

Transition digest #7-08 (July 29, 2008)

1. Training

A. Informational call from the HRTW Center

Title: HRTW Topical Call on youth advisory councils and youth advisors

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#

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

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

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2. ARTICLES:

A. Newspaper article

What Happens When Chronically Ill Kids Grow Up

Physically disabled young adults who weren't supposed to live this long find themselves hemmed in by an unprepared health care system

By Paul Knight

Published in the Houston Press June 26, 2008

This article does an excellent job in making the public aware of the challenges that youth with chronic health conditions face. It tells the story of several youth/young adults (and their families) as they age out of pediatrics and also lose health insurance coverage

<http://www.houstonpress.com/2008-06-26/news/what-happens-when-chronically-ill-kids-grow-up/full>

B. Transition to adulthood: delays and unmet needs among adolescents and young adults with asthma.

[Scal P](#), [Davern M](#), [Ireland M](#), [Park K](#)

Journal of Pediatrics. 2008 Apr;152(4):471-5.

C. Youth with Special Health Care Needs: Facilitating a Healthy Transition to Young Adulthood (Editorial)

M. Jane Park, Charles E. Irwin

Journal of Adolescent Health Volume 43, Issue 1, (July 2008) pages 6-7

D. Access to Care for Youth with Special Health Care Needs in the Transition to Adulthood

Debra S. Lotstein, Moira Inkelas, Ron D. Hays, Neal Halfon, Robert Brook

Journal of Adolescent Health Volume 43, Issue 1, (July 2008) pages 23-29

3. Conferences and Meetings

9th Annual Chronic Illness and Disability: Transition from Pediatric to Adult-Based Care Conference to be held in Houston, Texas, November 13-14, 2008.

Additional information is available through Baylor College of Medicine Office of Continuing Medical Education at <http://www.baylorcme.org/search/detail.cfm?cme=707>

Dear Friends of Youth in Transition:

On behalf of Dr. Albert C. Hergenroeder, I would like to extend a special invitation to you to attend an upcoming continuing medical education conference, 9th Annual Chronic Illness and Disability: Transition from Pediatric to Adult-Based Care, scheduled for November 13 - 14, 2008 at the Onstead Auditorium, located in the M.D. Anderson Basic Sciences Research Building. Please mark your calendar to attend this educational activity.

I would also like to request that you distribute this to your colleagues in an effort to promote the conference. Feel free to contact me if you have any questions or need further information.

Thank you for your assistance and involvement in making this conference a success. I hope to see you there!

Best regards,

Ellen

Ellen Seaback, CMP, CAE

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4. Video presentations

"Adolescent Health Care Transition -Principles, Perspectives and Promotion"

from the

Educational Streaming Media Program at Cincinnati Children's Hospital Medical Center

Interdisciplinary Grand Rounds

Thomas Webb, MD

Michael Southern, MD

Originally aired on August 22, 2007

<http://www.cincinnatichildrens.org/ed/cme/streaming-media/library/interdisciplinary-gr.htm>

5. Requests for assistance & Materials to Share

A.

I'm putting together a "transition resource" for teachers who work with students with autism spectrum disorder.

I plan to include handouts, strategies etc. on transitions that occur on a day to day basis and info. on major transitions i.e. entry to school, middle school to high school, high school to the community.

If anyone has any thoughts on stuff that would be useful for schools, or knows of anything like this please inform

Much thanks,

Mary Ierullo

mary.ierullo@surreyplace.on.ca

B.

I have a request from a colleague who is looking for a clinic for adults with CP in the New York -New Jersey area. Any ideas?

Ronna Linroth

Manager Adult Outpatient Services

Gillette Lifetime Specialty Healthcare

435 Phalen Boulevard

St. Paul, Minnesota 55130

PH: 651-634-1920 FX: 651-265-7356

Web: <http://www.gillettechildrens.org>

C.

I would like to share my career education materials with anyone who is interested. I have completed part one of 3. Occupational exploration (308 pages- lessons & tests)

self appraisal and educational planning units to follow,

___I have DISADD-DISABILITY INTERNET address-205 pages

"The work place" -44 pages.

Occupational Exploration learning activities_____97 pages.

This career education program answers the questions

Who Am I?, Where am I going? How do I get there? What do I do when I get there?

Bob McKellar

Davis, Ca.

RFmckellar@cs.com

D.

The following website provides some good examples of "people first" language.

www.disabilityisnatural.com/peoplefirstlanguage.htm

Patricia Smith, RNS

Children's Medical Services

Gainesville, FL 32608

E-mail patricia_smith@doh.state.fl.us

E.

I am looking for information on introducing information to youth and their families on the youth's rights to privacy and what confidentiality means. Do you have any videos, handouts etc. Also looking at tools to teach staff.

Sincerely,

Catherine Dunseith, MSW

Adolescent Transition Coordinator

Calgary Health Region

Phone: 403-955-7252

Fax: 403-955-2404

Catherine Dunseith catherine.dunseith@calgaryhealthregion.ca

6. Topics for discussion and contribution

My thanks to those who have contributed to the list with resources and requests. 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, **as well as** 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

Felicity Sloman fslooman@bloorview.ca

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/>