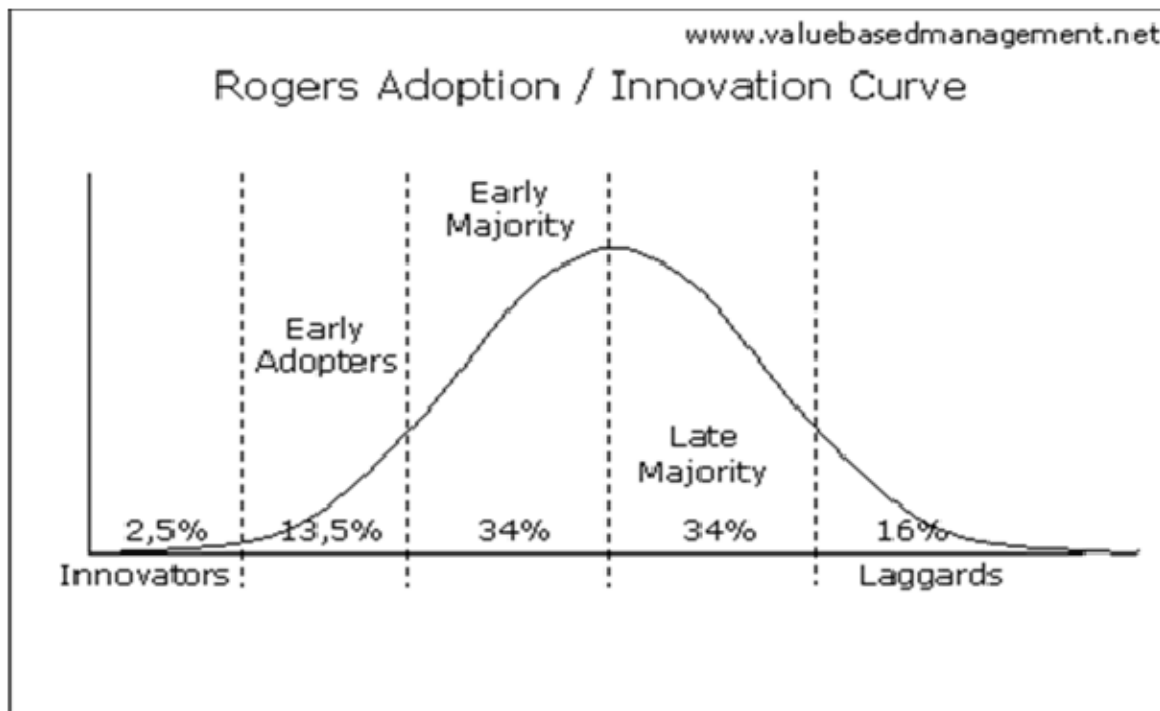


## Transition Digest #1-10 (Jan 6, 2010)

### Transition Digest #1 for 2010

Some thoughts and reflections as we begin a new decade...

Health Care Transition is a major change or innovation in the way in which health care is organized and delivered. The "adoption/innovation" curve – shown below - should be familiar to the social scientists on the lists.



The curve is designed to represent how change happens –how new and innovative practices are adopted.

Using this model, the innovators in the US were people like Surgeon General Koop, who organized the first "health care transition" Conference "Growing Up & Getting Medical Care" in 1989. The recommendations that came out that conference were:

- Start transition process early
  - Promote autonomy and self-mgt skills of youth
  - Educate pediatricians about good transition practices
  - Build bridges between pediatric and adult medicine
  - Provide adult-oriented physicians training in management of childhood-onset conditions
- See: <http://hctransitions.ichp.edu/sgconference.html> for full report

Sound familiar? Today (20+ years later) we continue to try to figure out how to put these good ideas into practice

Another innovator was Bob Blum, MD who ran the National Center for Youth with Disabilities at the University of Minnesota from 1988 to 1994. Like the proceedings from the Surgeon General's Conference, the training materials from NCYD are as useful today as when they were developed (but they were done before the days of desk-top publishing and PDFs)

The other innovators were the co-authors of the 1993 Society for Adolescent Medicine Position paper Transition from child-centered to adult health-care systems for adolescents with chronic conditions, which gave us the definition we continue to use today:

"The purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented healthcare systems"

Seems to me that the period of innovation began in 1988/9 and ran through 1993 with the publication of the SAM position paper.

Then, in the US came the early adopters (1993 – 2003)

The US Maternal and Child Health Bureau, the American Academy of Pediatrics and the Society of Adolescent Medicine. These organizations developed policies & guidelines; supported demonstration projects; developed, or funded development of materials and trainings; raised awareness & engaged stakeholders and "Institutionalized" the issue.

For example, MCHB funded the Healthy & Ready to Work (HRTW) Workgroup (1995-2001) at the Institute for Child Health Policy and funded a series of HRTW Demonstration Grants (1996 & 2001). The Bureau also funded the National HRTW Resource Center (starting in 2002; see: <http://www.hrtw.org/>)

In order to help assure that time, effort and resources would continue to be devoted to the issue of health care transition, MCHB specifically identified transition as one of its six national goals for CSHCN; and the provision of transition services was measured in the National Survey of CSHCN (2001). It was also defined as a Block Grant performance measure, so state Title V CSHCN Programs were required to report about their transition related activities in their annual report.

It seems the period of early adoption ended in 2002 with the publication of the "Consensus Statement on Health Care Transitions for Young Adults With Special Health Care Needs – which was adopted by the American Academy of Pediatrics, the American Academy of Family Physicians and the American College of Physicians-American Society of Internal Medicine. See: position paper <http://aappolicy.aappublications.org/cgi/content/full/pediatrics;110/6/S1/1304>

The period that follows is called "early majority" – and represents the period of time it takes for the practice to be broadly adopted– the time it take to go from "unusual" to "usual" – or "what it expected". That's the phase we are in now...

Another way of looking at this innovation and change is to use Gladwell's idea of a "critical mass" or "tipping point" - the levels at which the momentum for change becomes unstoppable... (see: [http://en.wikipedia.org/wiki/The\\_Tipping\\_Point](http://en.wikipedia.org/wiki/The_Tipping_Point));

Frankly, from 2003 to 2007 or so it seemed to me that, in the US very little progress was made in moving from policy to practice; and having health care transition become a standard – or expected service/support. Probably a lot was happening "behind the scenes"; programs were in development; studies were underway; young professionals were still trainees. Much more seems to be going on in the last two years. Many more articles in the literature; more presentations at conferences. Many more young professionals expressing an interest in providing care to young adults with chronic medical conditions and disabilities. Maybe we are approaching the point where the momentum for implementation of meaningful transition services and supports will be unstoppable. Let's hope...

To those of you outside the US – does this model of innovation, early adopters, and early majority (or tipping point/critical mass) fit with the process through which "health care transition" has evolved in your health care system?

## 1. A request

I am interested in more resources regarding 'managing chronic illness for individuals with cognitive challenges'.

As you know diabetes, celiac disease and other chronic health conditions do not exclude individuals with mental retardation, autism and other challenging cognitive disabilities. Where can they get the learning that they need to stay healthy?

Young adults who have diabetes and cognitive challenges may be physically active and manage the exercise piece of self care, but may not have a working concept of numbers, quantity or value. Since diabetes is "all in the numbers" this is a big problem. Even with parental involvement and oversight, very little is available that is really geared to these individuals. In most instances, support is directed to them and they are given little to no responsibility for the management of their special health care need. This does not promote full growth and development of these individuals.

One example of something that does work:

Parents of a young man with diabetes and cognitive challenges have developed a simple 8 page booklet that fits in the pocket of a young man's glucose meter. It is based on his protocols (that were developed by physicians at MASS GENERAL Diabetes Center in Boston). He keeps the meter and booklet with him at all times.

The information in the book can be used by anyone who works with this young man. For example, at school, meals can be made using 60 carb menus because he cannot 'count carbs'. Because he also cannot understand what 'BG of 120-140' means, the book has every number from 120-140 in a block of numbers. Each block of numbers has needed insulin units at the end. Now he can see the BG # and he can identify how much insulin to take, with an OK from staff. They say it's pretty cool. Not just for

him but anyone else who struggles to manage their insulin and food intake. It also includes day and bedtime snacks, 'pasta or pancakes protocol' (add 3 units) and emergency contact info.

Anyone aware of any studies that have looked at this issue?

Terri

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Moderators note:

Please send your responses to Terri at [tmclaugh@fcsn.org](mailto:tmclaugh@fcsn.org)  
And to me at [jgr@ichp.ufl.edu](mailto:jgr@ichp.ufl.edu) and I will post to a future Digest.

**Below are activities you can engage in to improve your knowledge and skills; and resources you can use to enhance your understanding and practice.**

## 2. Training

### **Earn 3 Graduate Credits Online Taking an Interdisciplinary Seminar on Health Care Transition**

Disciplines: Medicine, nursing, education, social work, law and other health professions  
Course: EEX 6936: Health Care Transition (HCT): An Interdisciplinary Approach  
Audience: graduate students in medicine, nursing, education, social work and law

Topic: The purpose of this course is to respond to an increased number of students with special health care needs (SHCN) who are graduating from school and entering the workplace and post secondary education programs. In this course participants will study the issues facing students with SHCN, highlighting the collaboration between the multiple medical and educational disciplines. Our approach will be to provide background information in each discipline prior to discussing the relationship with one another.

Modules:

Module 1: Young Adults with Special Health Care Needs  
Module 2: Healthcare View of Health Care Transition (HCT)  
Module 3: Education View of HCT

Module 4: Family View of HCT  
Module 5: Young Adult View of HCT  
Module 6: Interdisciplinary Approach

Cost for 3 credits:  
\$1,349.10 (Florida resident)  
\$1,452.63 (Non-FL resident/off campus)

For Information email:  
Jeanne B. Repetto, Ph.D., Associate Professor  
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University of Florida  
Email: [jrepetto@coe.ufl.edu](mailto:jrepetto@coe.ufl.edu)  
Registration deadline – January 11, 2010

### **3. Conferences and Meetings**

#### **A. Transitions 5 Conference**

For information about the conference, which will be held on May 31 and June 1, 2010 in Toronto Canada, go to:

<http://www.bloorview.ca/programsandservices/transfertoadultservices/transitionsconference.php>

#### **B. Chronic Illness Initiative Symposium (DePaul University)**

Save the date of May 12, 2010 for The Chronic Illness Initiative Symposium. Details available at a future date.

If you are interested in submitting a proposal addressing this year's theme (Chronic Illness from the perspective of the Arts), go to:

[http://www.sn1.depaul.edu/StudentResources/Chronic\\_Illness/index.asp#Symposium](http://www.sn1.depaul.edu/StudentResources/Chronic_Illness/index.asp#Symposium)

**NOTE:** The CCI site has links to a number of resources that may of value to college age students with chronic medical conditions and disabilities. See:

[http://www.sn1.depaul.edu/StudentResources/Chronic\\_Illness/index.asp](http://www.sn1.depaul.edu/StudentResources/Chronic_Illness/index.asp)

### **4. Call for Papers**

#### **Special issue on Youth Health Care Transition International Journal of Child and Adolescent Health 2010;3(4)**

This is a call for papers dedicated to the subject of health care transition for youth and young adults that will be published in 2010. We welcome papers from a wide range of professional perspectives and clinical areas. The papers should address some aspect of the process of transition from child-centered health or habilitative systems to adult-centered health or habilitative systems. We particularly seek translational work evaluating the transition process, testing innovative programs to support transition,

or assessing transition outcomes for different populations of youth and young adults. We also want to encourage young investigators from different countries to describe the current state of health care transition experiences around the world.

The articles may focus on the transition experience of populations defined by a particular condition or across conditions. Other populations of interest are youth with developmental disabilities, in the foster care or in the juvenile justice system.

Special issue editors/guest editors for this issue will be  
David Wood, University of Florida (E-mail: david.wood@jax.ufl.edu),  
John Reiss, University of Florida, (E-mail: jgr@ichp.ufl.edu),  
Maria Ferris, University of North Carolina (E-mail: maria\_ferris@med.unc.edu) and  
Linda Edwards, University of Florida (E-mail: linda.edwards@jax.ufl.edu)

Articles are due April 1, 2010 and should be submitted to professor David Wood, MD, MPH, UF College of Medicine-Jacksonville, Co-Director, Jacksonville Health and Transition Services (JaxHATS) (E-mail: david.wood@jax.ufl.edu) as email attachment (Rtx or doc file). The articles should comply with the requirements of the International Journal of Child and Adolescent Health (Uniform Guidelines for Biomedical Journals-Vancouver style) located in the following web-site:

<http://jmerrick50.googlepages.com/IJCAH-Leaflet.pdf>

The International Journal of Child and Adolescent Health is a peer-reviewed journal published by Nova Science (New York) aimed at the scientific community interested in the broad area of child health, adolescent health and human development.

Thank you for your collaboration on behalf of the co-editors and editor-in-chief

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## **5. Resources**

### **A. Youth Leadership Toolkit**

The Becoming Leaders for Tomorrow Project at Utah State University has developed a toolkit that is designed to increase understanding of the importance of the perspectives that youth and young adults bring and to provide information and tools that help to effectively include them in addressing the challenges of transitioning to adulthood and increased independence.

The toolkit consists of a guidebook and a DVD. The DVD includes nearly 2 hours of young adults sharing their hints and tips for other youth and young adults; parents; doctors; and other professionals. The guide book is for facilitators and provides some background and several discussion points and questions to use during training event..

This DVD includes one of my favorite videos – “Respecting the Young Adult Patient”, which can be seen on YouTube:

<http://www.youtube.com/watch?v=RJVgU7aGUZw>

More information about this project is available at:

[http://blt.cpd.usu.edu/Leadership\\_Toolkit.html](http://blt.cpd.usu.edu/Leadership_Toolkit.html)

The guidebook can be downloaded

[http://blt.cpd.usu.edu/Youth\\_Leadership\\_Toolkit\\_Guide.pdf](http://blt.cpd.usu.edu/Youth_Leadership_Toolkit_Guide.pdf)

Or you can request a copy of the guidebook and the DVD by contacting Al Romeo

Alfred N. Romeo, R.N., PhD.

Becoming Leaders for Tomorrow <http://blt.cpd.usu.edu/>

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## **B. Community Supports for Transition**

### **Community Supports for Transition**

January 20, 2010

3:00 - 4:00 Eastern Time

[http://www.hrtw.org/hrtwu/calls/01-20-10\\_Overview.html](http://www.hrtw.org/hrtwu/calls/01-20-10_Overview.html)

Many Youth with Special Health Care Needs (YSHCN) are likely to require community supports to make a successful transition to adulthood including in-home supports and/or personal care services, employment, transportation, and recreation supports in order to remain healthy, active and productive. Join the Healthy & Ready to Work National Resource Center, Champions for Inclusive Communities, and an outstanding panel of community service experts to learn about how to make connections and support the successful transition of YSHCN to all aspects of community living using the myriad of community resources and long term care waivers.

At the end of the call participants will be able to:

- Describe key elements of communities organized to support transition
- Discuss Home and Community Based Waivers
- Identify ways HCB waivers and community supports can help young people find and maintain employment and be involved in their communities
- Assist health care providers and families to prepare youth to access and use supports

Target Audience: Directors and transition coordinators of state Children and Youth with Special Health Care Needs programs, health care providers, social workers, care coordinators, Family to Family Health Information Centers, MCHB grantees, family and youth leaders, workforce developers, and educators.

The call is free, but pre-registration is strongly recommended.

Continuing Education Credits awarded through the University of Kentucky, College of Nursing will be available for nurses who participate in HRTW Topical Calls. For more information, go to [www.hrtw.org/hrtwu/cec.html](http://www.hrtw.org/hrtwu/cec.html).

For more information about this Topical Call and for links to resources, go to [www.hrtw.org/hrtwu/](http://www.hrtw.org/hrtwu/) and click on the January 20, 2010 call. Presenters will start promptly at 3:00 Eastern Time, so please call-in early.

## **C. Embedding Health Outcomes in the Individualized Education Program**

"Embedding Health Outcomes in the Individualized Education Program" is a video recording of a 40 minute teleconference that provides information and specific examples of health related goals for an IEP. This recording is available, at no cost, from the Wisconsin Department of Public Instruction web site.

<http://dpimedia.wi.gov/main/Viewer/?peid=f44dfa70439241dd85e99cce0cb70e26>

One of the presenters on this teleconference is Liz Hecht, from the

## **D. Health and the IEP**

The Wisconsin Community on Transition Health Practice Group has developed a set of health-related training materials that can be used with schools, health providers, families and directly with youth to help youth with disabilities learn to more effectively manage their health care concerns.

The health care training kit is available for \$35, which includes shipping and handling.

The kit includes:

Health and the IEP cd-rom:

The cd-rom contains three PowerPoint presentations and companion handouts on how medical and health transition issues can be addressed in the Individualized Education Plan (IEP) process. These presentations can be used as individual trainings or slides can be used in other agencies' trainings with credit to the Wisconsin Children/Youth with Special Health Care Needs Program and Waisman Center.

Transition to Adult Health Care: A Training Guide in Three Parts Second Edition

The training guide explains how to conduct a health training and options for using the workbook and pocket guide. While the training is focused on preparing youth with special health care needs for adult life, the content is important for any young person.

Workbook for Youth

This content focuses on helping youth develop and practice the skills needed for managing their own health care, such as talking to their doctor and refilling prescriptions.

My Health Pocket Guide

The portable pocket guide can help youth keep track of health care information. It is small enough to carry in a planner or calendar. Youth can use the tips and reminders as a guide when meeting with health providers.

### The Transition to Adult Health Care Checklist: Preparing for Life as an Adult

This booklet for youth preparing for the transition to adult life provides an overview of the knowledge, skills and actions that need to be addressed as part of transition for youth with special health care needs. It includes skills checklists and an overview of Wisconsin transition resources and supports.

Multiple additional copies of the following materials may be purchased singly at the following costs:

The Workbook for Youth: \$5 each for additional copies

My Health Pocket Guide: \$1 each for additional copies

Transition to Adult Health Care Checklist: \$5 each for additional copies

All materials are available to download for free at

<http://www.waisman.wisc.edu/wrc/pub.html>

Order Form: [http://www.waisman.wisc.edu/wrc/pdf/cyshcn\\_orderform.pdf](http://www.waisman.wisc.edu/wrc/pdf/cyshcn_orderform.pdf)

## 6. New HCT articles from the Literature

(or at least they are new to me)

**A. ‘I’m fine doing it on my own’: partnerships between young people and their parents in the management of medication for asthma and diabetes, Journal of Child Health Care, Vol 12(2) 116-128 (2008)**

### **Abstract**

Recent UK policy has highlighted the importance of a young person’s family in their care and the need for health professionals to work in partnership with young people and their parents. This research provides health professionals with an insight into how the responsibilities for different aspects of medicine management are shared between young people and their parents in the home. It highlights the dynamic nature of partnerships between parents and young people and the considerable role of young people in medicine management in the home, which contrasts with their more limited involvement in consultations with health care professionals. The findings are based on semi-structured interviews conducted in the participants’ own homes, with 69 young people aged 8–15 years (43 young people with asthma; 26 young people with diabetes) and their parents (138 interviews in total), recruited through general practice (GP) surgeries.

**B. D. Allen and J. Gregory. The transition from children’s to adult diabetes services: understanding the ‘problem’. Diabet. Med. 26, 162–166 (2009)**

### **Aims**

The importance of getting transition right for young people with diabetes is increasingly recognized and a strong professional consensus has emerged on best practice in this domain. Research evidence to inform the design of transitional healthcare services is weak, however, and prevailing views about ‘the problem of transition’ are based on a number of assumptions about adolescence, adulthood and chronic disease management which have been accepted uncritically.

## **Methods**

Drawing on youth studies and the sociology of chronic disease management, in this paper we describe how 'the problem of transition' has been defined in the professional and UK policy literature and examine the assumptions that underpin it.

## **Results**

We argue that the overwhelming emphasis is on how best to support young people in fitting in with the healthcare system. This has produced an orientation which is more concerned with supporting young people in the process of becoming adults rather than giving attention to their contemporaneous experiences and needs. Two years after the introduction of the UK National Service Framework for diabetes, the challenge of transitional services remains.

## **Conclusions**

We suggest that the time has come to consider alternative formulations of the 'problem'. Rather than asking how best to manage transition, we might ask how best to meet the needs of young people with diabetes at this stage of the life course. This requires an understanding of their experiences, the social networks in which they are embedded and consideration of how self-management might be supported by the healthcare system.

### **C. ReKate. The Pediatric Neurosurgical Patient: The Challenge of Growing Up. *Semin Pediatr Neurol* 16:2–8 2009.**

Adults treated in infancy for conditions such as spina bifida and hydrocephalus are not cured of their conditions even after reaching adulthood. However, patients who have received coordinated care within a children's facility are unlikely to find the same type of coordinated care when they become adults. This article explores the various causes of these difficulties, which are not uniform across geographic areas, and the need for and challenges of planning the transition of care of pediatric neurosurgical patients from pediatric neurosurgeons to general or adult neurosurgical practices.

### **D. Suris JC, Akre C, Rutishauser C. How adult specialists deal with the principles of a successful transition. *J Adolesc Health*. 2009 Dec;45(6):551-5.**

**OBJECTIVES:** To evaluate whether adult specialists comply with the basic principles for a successful transition of adolescents with chronic disorders, and to determine whether the characteristics of the adult specialists have an influence on applying these principles.

**METHODS:** Out of 299 adult specialists in four French-speaking Swiss cantons, 209 (70%) answered a paper-and-pencil mailed questionnaire between May and July 2007. Only those having received the transfer of at least one adolescent in the previous 2 years (N=102) were included in the analysis. We analyzed four dependent variables: discussing common concerns of adolescent patients, seeing the patient alone, having a transition protocol, and having a previous contact with the pediatric specialist. A logistic regression was performed for each dependent variable controlling for the physicians' characteristics (number of transfers, age, gender, workplace, and perceived experience).

**RESULTS:** Fifty-four percent of the physicians did not spend time alone with their patients, and sensitive issues such as sexuality or substance use were not widely discussed with their young patients. Most respondents (59%) did not have an established protocol, and 54% did not have any contact with the pediatric specialist. In the multivariate analyses, the adult specialists' characteristics had little impact.

**CONCLUSIONS:** For many adolescents with chronic disorders the transition from pediatric to adult healthcare seems to be limited to a simple transfer, often lacking adequate communication

