

Transition digest #10-08 (Oct 12, 2008)

1. Training Materials and Related Resources

A. "I'm Tyler,"

This 12 minute DVD was written and produced by Tyler Greene, from Waterloo, Iowa. It emphasizes what individuals with disabilities can do. It recently won a "Yes I Can" award from the Council for Exceptional Children. Over 4000 copies of the DVD are being used around the country to inspire others. Tyler is a member of the Kids as Self Advocates (KASA) National Board.

To learn more about Tyler and view his video, visit www.imtyler.org

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2. ARTICLES:

Many of the following articles were listed as being of interest to those caring for young adults with special health needs in the Adolescent Resource Newsletter (October, 2008). Dr Janet E McDonagh, Clinical Senior Lecturer in Paediatric and Adolescent Rheumatology 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)

A "Before I die" by Jenny Downham

A book which gets into the mind and soul of a 16 year old with terminal cancer. "Novels for young teenagers do not usually feature drugs and casual sex with in the first 20-odd pages. But most books for teenagers will not leave an adult reader's eyes so blurry with tears that it's hard to see the final chapters. Jenny Downham's extraordinary first novel does both" Sunday Times
Insights into Teenagehood!

B. A Welsh clothing company with fair trade, eco-friendly ambitions are 13 this year and have produced an interesting booklet where they went out and asked some other 13y olds what life was like for them

http://www.howies.co.uk/images/cms/downloads/winter2008/howies_teenbook_winter2008.pdf

<http://www.13up.howies.co.uk/>

C. Royal Australasian College of Physicians Policy Statement 2007: Transition to Adult Health Services for Adolescents with Chronic Conditions.

<http://www.racp.edu.au/page/publications-and-communications>

D. Royal Australasian College of Physicians: Routine Adolescent Psychosocial Health Assessment – Position Statement

<http://www.racp.edu.au/page/health-policy-and-advocacy/paediatrics-and-child-health>

E. Brown BV. A Federal Monitoring System for Early Adult Health, J Adolesc Health. 2008 Sep;43(3):277- 84.

F. Laurent C. Adolescent services: smells like teen spirit. Health service Journal 1 Sept 2008

www.hsj.co.uk

[http://www.hsj.co.uk/insideknowledge/features/2008/09/adolescent_services_smells_like_teen_spirit.html?tmcsTrackingInfo=\\$NGIXLriNJPJzLxRWlrZZYReQaGMF1ZPFyObl_dtvnJ310I3yK9gGUCGyMDw51EjrMbntwrhWGa4\\$](http://www.hsj.co.uk/insideknowledge/features/2008/09/adolescent_services_smells_like_teen_spirit.html?tmcsTrackingInfo=$NGIXLriNJPJzLxRWlrZZYReQaGMF1ZPFyObl_dtvnJ310I3yK9gGUCGyMDw51EjrMbntwrhWGa4$)

G. Sawyer SM. In search of quality care for adolescents and young adults with chronic conditions. J Paediatrics Child Health 2008;44: 475-477

H. Steinbeck KS, Brodie L, Towns SJ. Transition in chronic illness: who is going where? J Paediatrics Child Health 2008;44:478-482

I. Gerber BS et al. Evaluation of an Internet Diabetes Self-Management Training Program for Adolescents and Young Adults. Diabetes Technology & Therapeutics. February 1, 2007, 9(1): 60-67.

Conclusions: The study demonstrated feasibility of using an Internet program to meet the informational and social needs of adolescents and young adults with diabetes. Participant involvement relied heavily upon reminders and encouragement from a diabetes educator and immediate family members.

J. Ellen Giarelli E. et al. Adolescents' Transition to Self-Management of a Chronic Genetic Disorder Qualitative Health Research, Vol. 18, No. 4, 441-457 (2008)

Abstract.

Self-management of chronic illness requires acquisition of self-care skills such as seeking knowledge, adhering to recommendations, practicing healthy behaviors, and life-long self-surveillance. This article describes the core problem and psychosocial processes by which parents transfer, and children take on, the responsibility for managing a chronic genetic condition. Individuals with Marfan syndrome (MFS), their parents, and health care providers were the sources of empirical data. A sample of 108 providers, parents, and individuals with MFS were recruited through a genetics clinic and the National Marfan Foundation. The core problem of "becoming fit and fitting in" is resolved via concurrent psychosocial processes: shifting perspective, shifting orientation, shifting sphere, shifting ownership, and shifting reasoning. Transition to self-management is more than planning the transfer of services from pediatric to adult care, and involves gradual changes in knowledge, attitudes, and behavior

influenced by parents, peers, and health care providers. Transition to self-management is part of an evolving model of participation in life-long surveillance.

<http://qhr.sagepub.com/cgi/content/abstract/18/4/441>

3. Conferences and Meetings

A. Opening Doors: A State of the Science Conference

Opening Doors: A State of the Science Conference
November 10-11, 2008 at the Hyatt Regency in Bethesda, Maryland

Registration Now Open!

Register online: <http://www.openingdoorsforyouth.org/sos/>

This conference examines the state of the science related to early screening, community inclusion and transition for children and youth from underserved populations, including new immigrant communities. There will be many opportunities for discussion among researchers, clinicians, policy makers, parents, youth and community based organization leaders. We will share the lessons we are learning with the Opening Doors project in Boston as an example of community based participatory research.

For more information, visit our website at
<http://www.openingdoorsforyouth.org/sos/>

or

Contact Berenise Reyes-Albino at
berenise.albino@umb.edu or 617-287-4314.

(Second posting)

2008 Transition Conference Bridge to the Future - Imagine the Possibilities 10/27 - 10/29 Peoria IL

This Conference is dedicated to encouraging the development and implementation of challenging, yet achievable, person-centered goals for young people living with disabilities. The conference is being structured to include interactive workshops that address the topics of post secondary education/training, health care, community, and employment for youth with disabilities.

You can register for this conference on line at

<http://www.cccmeetings.com/transition.pdf>

(Second posting)

B. First World Congress on Spina Bifida Research and Care

The Spina Bifida Association (SBA) has announced the First World Congress on Spina Bifida Research and Care – to be held on March 15-18, 2009 in Orlando, Florida.

Announcement and Invitation for Abstracts

Transition Issues will be one of the core themes at the First World Congress on Spina Bifida Care, a multidisciplinary professional conference for all health specialties involved in spina bifida. We are inviting those involved in transition-themed research or programmatic development for individuals living with spina bifida to submit abstracts for consideration of poster or platform presentation. The new submission deadline is December 1, 2008.

Please see this website for registration and abstract submission information:

www.medicalconference.spinabifidaassociation.org

(Second posting)

C. 2008 Transition Conference Bridge to the Future - Imagine the Possibilities 10/27 - 10/29 Peoria IL

You can register for this conference on line at

<http://www.cccmeetings.com/transition.pdf>

(Final posting)

D. The 9th Annual Chronic Illness and Disability: Transition from Pediatric to Adult-Based Care Conference \.

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

Register on line for this conference at:

<http://www.baylorcme.org/search/detail.cfm?cme=707>

4. On-line presentations and Teleconferences

A. Role of Youth in Making High Schools Inclusive

Featuring Youth Leaders from KASA (Kids As Self Advocates) Sponsored by the LRE Part B Community of Practice & Family Voices

AGENDA

- 3:30 – 4:30 pm Panel Featuring Youth/Young Adult Leaders with Disabilities on the Role of Youth with and without Disabilities in Making High Schools More Inclusive
- 4:30 – 5:00 pm Questions & Answers, Discussion
- Explore why inclusive education is essential, the challenges in achieving this goal and lessons learned from the perspective of youth with disabilities * Learn about effective strategies (ways to make it work) for working with youth with and without disabilities to address barriers to inclusion at the high school level, including school environment, social skills, accessibility, etc. * Learn about resources to build youth leadership in making high schools more inclusive.

Presenters

Emily Bill, KASA Adv. Board member · Mallory Cyr, KASA Adv. Board member · Micah Fialka-Feldman, KASA Adv. Board member, Chair of the KASA Task Force, ·Sarah Ingerson, KASA Adv. Board Co-chair ·Hamza Jaka, KASA Adv. Board member Facilitators Diana Autin, Co-Director NE-PACT/Region 1 PTAC @ SPAN Naomi Ortiz, Director, National Kids As Self-Advocates project, Family Voices

For more info about Kids As Self-Advocates, go to www.fvkasa.org

This event is sponsored by National KASA (Kids As Self Advocates of Family Voices), the Region 1 Parent Technical Assistance Training Center/Family Voices-NJ/F2F- NJ at the Statewide Parent Advocacy Network of New Jersey, and the LRE Part B community of TAcommunities. For more information about the TA communities see more at www.tacommunities.org.

For more information and to register, go to:

http://www.surveymonkey.com/s.aspx?sm=fTaJFRd5gdwv8PnZ9Ijh_2bg_3d_3d

B. Communicating Effectively with Healthcare Professionals

The National Family Caregivers Association is hosting a FREE Family Caregiver Teleclass to teach family caregivers how to improve their communication with healthcare professionals and become better healthcare advocates for themselves and their loved ones.

This FREE two-part series features 2 one-hour phone calls on:

Thursday November 6th and 13th at 2:00 PM Eastern

You can participate by telephone or you may be on the phone AND follow along on the TeleClass Web site, however this is an option and NOT required.

Part 1: November 6

- Develop a basic understanding of how the U.S. healthcare system operates
- Understand your role on your loved one's healthcare team
- Describe how good communication can facilitate optimum health care
- Know how to prepare for doctor office visits

Part 2: November 13

- Develop strategies to establish rapport/collaborate with your loved one's healthcare providers
- Distinguish between different styles of communicating with healthcare professionals
- Compose assertive messages for communicating in healthcare situations
- Be prepared for and cope with an emergency room visit

More information on this free National TeleClass is available at:

http://www.thefamilycaregiver.org/national_family_caregiver_month/teleclass.cfm

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5. Call for Papers & other news

A. Special Issue: Health Care Transitions of Adolescents and Young Adults with Pediatric Chronic Health Conditions (second posting)

Issue Editors: Ahna Pai and Lisa Schwartz

To address the critical issues surrounding health care transitions for adolescents and young adults (A/YA), The Journal of Pediatric Psychology requests papers for a special issue on health care transitions of A/YA's with pediatric chronic health conditions.

The goals of the special issue are to promote the development and refinement of: a) models of transition readiness that include the emotional/social aspects of transition; b) measures/assessment tools that assess readiness for transition; c) methods to study the transition process; d) interventions to prepare for and support the process of transition (e.g., enhancing disease self-management, communication, changing negative beliefs, barriers to adherence); and 4) multi-disciplinary clinical models of transition preparation.

Of particular interest is research that addresses systems issues (e.g., patient, providers, families, health care system) related to transition and transfer to adult care; disease, functional, and psychosocial outcomes of transfer; risk and resiliency factors related to successful transition; prospective studies of the psychological outcomes of young adults with chronic health conditions who have made the transition to adult health care; and examination of provider practice in the transition of patients. Submissions may employ a wide range of methodologies and designs including case, descriptive, prospective, and intervention studies.

The deadline for receipt of manuscripts is January 12, 2009. Manuscripts should be written in APA format, following the guidelines of the Journal of Pediatric Psychology. Inquiries regarding

potential topics may be directed to Lisa Schwartz (schwartzl@email.chop.edu) and Ahna Pai (Ahna.Pai@cchmc.org).

Posted at the request of:

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B. First World Congress on Spina Bifida Research and Care (see above)

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6. Topics for discussion and contribution

My thanks to those who have contributed to the list with resources and requests. As always, I invite each 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 fsloman@bloorview.ca

If you have colleagues and friends who might like to receive the Health Care Transition Digests, tell them they can subscribe by going to:

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

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/>