE

#5 The Clinical, Psychosocial, and Socioeconomic Concerns of Urban Youth Living With Diabetes By Leslie Gee, Tracie L. Smith, Marla Solomon, Michael T. Quinn, and Rebecca B. Lipton In Public Health Nursing Vol. 24 No. 4, pp. 318–328

ABSTRACT Objective: Young people with chronic diseases face the challenge of moving from the pediatric to the adult health care environment, in addition to the normal hurdles of young adulthood. To most effectively help them through this process, we must first understand their perspective. **Design:** Qualitative study of the social and emotional impact of having diabetes. **Sample:** Young adults (n523), aged 19–26, who had been living with diabetes for a median of 12 years (range 4–19) were contacted; all but one were from underserved ethnic minorities.

Measurements: Semi structured telephone interviews were conducted, transcribed, and coded. **Results:** Having diabetes profoundly affected the life choices and expectations of these young people; their feelings and attitudes evolved over time. Financial and insurance concerns were key, because managing diabetes care on one's own as an adult was a major challenge. Most young people reported that family, friends, and coworkers were sources of support, but that disclosure of their diabetes was problematic. **Conclusions:** Offering emotional and practical support to young adults coping with diabetes is key to ensuring adequate medical management as they move into the adult system and assume full responsibility for their health.

#6 Preparing for Adulthood: Health Care Transition Counseling for Youth With Arthritis by Peter Scal, Keith Horvath, And Ann Garwick in *Arthritis & Rheumatism (Arthritis Care & Research)* Vol. 61, No. 1, January 15, 2009, 52–57

Objective. To determine the proportion of adolescents with arthritis who receive health care transition services and to compare the rates with those reported for adolescents with other special health care needs and adolescents with diabetes. Methods. We used data from the 2005–2006 National Survey of Children with Special Health Care Needs. A parent/ guardian identified youth ages 12–17 years with arthritis (n = 1,052), diabetes (n = 389), and special health care needs (n = 18,189). Four questions examined the extent to which providers discussed health care transition issues, including 1) transfer of care to adult providers, 2) health care needs of adults, 3) acquiring health insurance, and 4) encouraging self-care responsibility. Bivariate comparisons assessed the associations between sociodemographic characteristics and health care transition services, and multivariate regression models compared outcomes between conditions.

Results. Many adolescents with arthritis are being encouraged to assume self-care responsibilities (74.8%); fewer discussed how health needs will change in adulthood (52.1%), acquiring insurance (22.5%), or transferring care to a provider who sees adults (19.0%). These results are similar to youth with other special health care needs, but behind youth with diabetes. Conclusion. Among this sample of US adolescents, many report discussions about health care needs and self-management, but few are addressing critical aspects of the transition to adult-oriented health care.

#7 Developmental and Behavioral Disorders Grown Up by Judith S. Palfrey, MD, Susan M. Foley, PhD, Niraj Sharma, MD in *Journal of Developmental & Behavioral Pediatrics* - Vol. 29, No. 6, December 2008

#8 Transition of Adolescents With Inflammatory Bowel Disease From Pediatric to Adult Care: A Survey of Adult Gastroenterologists by Elizabeth J. Hait, Rene´e M. Barendse, Janis H. Arnold, Clarissa Valim, Bruce E. Sands, Joshua R. Korzenik, and Laurie N. Fishman in *Journal of Pediatric Gastroenterology and Nutrition* 48:61–65 (2008).

ABSTRACT Objectives: Transition of patients with inflammatory bowel disease (IBD) from pediatric to adult providers requires preparation. Gastroenterologists for adult patients (‘‘adult gastroenterologists’’) may have expectations of patients that are different from those of pediatric patients. We sought to explore the perspectives of adult gastroenterologists caring for adolescents and young adults with IBD, to improve preparation for transition. Materials and Methods: A survey sent to 1132 adult gastroenterologists caring for patients with IBD asked physicians to rank the importance of patient competencies thought necessary in successful transition to an adult practice. Providers reported which problems occurred in patients with IBD transitioning to their own practice. Adult gastroenterologists were asked about medical and developmental issues that are unique to adolescence.

Results: A response rate of 34% was achieved. Adult gastroenterologists reported that young adults with IBD often demonstrated deficits in knowledge of their medical history (55%) and medication regimens (69%). In addition, 51% of adult gastroenterologists reported receiving inadequate medical history from pediatric providers. Adult providers were less concerned about the ability of patients to identify previous and current health care providers (19%), or attend office visits by themselves (15%). Knowledge of adolescent medical and developmental issues was perceived as important by adult gastroenterologists; however, only 46% felt competent addressing the developmental aspects of adolescents.

Conclusions: For successful transition, adolescents and young adults with IBD need improved education about their medical history and medications. Pediatric providers need to improve communication with the receiving physicians. In addition, adult providers may benefit from further training in adolescent issues. Formal transition checklists and programs may improve the transition of patients with IBD from pediatric to adult care.

#9 Transition From Pediatric to Adult Care: Internists' Perspectives by Nadja G. Peter, Christine M. Forke, Kenneth R. Ginsburg and Donald F. Schwarz in *Pediatrics* 2009;123;417-423

OBJECTIVE. The goal was to understand the concerns of adult health care providers regarding transition for young adult patients with childhood-onset conditions. **METHODS.** Internists from the 2000 American Board of Medical Specialties directory were selected randomly. A 2-stage mail survey was conducted from August 2001 to November 2004. In stage 1, providers stated their concerns regarding accepting care of transitioning young adult patients. In stage 2, providers ranked their concerns.

RESULTS. A total of 241 internal medicine providers were selected for participation. In stage 1, 134 of 241 physicians were eligible to participate, and 67 (50%) of 134 completed stage 1 surveys. In stage 2, 112 physicians were eligible, and 65 (58%) of 112 responded. Concerns elicited in stage 1 were clustered into 6 categories: patient maturity, patient psychosocial needs, family involvement, providers' medical competency, transition coordination, and health system issues. In stage 2, concerns rated highest were lack of training in congenital and childhood-onset conditions, lack of family involvement, difficulty meeting patients' psychosocial needs, needing a superspecialist, lack of adolescent training, facing disability/end-of-life issues during youth and early in the relationship, financial pressures limiting visit time, and families' high expectations.

CONCLUSIONS. Internists clearly stated the need for better training in congenital and childhood-onset conditions, training of more adult subspecialists, and continued family involvement. They also identified concerns about patients' psychosocial issues and maturity, as well as financial support to care for patients with complex conditions.

#10. And on a personal note, I am pleased to announce that the "Talking with Your Doctor and Other Healthcare Professionals" web site is now operational. This web site, which was developed with funding from Children's Medical Services (Florida Title V CSHCN Program), builds on the communications model that was first presented in the "Talking with Your Doctor" DVD video, and includes additional video segments as well as more tips and strategies to help youth and young adults communicate more effectively with health care providers.

To see this site, go to:

<http://hctransitions.ichp.edu/gladd>

In the coming year, we plan to add video segments that show patients who are modeling effective communication skills as they ask questions, provide information, participate in making decisions about their plan of care and communicate what they will do to stay healthy.

Please let me know if you have any questions about or suggestions for the further development of the site.

That's It.

Please forward this e-mail to those who might have an interest and please let me know about articles, programs, videos, and other items that may be of interest to others working on the issue of transition. (But I won't promise that I will get a new digest out anytime soon)...

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