

## Transition digest #5-08 (July 14, 2008)

### 1. An ah-ha

Several months ago I had the opportunity of hearing a presentation by Adriane Griffen, who serves as Director of Health Promotion and Partnerships of the US Spina Bifida Association heard. She used a phrase during her presentation that really struck me. -- “a child who is affected by Spina Bifida” -- and it occurred to me how much better that phrase is – compared to “a child with Spina bifida” or “a child who has Spina Bifida” - in communicating that Spina bifida – or any other health condition – is only one aspect of the individual and is not the “defining” characteristic of the child.

In a follow-up conversation, Adriane confirmed that she specifically makes an effort to say people who are affected by SB because it is only one dimension of their lives.

I think this phrasing that should be used more .....

### 2. Resources.

#### A. Informational call from the HRTW Center

**Title:** Youth Involvement - Get YAC'in!

**Time:** 3pm - 5pm EST

**Date:** 30 July 2008

**Target Audience:** State CSHCN Youth Advisory Council Members, State Title V CYSHCN Programs, Transition Coordinators, Family & Youth Leadership Organizations

**Dial in #** 1-800-567-5900

**Access Code** 870036#

**Call-In Times** **eastern:** 3pm - 5pm

For more information, and to access archives of prior calls, go to:

<http://www.hrtw.org/hrtwu/topicalCalls.html>

Topics addresses in prior calls include:

Ways Title V can support pediatric and adult medical home

GOT DATA! And Innovative Practices, Too!

Integrating Health-Related Needs Into Individualized Education Plans and 504 Plans

Block Grant: Tips for Reporting Transition Progress

Transition & Cultural Competence: Is there intergenerational tension?

Youth Advisory Councils: Strengthening Youth Involvement in State Title V Programs--November 3, 2006

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B. Bloorview's Growing Up Ready program [timetable and checklists](#) are available on-line.

The timetable covers social and recreation activities, everyday skills like brushing teeth and household chores, teaching children about their health needs and how to advocate for them, and how to nurture interest in work experiences and a career.

"The checklists help families identify what areas their child needs to work on and can be a starting point for discussion with professionals if parents aren't sure about how to introduce a concept or activity," says Carie Gall, occupational therapist with Bloorview's Life Skills and Wellness Institute.

<http://www.bloorview.ca/resourcecentre/familyresources/growingupready.php>

C. MORE NEWS FROM BLOORVIEW ---

New clinic helps youth with disabilities transition to adulthood

June 18, 2008 – Toronto – Canada's leading children's and adult rehabilitation hospitals have joined forces to run a one-of-a-kind clinic that helps youth with disabilities better navigate adulthood.

Bloorview Kids Rehab and Toronto Rehab have opened the LIFEspan clinic – a clinic designed to fill gaps in adult services that put youth with disabilities at risk of developing preventable, secondary health conditions when they graduate from children's services.

For more about this new initiative, see:

<http://www.bloorview.ca/newsroom/stories/lifespan.php>

D. MyHealth Passport is a wallet sized card that lists a person's medical conditions, past procedures/treatments, medications, allergies, etc.

At this time, the passport is available for people with solid organ transplants, rheumatologic problems (like lupus and arthritis) cystic fibrosis and a number of other issues. There is also a generic passport.

Personal information can be entered and printed. The teen (or adult--anyone can use it) decides what information to put in, but should create the Passport with a health care provider who can provide them with accurate information. Adolescents are encouraged to carry the passport with them at all times and present it to providers when needed.

Access [MyHealth Passport](#) online go to:

<http://www.sickkids.on.ca/myhealthpassport/>

For more useful resources from the Transition Treatment Team at the Hospital for Sick Children in Toronto, go to

<http://www.sickkids.ca/good2go/>

and click on “Transition Intervention Menu” – on of the items listed down the left side of this web page.

Other items listed under this menu include

Readiness Checklists

Easy Interventions

Clinical Pathways

Materials for Families

Graduation

Graduation Letter

Facilitation of first adult appointment

Special transition clinics

#### E. “Now That You’re In High School”

The Institute for Child Health Policy at the University recently completed development of a transition booklet for high school aged youth. This booklet, "Now that You Are in High School" builds on "Since You're Not a Kid Anymore", by adding health care transition related activities and strategies for youth in high school.

For a "review" version of the high school booklet...just off the press

See <http://hctransition.wetpaint.com/page/HCT+HS+Booklet+Review>

This booklet will be available in a week or so, as a PDF from the HCTransitions web site:

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

F. A comprehensive practice guide on effective transition from children's to adult services for young people with complex health needs has been published by the UK Department of Health and the Department for Schools, Children and Families.

The guide will help ensure that the young person and their family is better prepared for the move to adult care and that the adult care team has been involved in planning for the transfer

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_083592](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_083592)

#### ARTICLES:

The following articles were among those listed as being of interest to those caring for young adults with special health needs in the Adolescent Resource Newsletter (July, 2008). Dr Janet E McDonagh, Clinical Senior Lecturer in Paediatric and Adolescent Rheumatology [www.dreamteam-uk.org](http://www.dreamteam-uk.org)

(News letter inquiries to Mrs. Barbara Moore, Academic Secretary to Dr Janet E McDonagh  
Email: [b.g.moore@bham.ac.uk](mailto:b.g.moore@bham.ac.uk))

Lotstein DS, Inkelas M, Hays RD, Halfon N, Brook R. Access to care for youth with special health care needs in the transition to adulthood. *J Adol Health* 2008;43:23-29.

McLaughlin SE, Diener-West M, Indurkha A et al. Improving transition from pediatric to adult cystic fibrosis care: lessons from a national survey of current practices. *Pediatrics* 2008;121:e1160-6

Park MJ, Irwin CE. Youth with special health care needs: facilitating a healthy transition to young adulthood. *J Adol Health* 2008;43:6-7.

Wiegerink DJ, Roebroek ME, Donkervoort M et al. Social, intimate and sexual relationships of adolescents with cerebral palsy compared with able-bodied age-mates. *J Rehabil Med* 2008;40(2):112-8.

Committee on Adolescence. "Achieving Quality Health Services for Adolescents." *Pediatrics* 2008; 121: 1263-1270. <http://aappolicy.aapublications.org/cgi/reprint/pediatrics;121/6/1263.pdf>

## 6. Topics for discussion and contribution

I invite all of you to think about resources – [meetings](#), [conferences](#), 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).

Or issues you would like to have list members comment on ...

You can send a message to the list by hitting "reply" or by sending an e-mail to

John Reiss [jgr@ichp.ufl.edu](mailto:jgr@ichp.ufl.edu)

Felicity Sloman [fsloman@bloorview.ca](mailto:fsloman@bloorview.ca)

The End

Look forward to your future contributions to the list -

John Reiss, List Moderator

and

Felicity Sloman - Co List Moderator