

Transition digest #9-08 (Sept 30, 2008)

1. Training Materials and Related Resources

A. My PKU Toolkit

My PKU Toolkit is a guidebook for transition for those with PKU. The Toolkit was developed by Children's Hospital of Boston with funding from the Bureau of Maternal and Child Health through the New England Genetics and Newborn Screening Collaborative.

Topics include: basic info on PKU, how to manage the diet in the context of you life, what is transition, maternal PKU, and a list of web sites & other references. The Toolkit includes a set of forms including: My Portable Health History, plus several diet-related forms.

An on-line version of the toolkit is available at:
<http://www.newenglandconsortium.org/toolkit/index.html>

Forms from the Toolkit can be accessed on the Web at:
www.myPKUtoolkit.com

It is my understanding that hardcopies of the toolkit are being made available, free of charge, by Applied Nutrition.

A request form (available from Applied Nutrition) can be obtained by faxing to 973-734-0029.

B. "Talking with You're Doctor and Other Health Care Professionals"

This 18 minute video is designed to teach adolescents and young adults (AYAs) how to communicate more effectively with health care providers.

You can view a high resolution version of this video on the ICHP Web site at:

<http://video.ichp.ufl.edu/twyd.php>

This instructional video is now be available on a DVD for \$5 per copy (includes shipping). To order, e-mail John Reiss at jgr@ichp.ufl.edu

C. Check out the NEW Growing Up Ready web from Bloorview Kids Rehab

<http://www.bloorview.ca/resourcecentre/transitions/index.php>

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2. ARTICLES:

none

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3. Conferences and Meetings

A. 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. 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.

You can now register on line for this conference at:

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

The conference brochure can also be downloaded from this site:

(Third posting)

C. Opening Doors: A State of the Science Conference

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

Registration Now Open!

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

About the Conference

For practitioners and researchers in rehabilitation, education and public policy; community-based organizations; and families and youth.

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. The conference is designed to optimize interaction among all participants.

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.

D. 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.

Our keynote speaker will be:

Susan Sawyer, MBBS, MD, FRACP, Director, Centre for Adolescent Health, Royal Children's Hospital; Chair and Professor of Adolescent Health, Department of Paediatrics, University of Melbourne, Melbourne, Australia. Dr. Sawyer is world-renown for her work in transition issues for adolescents with chronic health conditions.

The Future is Now
First World Congress on Spina Bifida Research and Care
March 15-18, 2009
Walt Disney World
Swan and Dolphin Resort
Orlando, FL

Please see this website for registration and abstract submission information:

www.medicalconference.spinabifidaassociation.org

Posted at the request of:
Thomas S. Webb, MD, MSc
Asst. Professor of Clinical Medicine and Pediatrics
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4. On-line presentations

A. Follow-up to National Public Radio story on transition to college of young man with asperser's

On September 11, NPR did a story on the transition to college of young man with asperser's. To read the transcript and to listen to the Sept 11 broadcast, go to:

<http://www.npr.org/templates/story/story.php?storyId=94429083>

On September 17 Roger and Sita Diehl, who runs Tennessee's National Alliance On Mental Illness (NAMI), answer listeners' questions about what their family did to help Roger, and offer advice on how to help kids with mental illness or learning disabilities get ready for college.

To read their answers, go to:

<http://www.npr.org/templates/story/story.php?storyId=94728606>

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5. Call for Papers & other news

CALL FOR PAPERS

Special Issue: Health Care Transitions of Adolescents and Young Adults with Pediatric Chronic Health Conditions

Issue Editors: Ahna Pai and Lisa Schwartz

Over thirty percent of children ages 10-17 have a pediatric chronic health condition and over 90% of these children will make the transition into adulthood. As a result, an increasing number of adolescents and young adults (AYA) with a chronic health condition will undergo a health care transition from pediatric to adult based medical care. The transition to adult care is often difficult given the vulnerable developmental period and the many barriers associated with the health care transition process (e.g., attachment to the pediatric system and to pediatric health care providers, pediatric providers' and parents' difficulty facilitating transition, difficulty

establishing medical care with an adult care provider, difficulties negotiating the unfamiliar adult health care system, lack of communication between pediatric and adult providers, differences between pediatric and adult approaches to care). Many consensus statements have highlighted this critical issue and have called for multi-disciplinary action (Healthy People 2010, DHHS, 2000; Society of Adolescent Medicine, 1993, 2003; American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians-American Society of Internal Medicine, 2002). While disease knowledge and skills have been emphasized as important components for successful transition, there is little empirical data to support this and a lack of attention to the psychosocial complexities of the transition process. Further research is desperately needed to determine how best to facilitate optimal health care transition.

To address the critical issues surrounding health care transitions for 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:

Ahna L.H. Pai, Ph.D.

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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

The End

Look forward to your future contributions to the list -

John Reiss, List Moderator

and

Felicity Sloman - Co List Moderator