

## Transition digest 3-08 (January 22, 2008)

Colleagues:

Here is Transition digest #3 for 2008 (January 22, 2008)

### 1. Resources.

A. One of the activities of the American Academy of Pediatrics is its federally funded National Center of Medical Home Initiatives for Children with Special Needs. The mission of this Center is to support physicians, families, and other medical and non-medical providers who care for children with special needs so that they have access to a medical home. The Medical Home web site include a section on health care transition.

See:

<http://www.medicalhomeinfo.org/health/trans.html>

B. One of the resources recently added to their transition resources is:

#### **It's Time To Transition! A Workbook for Young Adults, Their Families, and Their Medical Providers.**

This workbook was developed by Laura Pickler, MD, MPH to help organize the medical transition process into a smooth and successful move from pediatric focused to adult focused health care.

The workbook is available on the web as a PDF at:

<http://www.cdphe.state.co.us/ps/hcp/transition/workbook.pdf>

I contacted Dr. Pickler about her workbook, and she was kind enough to provide the following information about the development of this tool and how it should be used:

"It's Time To Transition" was initially drafted to focus on the medical information transfer required for transitioning young adults in 2004. My experience with official medical records requests was that if they ever were sent they came months after they were needed in the adult system and often consisted of reams of paper that were impossible to cipher through and often illegible. Many key diagnostic reports were lost or just duplicated at the expense of the patient or their family. I piloted the workbook in my pediatrics and adult clinics for special needs individuals and have shared it with the Spina Bifida Association, Family Voices, Colorado Department of Education Transition programs, and during a number of parent advocacy retreats. A paper format was favored over electronic due to the needs of my patients (many did not have reliable computer access) and the diversity of electronic medical record formats of the adult medical community. A similar electronic document is available privately if families are able to afford this service (Lynxcare information at [www.lynxcare.net](http://www.lynxcare.net).)

The workbook really operates best under a Medical Home model which assumes that one provider is inadequate to care for a young adult with special needs. The young person should be making a change from one system of care to another. The primary care physician may coordinate efforts but may not be the central person doing most of the medical management. The workbook is meant to be flexible for the young person's individual needs with unnecessary pages discarded in the workbook format. The goal is that all the information should fit in no larger than a 1 inch three ring binder. Ideally the young adult, their main provider of care (or a representative from that office like a care coordinator, RN or MSW) and responsible adults (parents) all work together over about a year to complete the workbook. My experience is that it may take that long to compile the information and that gaps in readiness are frequently identified in the process of putting everything together.

Transition should occur only when the patient is ready, not at any predetermined chronological age. Not during times of acute illness, diagnostic uncertainty, major psychosocial stress or change. I also don't recommend changing all medical providers at the same time. If there are multiple specialists involved they should make the change to their adult counterparts in an intentional, coordinated way. In my practice primary care usually transitions last.

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C. Dr. Pickler remarks reminded me that children and youth with chronic health conditions and disabilities can experience multiple transitions of care – from intensive care to a regular ward; from hospital to home; between and among primary and specialty care physicians; and from one community and school based program to another. As we look for promising practices in the transition from pediatric to adult care, there should be lessons to be learned from those other transitions.

D. Through a search of the Web, I discovered a report, that was developed for the Canadian Association of Paediatric Health Centres in 2006 that focuses on the transition from hospital to community. This report, Finding Our Way Back Home: A National Resource on Promising Transition Practices.

[http://www.caphc.org/documents\\_programs/bell/finding\\_way\\_home\\_final.pdf](http://www.caphc.org/documents_programs/bell/finding_way_home_final.pdf)

(While report explicitly excludes the issue of transition from pediatric to adult care, I believe there are many lessons to be learned from the projects described in this report, which strive to assure continuity of care for children and youth with complex chronic conditions)

E. I also came across a 2007 report developed by the World health Organization (WHO) entitled The Adolescent with a Chronic Condition: Epidemiology, developmental issues and health care provision

The purpose of this paper is to present data related to the epidemiology of chronic diseases during adolescence, to review their impact on the bio-psychosocial processes of adolescence and to provide evidence-based suggestions on how to manage young people with chronic conditions in a comprehensive and holistic way.

My quick read through this 44 page report shows it to contain a wealth of information (including almost 300 references).

F. I would also suggest that you take a look at a video entitled “Respecting the Young Adult Patient”.

This 8:00 minute video was developed by the state Title V CSHCN Program in Utah - edited from a young adult panel presentation at a medical home conference. The video can be viewed on YouTube:

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

It shows both the wisdom and humor of young adults – who provide advise about how to help support independence and respect young adults for the people who they are.

## **2. Invite your friends**

The Transition list is open to all with an interest in the issue of health care transition. If you know of others who would like to subscribe, let them know that they can sign-up for the list themselves.

They can join by going to the list sign-up Web page:

<http://hctransitions.ichp.ufl.edu/listserv.html>

They enter their e-mail address and name and hit the subscribe button.

When their subscription is approved, they get a set of instructions on how to use the list and access archived messages.

(Members need to be approved in order to prevent spammers from joining the list, and from posting unwanted messages. Also, all postings are reviewed by a moderator before being included in a digest.

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## **3. The Health Care Transition Community**

And finally, 16 list members have joined the "Health Care Transition Community" (social networking site) although only 6 of us have put our face with our name. Felicity and I will not try to enhance the site or use its forum features until there are more members. The invitation to join stands. Go to:

<http://healthcaretransition.ning.com/>

And you don't have to post a picture if you don't want to...and you can view the page without joining.

If you want to participate - add information about yourself. To join the community you will need to sign up for the host Ning site (at no cost).

## **4. Topics for discussion and contribution**

I invite all of you to think about resources – articles, web sites, videos, that might be of interest to your colleagues on the list. (The list now has about 1000 members with working e-mail addresses).

One topic that may be of broad interest is “Readiness” –

What does “readiness” entail and do we measure it?

Does “ready” mean different things to different people – youth/young adults, families, pediatric providers, adult providers?

Can we use readiness data/information to tailor services and supports for youth and families?

The end

Look forward to your future contributions to the list -

John Reiss, List Moderator

and

Felicity Sloman - Co List Moderator

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