Follow-up notes from Health and Literacy: Constructing Curriculum
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Summary of Presentation:
The *Pain and Dementia toolkit* was developed by a nurse, a teacher and an occupational therapist for community organizations (like church groups, seniors clubs, public libraries) who wished to put on a workshop for their members. A number of seniors, organizations for seniors and healthcare workers were involved in advising on the content and delivery of the Toolkit and workshop. The toolkit guided the organization through putting on a workshop to caregivers (family and spouses) how to recognize when someone with dementia was in pain. This is an important skill because people with dementia cannot always express pain in the expected manner. Research tells us that persons with dementia often have undiagnosed and untreated pain.

The presentation at the Calgary conference presented what is sometimes called '*negative knowledge*' (Vinson's blog is a good place to start if you want more background on this) http://blog.jackvinson.com/archives/2006/08/01/negative_knowledge_expertise_and_organisations.html.

Negative knowledge is about knowing what you don't know (echoes of Cliff here!). This means that the problems, roadblocks and negative events can teach us lesson in the same way that successes can. In this case the roadblocks were related to testing whether people actually did learn new information from the presentations in the toolkit. Road blocks included:

- Time delays
- Lack of funding
- The team and key members of the advisory group had scattered
- Many levels of permission are required for a university to do field-testing in the community
- Making sure that our field-test was with the people the toolkit and workshop was designed for
- Community organizations seemed reluctant to take this on

In the presentation I mentioned:

A. the KAWA model which occupational therapists use to guide their practice to be less biomedical and more holistic http://www.kawamodel.com/

B. Complex adaptive systems theory which helps us understand that when many elements are interacting they cannot be controlled in a simple cause- and- effect manner- many health issues are complex (for example diabetes- yes, insulin and diet help but there is no cure and many personal (eg. Stress, exercise), social (lack of money to buy healthy

food) and environmental factors (climate, living conditions) influence how well a person manages his or her diabetes. The best article I think to introduce the topic is the BMJ 2001 Plesek and Greenhalgh article (attached) and at http://www.bmj.com/cgi/reprint/323/7313/625 which I believe can be downloaded for free.

C. The final, and I think critical, information to take away from the presentation was the parallels with what **Knowledge Translation/transfer/management** specialists are trying to achieve in changing healthcare providers beliefs and practices. There is an excellent KT resource - Research Transfer Network Alberta (free to join) http://www.ahfmr.ab.ca/rtna/rt.php and I think some great connections are possible with this group who are interested in the same thing as Health Literacy experts to a large extent.

I hope people will find this useful. I certainly appreciated so much meeting you all and feel I have benefitted greatly from your comments and questions. I look forward to the continued dialogue the Institute (with Linda and Audrey's skillful guidance) has generated.

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