Transition digest 2-08 (January 9, 2008)

Colleagues:

There are several announcements regarding meetings and resources

1. Hold May 21-23!

Bloorview Kids Rehab and the Transitions Conference Steering Committee are pleased to announce the 4th bi-annual conference on the subject of Transitioning. This conference will be held on May 21- 23, 2008 in Toronto, Ontario, Canada. The these of this conference is 'Participation' and will address a ranges of issues including personal maintenance, morality, social relationships, education, employment, leisure, spirituality, and community life. Additional information about registering for this conference will be available soon. For more information, go to http://www.bloorview.ca/education/index.php (Look down the page for the link under Events for Transitions Conference 4) or contact

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2. Call for Abstracts and Papers

Call for Abstracts and Papers
Academy Health Child Health Services Meeting

The Child Health Services Research Meeting provides a unique opportunity for the community of child health services researchers, providers, and policy professionals to learn about the latest child health services research, develop new skills, and discuss critical policy issues for children. This one-day meeting is cosponsored by AcademyHealth and the Agency for Healthcare Research and Quality and is held prior to the AcademyHealth Annual Research Meeting. This year the meeting will be held June 7 in Washington DC.

For information about the meeting

http://www.academyhealth.org/interestgroups/chsr/index.htm

To submit and abstract or panel.

http://www.academyhealth.org/childhealth/abstracts/abslogin.cfm
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My thanks to Karen Kuhlthau, Ph.D. at the Center for Child and Adolescent Health Policy, Massachusetts General Hospital for letting us know about this call for papers and abstracts.

This is a great place to draw further attention to the importance of transition.

If would be great to get some transition papers/panels at this conference !!!

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3. Resources and materials

This is from Miriam Kaufman at the Hospital for Sick Children in Toronto, Canada

Over the several months, we have gotten our website up and running at www.sickkids.ca/good2go.

It contains an evergrowing bibliography, our "transition menu" and lots more.
Three things I wanted to highlight:

1. Many people present posters at various meetings, but if you don't go to the meeting, you don't get a chance to see the posters. We are happy to post transition posters on our website. At this point the only ones up are from Toronto, but we are expecting some from Portland any day now. Check this feature out at
http://www.sickkids.ca/good2go/section.asp?s=Publications&sID=19143&ss=Posters&ssID=22993

If you want to submit one, please send it in pdf format to me (miriam.kaufman@sickkids.ca).

2. MyHealth Passport is a program that creates a wallet sized card with pertinent health information. Ideally, the teen or adult creates it with a health care provider. This allows an opportunity for evaluation of the patient's knowledge and a chance to educate them. In 8 months it has been tried by over 200 consumers and even more providers checking it out. It is easy to use, with lots of check boxes and dropdowns. Templates exist for all solid organ transplants, kidney disease (it says "under construction" but it is quite usable), diabetes (ditto) and about 10 other conditions.
The average kid takes about 10 minutes to create it. They can email it to themselves and also print it and cut out to wallet size. You can access it through the Good 2 Go website or directly at www.sickkids.on.ca/myhealthpassport.

Or you can just google MyHealth Passport.

{If you are going to test it out but not create a real passport, please enter 100 as your age on the first page--but feel free to make one for yourself, in which case use your real age. My 92 year old father carries one]

3. If you have a transition website that isn't listed in our Links section, send us the URL and we will add it.

My thanks to Miriam for making us aware of these materials, and making us aware of our opportunity to contribute to a repository of health care transition related poster sessions and add to their list of links.

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I also received several responses to my question about emotional relationships and their impact on transition.

Response from Ronna Linroth, Manager Adult Outpatient Services, Gillette Lifetime Specialty Healthcare

In regards to your request about the emotional relationships and their impact on transition between a pediatric and adult healthcare setting. I fully concur with your comments and have found little to guide us as we navigate these highly charged waters. Our chartered Transition committee had developed a really nice working binder called " Make Your Move" that is made available to our patients at age 14. We found that for some families the distribution of the manual triggered grief and anger or what appeared to be disinterest; most noteably those with youth with such significant impairment that they would not make any benchmarks of independence. We have decided to create a second manual that will approach transition a little differently and it will start out by acknowledging the grief. We are using the work of Joan Proska on Cyclical Grief in our introductory chapter. We are on Phase III of our Transition work at Gillette which will involved development of a curriculums for patients/families/providers as we believe that skill building needs to occur in all aspects. This is not a simple thing nor is it sufficient to acknowlege that this is an emotional time. We have to prepare each of the individuals in the relationship as to how to navigate the change.

We brought the mother of a 12 year old daughter with significant disability to speak to the Transition Committee on her "gut" reaction to Transiiton and the binder. She spoke about how fearful it is to address the changes that occur at this stage of life and helped us understand her perspective on transfer of care, possible changes in living situations, being the one to make the decision (children without disabilities are generally eager to leave home and here parents may be saying it is time to try a new living situation or are determined to keep them home for as long as they can). This mother talked about how much of her life has been spent in waiting rooms and medical appointments. For some the medical community is their social community. It takes a lot of energy to establish new relationships and navigate new systems.
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Response from a parent who works in the field as a Social Worker (posted with permission, I decided to delete identifying information)

I'm a parent who just this past summer got my 20 year old transitioned to an adult health care provider. As a mother who works in the field as a Social Worker I tried to get this done when she was 16. We had the discussion, she read the literature, so she knew this was an expection. She was still in high school when I scheduled an appointment for her with her pediatrician to talk about this. I did not go in the room with her so she

could have complete privacy. She came out happy as can be with a great big smile on her face and let me know that *they* decided she did not *ever* have to leave his care.

I could have wrung both of their necks. What was the big attraction? For her, it was the fact that he would prescribe liquid amoxicillian at her request (she can swallow pills). She was 18 years old and got away with this. I don't remember why she decided to change doctors but I do remember at the last visit. At the last moment, she gave him this huge hug and told him she always loved him. He blushed and kind of went "aw shucks". She's got a pretty good relationship with her new PCP. It's a woman and now I remember why she changed docs...she knew it was time for pap smears and no way was she going to let Dr. Y (her pediatrician) go there. The nurses and office staff at Dr. W (new PCP) think she's really awesome which makes me feel good.

L.M.

and this, also from L.M. about the experience of being on the front lines, trying to deal with the realities of transition

Let me tell you about what has been chapping my behind lately when it comes to transition. Remember, I'm on the front line. I am so sick of being forced to do transition activities knowing full well that after all is said and done; that much has been said and not a whole lot done. It's like a bridge building project between the care coordinator and the family and for all our labor by the time they leave this program, the bridge doesn't connect to anything. "...care coordinators cannot be held accountable for accessing resources that do not exist in the community, state, or region."pg.10   That statement if fine if you are a care coordinator in the private sector. It won't wash with *our* families because they see us as *the g-o-v-e-r-n-m-e-n-t*. The families of neuro-atypical(ASD) who have aged out over the past three years are calling me and they are not happy. Our experience with cc's in the public and the private sector is this. The cc from our insurance company sent a letter, *once*.

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And this:

I am newly hired into a Transition Coordinator position in Edmonton and your list was forwarded to me by Geraldine Cullen Dean in Toronto…

Just some thoughts in response to your question from the new kid on the block...   I would agree with you that the transition between pediatric and adult care providers can cause significant problems for all involved, with the most problematic issue being the patients/families withdrawing from the health care system following transfer.   I think there are several components to this issue and perhaps it would help to break the issue down into smaller segments, assessing readiness for transition for instance.. This would be a great topic for a discussion group at a conference.

The Chronic Disease Management Program within Capital Health in Edmonton as well as the system in Calgary are looking to trial Wagner's model of Chronic Disease Management with a youth focus. Children's Hospitals in both cities are looking to promote the program to our patients/families. We will be offering some group sessions to promote medical self management including a session on talking to health care professionals.. Terminating the therapeutic relationships and forming new ones would be a very important piece to this work…

In my previous work in Community Health, patient transfers between professionals occurred for a variety of reasons(staff changes, moving, change in health care status) The preparation for and process of the transfer varied a great deal from patient to patient and was largely based on the complexity of needs and how reliant the patient/family were on the health care system and the professionals involved. In order to transfer some of our patients successfully, it was necessary for the discharging team and the team to whom the patient/family was being transferred work together, sometimes for up a few months. Sometimes this work involved specialized training for the new team, the development of a care plan and the transfer of information between patient/family and teams and joint visits or appointments with both teams.   The "official transfer" did not occur until all parties felt comfortable that the care needs were being met.. Establishing trust was one of the key issues, and I'm sure you are aware how difficult that can be for some people and how long the process can take.

It helps if the professionals involved trust the team accepting the referral is able to meet the needs of their patients/families and I think this is another important piece to the whole scenario and can be a big factor in how the transition process unfolds, or if it indeed, does unfold. I understand there are several pediatric providers who don't transition their patients ..

Anyhow, better run to my next meeting…

Cathy

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And finally -

I have been thinking about ways that I can further support networking among professionals, families and youth/young adults around the issue of health care transition. A recent idea is to develop a "social networking" web site for members of our community. This type of site would allow individuals to share some information about themselves - why they are interested in the issue, if they are involved in a project or HCT related activity, if they have transition related experiences to share, or advice to offer. Members could also post a picture of themselves - like Facebook. That helps to put a face with a name - or name with a face - and make it easier to initiate contact - to ask a question or share an idea one to one.

I have developed a prototype site which I now call "Health Care Transition Community"

http://healthcaretransition.ning.com/

If you go to the sight now, you can see what i look like (or did look like 10 years ago). You can also meet Felicity Sloman, who has kindly agreed to assist manage the HCT Community site and to help manage the Transitions listserv. Felicity was instrumental in the development of the health care transition initiative at the Royal Children's Hospital in Melbourne, Australia and is currently spending a year working with the Transition Initiative at Bloorview Kids Rehab in Toronto

(For more on RCH's transition initiative see:
http://www.rch.org.au/transition/index.cfm?doc_id=8143)

Individuals who join are asked a set of questions about their interest in HCT, their area of expertise - or health condition, and some other things.

And you don't have to post a picture if you don't want to...

You can view the page without joining.

If you want to participate - add information about yourself, you will need to sign up for the host Ning site (at no cost). It is, hopefully, self explanatory.

Vote with your fingers - visit and join - to show that we should put some more energy into this new venture.

Look forward to your future contributions to the list -

John Reiss, List Moderator

and

Felicity Sloman - Co List Moderator

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