



BRINGING IN THE VOICES –REPORT OF THE TRANSITION FORUM FOR YOUNG PEOPLE WITH CHRONIC ILLNESS/DISABILITY

held Luna Park Sydney April 22nd 2005

WHO? 27 young people aged 16-28 with a range of chronic illnesses/disabilities

WHERE? Luna Park conference centre

WHY? To share their experiences of preparing to move or having moved from child to adult health services

ABOUT THE PROGRAM:

The program was facilitated by an external consultant and involved large and small group work that was predominantly interactive

SUMMARY OF CONCEPTS AND THEMES RAISED DURING SMALL GROUPS SESSIONS:

What does being a child / young person mean to you?

Childhood is a time of fun, hanging out with friends, playing games and sport, going to school and learning new skills, being with family and feeling safe and protected. There is a sense of being carefree, having few responsibilities and looking forward to growing up. It is also a time of being dependent, following rules and doing what you are told, taking the lead from adults and needing guidance. It can be associated with being moody, being bored, being naughty and doing bad things, getting into trouble and not listening to adults in authority. Several young people expressed childhood as a time where they were living day by day, overcoming challenges, being sick and attending children's hospital.

What are children's health services like?

The overwhelming feeling was that children's services are supportive, safe and friendly places with understanding, caring staff. They are colourful, bright and well equipped and there are lots of opportunities for having fun. Parents are made to feel welcome. The young people felt aspects that need to be improved include the lack of privacy, better food and a feeling of being ignored with doctors speaking mainly to parents. Some young people found children's services restrictive, with staff at times judgmental.

What does being an adult mean?

The main themes revolved around growing up, getting a job, forming new relationships, becoming parents, facing reality (such as paying bills) and taking on adult responsibilities. It's a time for a new experiences, more freedom and independence and you can make your own choices. Acquiring things such a buying what you want, setting up a home, buying first car were frequently mentioned. For this group of young people being an adult also means adult hospitals, getting old and death

How would you describe adult health services?

The adult hospital environment is dull and boring for young people. Adult health services involve having to deal with multiple departments, doctors who don't know you, your condition or your history. Staff seem less caring, everyone is busy and no-one coordinates care - it's impersonal and you feel like a number, not a name. Services cost more and there are more rules - eg tighter appointment times, more restricted visiting. Adult services represent lots of old people and death

What does being in transition feel like?

Transition is about change, being on a new unfamiliar journey and you don't know what to expect. It's a time of frustration, the unknown, and it can be scary, and confusing. You feel insecure, powerless, awkward and alone. You need to find out things for yourself, become independent, learn to manage your life and time. It's a challenging time, it means the next step in life, optimism, light at the end of the tunnel

How can we make adult services more youth friendly?

1. Improve the environment

Environment needs to be youth friendly with bright vibrant colours, better food, murals and young people's posters. There should be more flexible rules, PRIVACY, longer visiting hours, allowing friends in wards, pet visits if in for a long time

2. Improve activities /entertainment for young people including a dedicated space for young people to meet with free TV, music, internet access, activity groups and games, 'phone a friend service'

3. Improve attitude/approach of staff by showing more empathy, being welcoming, caring responsive listening and speaking in plain English.

4. Better communication and coordination between paediatric and adult health services with individual case management, health professionals sharing information, doctors researching and understanding your medical history

5. Being in a ward with other young people or at least grouped with other young people with similar needs

6. Provide the young person with choices and involve parent/carers in care and appointments (when young person chooses to).

7. Longer initial consultation with new doctors to get to know each other - making sure they know about you and your condition and have access to your previous records

What do young people need during the transition period?

1. Peer support system

2. Better handover of information 'When transfer happens the children's hospital should identify the most appropriate doctor at the new adult hospital, contact that person and connect the young person up', use case conferences, provide a summary of your medical history central medical records and personal handover of health information so you don't have to repeat everything to all the new people. Also doctors should respect the knowledge and experience of the young person.

3. Education for patients and carers - knowing what will happen from the beginning - being prepared, having information booklet/ video, personal briefing, FAQs

4. More gradual move over longer time –eg spread over a year from 18-19 yrs instead of when you turn 18. At least one of the paediatric medical team being involved during this time and having the opportunity to call on support from your previous team.

5. Individual case management – having a health professional who helps coordinate or communicate information across teams

6. Education for doctors and other health professionals – for paediatric doctors so that they educate you about what to expect; for adult doctors about the needs of young people and their chronic conditions

7. Being treated with respect, empathy and caring by health professionals who are interested in YOU

8. Other support services such as youth workers and CNCs. Support from those who know you - an opportunity to call on support from your previous child team.

SUMMARY OF POSTER SESSION

(see photos attached)

WHERE TO FROM HERE?

Following the poster presentations, participants were asked for suggestions on how they might be involved in the transition program in the future. Ideas included;

- Holding more forums to talk further about their transition experiences
- Receiving feedback on how their ideas for improving transition processes have been implemented
- All indicated that they would like to see the video that was taken on the day
- A peer support program was seen as a priority
- Several young people indicated that they would like to be a mentor for young people about transition

Members of the working group will follow up individually with all those who attended and determine how they would like to be involved. The information from the workshop will be used to educate health professionals about the issues of importance to young people and will also be used when recommendations are made to the Department of Health for planning of transition services.

EVALUATION

Committee members will hold a formal evaluation of the forum but the general feeling was that the day went extremely well and achieved the aims.

COMMENTS

I enjoyed:

- everything today- I loved it!
- today because I met many new and interesting people who were lots of fun
- today because I got to meet people in my own age group who have been in the same boat as me
- the different views of everyone
- sharing my experiences
- being in groups and discussing issues
- the structure, the ability to be heard, the venue, the people who ran it and listening to other people's experiences

I would have liked:

- maybe more time
- more social activities
- to have found out more information on the services available for my transition to adult services
- more time to discuss one on one
- more suitable rides
- to talk more about our life at school and how people treat us

I learnt:

- a lot
- about the other people who feel the same as me
- just to enjoy myself
- what is going to happen when I go to adult hospital
- about what others are going through
- how to connect with all different types of people and about transition
- how to take time out to listen and be patient when people are trying to speak

I was surprised by:

- how the groups worked together and how friendly the staff were
- to find so many people going through the same experiences
- how much the organisers care what we think
- how much fun I had

At any future forums I would like:

- to spend more time doing group discussions

- to be like today but to have a little more personal side of it as well as doctors views
- to be invited again!
- to talk about what we can do in the future for the next generation
- carers forum for young people/ parents

DESCRIPTIONS OF POSTERS:

Poster 1: 'Life.'

With the catchy slogan 'you gotta grab life by the balls' this poster depicted images representing the stages of growing up. The caption 'the fairytale is about to get real' expressed their belief that expectations of what you believe will happen often don't match reality and there is often disappointment – things are not how you thought they would be and real life is less than perfect. However the brightness of the images and smiling faces express an optimism that things will get better.



Poster 2: 'Unity'

This poster focused on the need to pull together. The boat was a metaphor for all the young people present at the forum being in the same situation of facing the challenges of moving from childhood to adulthood.



Poster 3: 'Perceptions'

The images of the eyes with sunglasses signified seeing things more clearly as you become an adult and also represents all the 'myriad of onlookers' who observe the process of growing up. The roller coaster represented the challenges and rough ride faced as you approach transition.



Poster 4: The fairy tale is about to get real.

The images of this poster represent the polarized messages of suffering and hope and suggest that transition represents 'the next phase' between childhood and adulthood. There is a feeling that 'the fairy tale is about to get real'. The phrase 'waking up bald' was chosen by a young man who had survived childhood cancer. Challenges of adulthood include becoming more independent and entering a new stage of life.



Poster 5: 'Outward bound'

The jaggedness of the red line symbolizes the separation of child and adult services. The lines going everywhere depict that the road to transition to adult health care is not an easy process. The words were used to convey emotions of each stage of development moving from the fun world of childhood to the challenging road to independence (trekking though the snow)

