



Transition workshops for young people with complex health needs

As many of you will know Jackie O'Carroll and Kath Hennell from Reflect and Change have been very involved in a DH funded project led by the Child Health Development Programme, looking at transition for young people with complex health needs, - young people with palliative care needs, those with life limiting conditions, those with severe disabilities and also young people who are technology dependent.

Kath and I have been facilitating workshops across Cheshire and Merseyside as 'part 2' of the project, which finishes at the end of June 2011.

The workshops have been very interesting - hard work for some, and an opportunity to move forward in joint working for all. Here are some of the feedback comments:

'Very informative and thought provoking'

'A useful opportunity to share thoughts and ideas. It raised dilemmas and identified solutions'

'Really good integrated discussion'

'The interactive way the workshop was delivered was very beneficial'

Each workshop has culminated in an Action Plan, identifying specific tasks and approaches. Areas of development include:

- Developing a transition pathway
- Developing a joint vision for successful transition
- Ensuring that the issues for these young people as they move into adult services are part of a clear strategic approach, with excellent clinical and strategic leadership
- Developing a database with detailed information of the needs of young people to inform adult services from age 16 years onwards
- Identifying a clear approach across children's and adult services regarding the implementation and impact of the Mental Capacity Act 2005 for this group of young people

It was very encouraging to have colleagues from adult services at the workshop and we hope that this involvement will grow and develop.

Appreciative Inquiry

Facilitating the transition workshops has been both challenging and exciting! We have been using a model called 'Appreciative Inquiry'. This is a way of looking at an issue that focuses on developing more of what is working rather than focusing on fixing problems.

The Appreciative Inquiry Change Process focuses on five 'D's':

- ❖ **Definition** – decide what specific area to focus on
- ❖ **Discovery** – find examples of good practice and positive experiences
- ❖ **Dream** – envision how things could be
- ❖ **Design** – find different ways to move forward
- ❖ **Delivery** – Agree an Action Plan to take the change forward.

Appreciative Inquiry can be useful when looking at organisational change as well as specific issues. A useful introduction to the model, written by David Cooperrider who first developed it, can be found on the link; <http://appreciativeinquiry.case.edu/uploads/whatisai.pdf>

'Support and Share' – online community

Over the past nine months NHS NW has been supporting the development of a number of online resources, including an interactive web based resource for parents of disabled children. Reflect and Change have been involved in this and have sought to support and involve parents in the development process, alongside Health2works who were commissioned to build all the resources. In June it will be launched as an online resource for all parents and carers of disabled children and young people. We will keep you posted and as soon as the resource goes 'live' will be promoting it!

And finally a needs analysis of people living with HIV

Kath has been part of a research team along with colleagues Paul and Leo Kyprianou from Icarus undertaking a health and social care needs analysis for people living with HIV in four local primary care trust areas; Wirral, Liverpool, Sefton and Knowsley.

The needs assessment involved 201 people living with HIV in the Merseyside area completing a questionnaire specifically adapted from a national survey in addition to interviews with key health, social care and Third Sector professionals.

My involvement in this work and the findings from the study has been truly enlightening. HIV is a far bigger issue than probably most people are aware of, following the tombstone adverts in the eighties the public awareness campaign around this condition has faded away to very little.

I thought it may be interesting to share some of the findings with you:

- The population living with HIV is estimated to be 86,500
- If diagnosed early HIV can be managed as a long term condition and near normal life expectancy can be expected
- A quarter of people living with HIV are thought to be unaware of their infection
- Concerns about confidentiality shape people's attitudes towards disclosing their HIV status
- There was no consensus amongst respondents and the key stakeholders interviewed as to whether the treatment of HIV should be generic or specialist

- The importance of early diagnosis in respect of improved health outcomes and in reducing transmission rates highlights the need for an increase in testing
- Mental health is a significant area of concern with people living with HIV experiencing relatively high rates of anxiety and depression
- The personalisation agenda should mean that people will be increasingly able to decide what support they require and who should provide it
- The social care needs of older people living with HIV have not been adequately addressed, either nationally or locally
- There is a need for greater recognition of children's caring responsibilities where parents are HIV positive
- The Third Sector has an increasingly important role in extending choice for people living with HIV particularly and supporting people to self-manage
- Finance is a worry for many people living with HIV including paying for a wide range of services including accommodation, utilities and food
- People living with HIV often experience multiple forms of discrimination and disadvantage



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