



OVERVIEW OF TRANSITION FORUM FOR PARENTS OF YOUNG PEOPLE WITH CHRONIC ILLNESS/DISABILITY

BACKGROUND:

The Greater Metropolitan Clinical Taskforce Transition Care Program is an initiative funded by the NSW Department of Health that aims to improve the continuity of care for young people with chronic health as they move from paediatric to adult health services. Program Manager, Lynne Brodie, leads a team of 3 Transition Coordinators who are based at John Hunter Hospital in Newcastle, Royal Prince Alfred Hospital, and Westmead Hospital. These hospitals are affiliated with the 3 tertiary children's hospitals (John Hunter Children's Hospital, Sydney Children's Hospital at Randwick and Children's Hospital Westmead). The Program extends across all Area Health Services in NSW.

Parents forum held at Chatswood September 2nd 2005

The forum for parents/carers was the second in a series of forums titled '*Bringing in the Voices*'. The first forum targeting young people was held at Luna Park in April this year.

The forums aim to;

- a) increase health professional's understanding of what young people, parents and carers see as the issues around moving from paediatric to adult health services
- b) gain a better understanding of the transition priorities of young people and parents
- c) provide an opportunity for young people and their families to learn about and contribute to the Transition Program and perhaps develop some new friends and networks.

The forum targeted parents / carers of young people with a chronic illness/disability aged between 16 and 25 who were preparing to move or had already moved from paediatric to adult health services. The forum was also open to health professionals. A total of 42 attended the forum - 35 parents/ carers and 7 professionals. Few of the parents / carers knew each other prior to the forum.

Program

The program was facilitated by the GMCT Transition Care Program Manager and members of the working group. The morning session consisted of presentations by parents. The afternoon session was predominantly interactive involving small group discussions. Topics explored were;

- when to move to adult services: What are the factors that matter most re timing?

- what is needed from paediatric services to prepare for the move to adult services?
- where to move? What are the priorities from a parental perspective and what is needed from adult health services?
- what are the other issues parents face as their child matures and what supports do they need?

The program concluded with feedback and recommendations from the groups.

Some of the key recommendations arising from the discussion groups included;

- ◆ Need for a consistent approach to when transition should occur. It is important to define an endpoint with paediatric services eg at 17 or 18 years
- ◆ Preparation needs to start early. Parents felt that from 12- 14 yrs onwards is the optimal time - minimum 2 years before leaving paediatric services
- ◆ Parents and young people need more choice and involvement in decisions around where to transfer and who will manage their adult care
- ◆ There needs to be good communication and a collaborative approach between referring and new teams It would be ideal to have a meeting with whole team and the family GP to discuss transition process as they are a 'constant'
- ◆ Need to link education and health transition
- ◆ An individual approach for transition should be taken for each family
- ◆ Health records need to be kept in a central point and easily accessible
- ◆ There is a need for one point of call such as a case manager to coordinate care
- ◆ It is important to educate staff in adult facilities about the needs of young people and to seek out those who are interested.
- ◆ More therapy services are needed
- ◆ Need for increased advocacy for young people with chronic illness – those who are most vulnerable and who have the least opportunities seem to get the least.
- ◆ Leisure opportunities are scarce - need holiday places for disabled
- ◆ Need for an area where young people in adult facilities can meet. Overall there is a need for more opportunities for socialising and group activities for young people with disabilities
- ◆ When parents get older, networks change and they need to work hard to sustain supportive networks. Problem of ageing parents and carers needs to be discussed more
- ◆ Respite services are very scarce – need home respite plus somewhere outside the home for socialization
- ◆ Financial support is needed eg for transport, accommodation, paying for medications and gastrostomy feeds and other equipment
- ◆ Day Programs are scarce – only provide 18 hours a week
- ◆ Need information on services & how to get them and how to negotiate services.

Groups were also asked to explore what the hardest things were for parents around the transition period.

- ◆ Lack of planning around when to move -the time factor is often determined by when the specialist is ready to transfer care rather than a negotiated process. Attitude of 'you've got to go' rather than a planned approach

- ◆ Locating an appropriate adult specialist
- ◆ Lack of support such as ward grannies / cares within adult hospitals
- ◆ Disconnecting from the paediatric team
- ◆ Knowing that something needs to change but having no idea how to go about it and not receiving help

An Executive summary listing the main points raised by parents at the forum is being prepared and will be tabled at the GMCT Executive before forwarding to the DOH. This will be circulated to the working group and parents beforehand for comment.

Copies of the report can be obtained by calling Lynne Brodie on 98875578 or emailing lbrodie@nscchhs.health.nsw.gov.au

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- Transition coordinators, Rebecca Harris, Neroli Dickson and Ruth Wedd,
- Transition Executive Co-chair, Kate Steinbeck and consumer participant Betty Johnson
- The staff of the Dougherty Community Centre

- Most importantly the parents who participated in the forum