

## Hunter Region Neurology Transition Project Final Report - September 2006, Gilda DiCesare

### Background

During 2005, discussions between the Greater Metropolitan Clinical Taskforce (GMCT) Transition Coordinator and clinical staff working in the Neurology Team at John Hunter Children's Hospital (JHCH), highlighted the need for a formal transition process for young people requiring ongoing care as an adult. The neurology team estimates that they see about 350 young people (12 years and over) each year. A significant number of these young people will require transition to adult services each year. Many have both physical and intellectual disability with complex health needs.

A submission for one off funding for a 6 month project to develop a transition process that addressed the needs of this group of young people, was ratified by GMCT in 2006.

### Aim

The project aimed to:

- improve the continuity of care for young people with a neurological condition as they transition to adult care.
- facilitate adequate continued support and follow up in the adult health system.

### Description of Service Provision by the John Hunter Children's Hospital Paediatric Neurology Team

Neurology team members include:

- Two Neurology Consultants (1 FTE and 0.6 FTE)
- 1FTE Neurology Fellow
- 1 FTE Neurology Registrar
- 1 FTE Clinical Nurse Consultant
- Access to JHCH Allied Health Staff

The neurology patients are a very diverse group with a range of physical, sensory and cognitive capacities. Many patients have multi system involvement and complications. There are two distinct groups in paediatric neurology.

- 1) those who will always be dependent on a carer to provide for their needs and
- 2) those who are able to develop skills for independence.

A large number of patients have epilepsy and or seizures as a result of their neurological conditions.

Many more patients with a neurological condition arising in childhood are surviving into adulthood which is placing an increasing demand on adult health services. Some adolescent patients seen at the clinic are referred back to their GP when they leave the Paediatric Neurology Clinic and therefore do not require transition. Others are 'one-off' patients who also do not need to be transitioned.

The following services are some of the multi professional care that the adolescent patient may require other than the neurologist:

- Gastroenterologist
- Rehabilitation specialist
- Orthopaedic specialist
- Physiotherapist
- Occupational Therapist
- Dietician
- Psychiatrist

- Speech Therapist
- Social Worker
- GP
- Respite care

### Objectives were to:

- Collect data about the number and types of conditions of young people attending JHCH Neurology Department.
- Obtain consumer input for the project.
- Liaise with relevant clinical staff working with this group of young people.
- Investigate the resources currently available.
- Develop transition resources that meet the specific needs of the group.

### Steps taken to meet objectives:

1. Data was analysed from the JHCH data base system.
2. The needs of young people and their parents during transition was investigated through the following measures:
  - Face-to-face interviews with young people and their families attending clinic appointments.
  - Questionnaires were sent to all 13- 24 year olds who had attended the Paediatric Neurology Clinics in 2004/2005.
3. Discussions were held with Paediatric and adult neurology clinicians to identify their needs and concerns for young people transitioning. Regular meetings with the paediatric team were undertaken to try and engage their support and meet their needs.
4. The following investigations were made:
  - a. Investigation of transition resources currently available to young people.
  - b. A literature search
  - c. Review of Transition Models currently being trialled in other areas.
  - d. A review of the current GMCT Transition Care fact sheets
5. The information obtained from the above steps was then used to develop a transition resource package for both clinicians and young people.

### Outcomes

#### 1. Data Collection

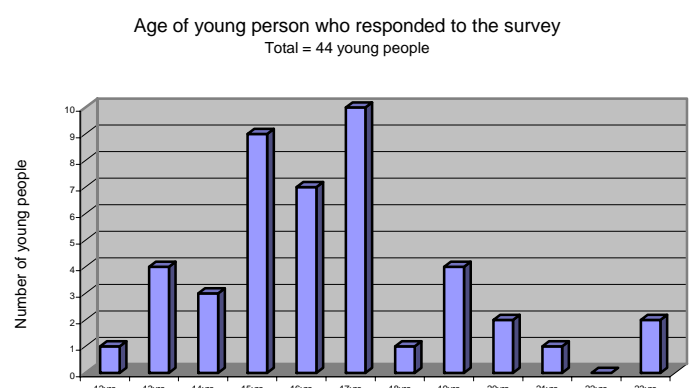
The data collected from the Paediatric Neurology Clinic appointments identified that approximately 284 young people attended the clinic during 2004/2005. The outpatient clinic database was the only way that data could be obtained for this group. There is no database kept by the JHCH Neurology Team.

#### 2. Consumer Input

Questionnaires were posted to all young people 12-24 years old who attended the Outpatient Neurology Clinic in 2004/2005. Questionnaires were also sent to their parents/carers listed as their next of kin on the database.

The questionnaires sent out were in two formats:

1. Transition Questionnaire for Young People
2. Transition Questionnaire for Parents / Carers
  - 284 questionnaires sent out.
  - 80 questionnaires were completed.



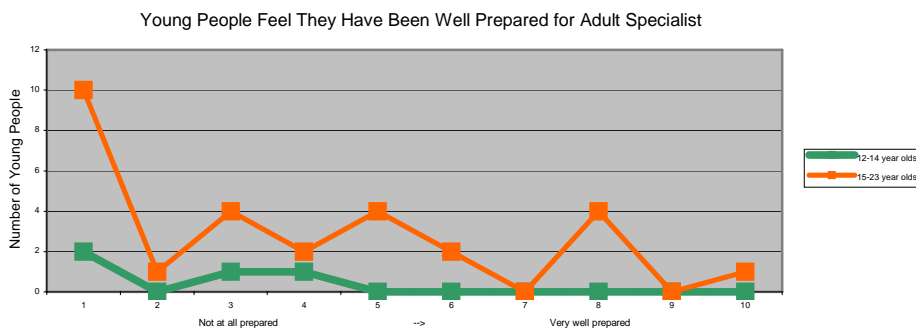
- 44 young people responded.
- 49 family groups (parent, grandparent, carer) responded.
- By completing the surveys, a number of families were confronted for the first time by the idea of transition
- 11 of the 18 young people/ families who responded that transition issues had been mentioned by their health team, had discussed the differences they would face between the adult and paediatric service.
- Overall, young people and their families members knew little about the move to adult services with only 7 indicating that they felt prepared.
- 6 of the 49 families indicated the young person was already seeing an adult service provider. This included orthopaedic specialists, neurologists, the spinal team and, ENT specialists.

### Responses from Parent Questionnaires:

- The majority of parents were happy with the amount of time they spent with the doctor.
- In terms of young people taking responsibility for looking after their own health care, parents did not respond positively.
- Overall parents did not feel they or their child were prepared for transition.

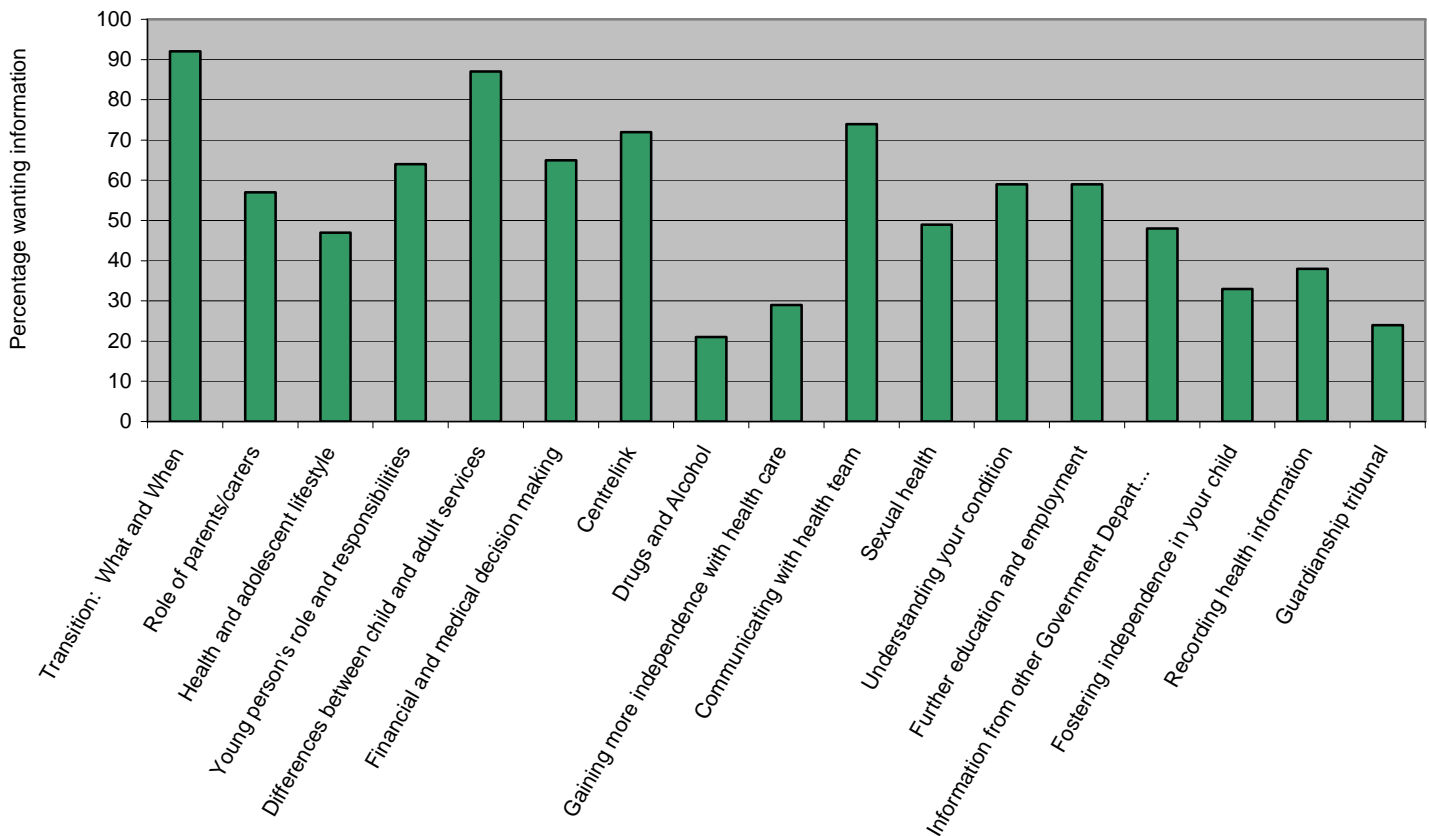
### Responses from Young People's Questionnaires

- There were mixed responses from young people in terms of their independent health care behaviour
- Overall young people did not feel prepared for the move to adult health services.



- The fact sheet question showed that young people and families were eager for information to assist the transition process.

Transition Fact Sheet Information Requested



- In addition to the questionnaires, 16 young people and their families were informally interviewed at clinic appointments. Their responses were in line with the above information. Their comments/quotes have been included with those from the questionnaires
- By completing the surveys, a number of families were confronted for the first time with the idea of transition.

### Quotes from Parents and Young people

*"The older my son gets the more medical services he requires but I am aware that there are less available to him."*

*"The older parents get, they feel worn down by the system that lets them all down."*

*"Maybe have written instructions (in teenager terms) to drum into them the importance of taking responsibility and the consequences for not being responsible."*

One mother who was crying and very upset when interviewed on the day of her son's last day with the paediatric team said, *"Nothing would have prepared me for today"*

Another mother said that a major problem had been *"I have been through 5 different GP's over the last few years"*. On a positive note she stated, *"we have a private OT who has been excellent in organising everything for my child's transition from school."*

One young person said he was *"eager to move on to adult hood. I am excited by the prospect."*

When asked about what he was looking forward to, a 16 year old said, *"Being treated as an adult a bit more. Getting information, not vague descriptions"*

*"We, Mum and I, saw Dr A for the last time before I turned 18. No transfer was mentioned. He waved us off and we left very confused."* (Young person 19 years)

### **3. Discussions with Clinical Teams:**

#### **a) The JHCH Paediatric Neurology Team:**

- The team members were eager for a formal process of transition as long as it didn't take up any more of their time in clinic, or 'be labour intensive'.
- There was also concern about a return visit to the Paediatric Clinic after the young person's first appointment with the adult team, due to the fear of criticism from the families about the lack of resources in the adult service. The Paediatric Neurologist worried that they would be 'seen as being able to fix it'.
- It was considered that a return visit could be optional and that a phone call could be just as effective to say good-bye.
- Both neurologists agreed that the transition should be completed by about 18 years of age.
- One consultant preferred that the family and GP make the decision which adult consultant they went to, the other directs the family to an adult consultant of his choice.
- All team members agreed the GP should be more involved with the young person's care,
- The team stated that the language of the package should be kept simple, to ensure that families with poor reading skills were able to read it.
- The CNC had concerns about the already stretched resources that exist within the department and the need to now add transition to this workload.
- The CNC was also concerned that there was no database to track the patients attending the JHCH Neurology Department.

#### **b) The JHH Adult Neurology Team:**

- One adult consultant described the transition as a 'funnel effect' (patients coming from one source going out to a wide variety and number of adult specialists). They felt that the adult consultants didn't really have much of a problem due to this. (It could be hypothesised that this says more about the adult clinician's lacking understanding about the problems surrounding transition, than the lack of a problem.)
- The clinicians felt that often the young person does not know enough about his/her condition, how to manage it and that parents still make all the decisions about management.
- The team feels overwhelmed by the lack of resources available for the adult population. They are often frustrated by this problem and find young people with complex health needs the most difficult to manage
- They felt that they would benefit from a central person who they could liaise with to facilitate the process of transfer of care and negotiate the lack of resources.
- The adult team did not see any value in attending (during transition) multi disciplinary meetings, mainly as adult health lacked allied health resources. It was stated 'it just reinforces the lack of resources'.
- Nor did they feel that it would benefit the young person or themselves to attend an appointment with the adult team 'to get to know their new consultant' prior leaving the paediatric service.
- They suggested that a summary from each of the paediatric allied health teams involved is required, as well as a detailed summary from the paediatric consultant.
- Most of the adult consultants felt they had adequate skills to converse with young people but often felt their main problem was dealing with the parents. The reason for this was not explored.
- There is no CNC attached to the adult team. There is a Case Manager attached to the stroke team who can assist with inpatient issues and support.

#### **c) Adult allied health:**

- Lacks resources for the general adult population let alone the heavy demands of young people with complex disabilities.
- There are strict criteria set down for accessing services that often make it difficult for the patient to obtain a service.
- There is no pivotal person who can facilitate access to these teams and often too much time is wasted trying just to find out who to contact for a specific issue.
- There is a wide gap between what is available as an inpatient versus outpatient with more resources being available as an inpatient.
- Families have reported that there are some good private allied health personnel but they are difficult to find and that 'most only want to deal with sports injuries etc that pay well, not disabled people'.

## 4. Investigations conducted

### a) Transition resources currently available to young people:

- The resources available are limited in Australia. There are some very good web sites dedicated to transition and resources available internationally.
- The GMCT website has links to information and web pages for young people with disability/ chronic illness. <sup>1.</sup>
- The schools provide support for transition to work and /or further education. <sup>2, 3.</sup>
- At the JHCH, transition resources are limited to the cystic fibrosis, diabetes and spina bifida teams. The neurology team does not have any resources available.

### b) Literature search

There is a wealth of literature supporting the notions that transition should be well planned beginning at about 13 years, should involve the family and address the young persons needs. (McDonagh 2006) Tuffrey and Pearce (2003) noted that little had been published on neurology. <sup>4,5</sup> Consideration needs to be given to psychosocial needs, support networks and education.

Reiss and Gibson(2006) <sup>6</sup> recommend that transition plans address:

1. The young person's goals
2. Their knowledge about their condition or disability
3. Their health behaviours
4. Tasks related to taking medications, tests, equipment use
5. Behaviours related to health care visits
6. Tasks related to transfer to adult providers
7. Tasks related to other aspects of adulthood
8. Skills for accessing care through the adult- oriented health care system.

### c) Review of transition models

The JHCH currently has three departments using transition models for its young people. The Cystic Fibrosis (CF) model incorporates check lists for the team to follow. The CF model covers all the necessary areas of the young person's needs both health and psychosocial. It also helps the young person to develop increasing independence skills for adulthood.

The Spina Bifida team has also begun utilising a model for young persons who are able to set goals for themselves. This team is also introducing transition clinics.

The Diabetes team utilises a model that integrates the care of a young person from the paediatric setting to an adult setting by graduated steps from paediatrics to the Young People's Clinic until they reach 30 years old.

### d) Review of current GMCT fact sheets

It is recognised in the literature that young people and families require written information to assist them through the transition process.

Families and young people indicated in the questionnaires that were eager for information to assist the transition process. The GMCT fact sheets were changed to address the needs of young people with a neurological condition and will be included as part of a resource package for young people undergoing the transition process.

## 5. Development of Resources

After analysis of the needs of the young people surveyees, the clinical teams and the resources currently available, a plan incorporating the following key aspects was identified as a priority.

- Overall preparation of the young person and family during the transition process.
- Checklists for young people suggesting certain actions to develop good skills for adult life and health care.
- Checklists that give consideration to the two distinct types of patient groups seen by the JHCH Neurology Clinic.
- Strategies to link young people with their GP prior to their transfer .

- Introducing 'time alone' with the doctor during clinic visits to enhance the young persons continuing development of skills (due to disability, in some cases this may not be appropriate).
- To provide an opportunity for closure. If families feel they need it, they can attend a return visit to the paediatric team to say goodbye.
- Providing a time scale that will allow enough time to achieve good outcomes.
- Provision of information in a youth friendly format.
- Information to be presented in a way that would be able to be comprehended by the majority of families.
- Adaptation of the GMCT transition fact sheets to suit the needs of neurology patients. This should include a specific section for parents of an intellectually and / or physically disabled young person.
- Resources for the clinicians.

**To respond to the above list, the following was developed:**

1. A formalised transition process for young people and their parents/carers.
2. A transition resource package for clinicians, and young people/families.

**1. The transition process** incorporates:

- A Transition Model for the JHCH Neurology Team
- Transition Checklists

Transition will be undertaken in a 3-stage process. Like learning to drive a car, the model and checklist utilise the Roads and Traffic Authority 'L' and 'P' plate logo for a youth friendly approach. Approval was sought from the RTA to use these logos.

- ⇒ Early stage 13yrs – 'Learning what is ahead' where the young person & family are introduced to transition.
- ⇒ Middle stage 14-16 yrs –'The active stage' where the young person & family gain understanding of transition process.
- ⇒ Final stage 17-18 yrs - 'The final stage' where the young person & family prepare to leave the paediatric system with confidence.

2. **Two resource folders** were developed that will assist in the facilitation of the transition process at the JHCH Neurology Department. These folders enable the transition process to be transparent for young people and their families while instructing clinicians in the steps to follow to ensure a smooth transfer to adult services.

The packages contain:

| Clinician                            | Young People and Parents/Carers |
|--------------------------------------|---------------------------------|
| Introduction to package              | Transition Model                |
| Transition Model                     | Individual Transition Plan      |
| Explanation of Transition Model      | Checklists                      |
| A copy of the Young person's package | Transition Fact sheets          |
| Transition Evaluation                |                                 |
| GMCT Transition referral forms       |                                 |
| CD on transition issues              |                                 |

The transition package provided to young people and their families are A5 size and designed to be youth friendly and easily portable in the hope that they will be brought back to each clinic visit.

The director of the JHCH has endorsed the pilot of the transition model and resources to start late in 2006. This will be undertaken by the neurology CNC.

At the conclusion of the project, a clinician folder was provided to each consultant, CNC, Fellow, Registrar and allied health teams. Thirty transition packages for the young people were provided to the neurology team to assist with the commencement of the pilot.

## Recommendations / Future Challenges

- This is a pilot project with limitations.
- A pilot of the package needs to be undertaken to assess its practicality in use.
- The proposed transition package will require ongoing assessment and evaluation.
- The CNC should book and attend the first appointment with the young person at the adult health service.
- Employment of a key person is recommended to assist the team to undertake transition within the Neurology Department.
- The young person should be well connected with their GP prior to transfer to the adult service.
- Ongoing work with the teams is required to incorporate transition into practice.
- Good communication and teamwork are keys to successful transition. Development of a multi-disciplinary meeting between the paediatric and adult team would aid the transition process for young people while allowing discussion about mutual issues affecting the provision of service to young people.
- Development of transition clinics is recommended for an optimal transition experience for young people. This would help to ensure that these young people do not fall through the existing gaps.
- Better resources in the adult allied health medical teams are required. Development of a data base to track the young people in the paediatric neurology department should be considered.

Young people will always challenge clinicians with their ambivalent motivation. Young people can usually only become motivated to participate if they can see the relevance of doing long-range planning. We need to accept that mistakes will occur and that a certain amount of flexibility is always important. The basis of a good outcome is good planning.

## References

1. Greater Metropolitan Clinical Taskforce Transition Program.  
[www.health.nsw.gov.au/gmct/transition](http://www.health.nsw.gov.au/gmct/transition)
2. An instructional Approach to Facilitate the Transition of High School Students With Disabilities Into Adult Life.  
<http://idea.uoregon.edu/~ncite/documents/techrep/tech24.html>
3. Board on Health Sciences Policy. Health Care Transition of Adolescents & Young Adults with Disabilities & Special health Care Needs: New Perspectives.  
<http://darwin.nap.edu/books/03091009/html/2.html>
4. McDonagh, JE., & Kelly, DA. (2003). Transitioning care of the pediatric recipient to adult caregivers. *Pediatric Clinics of North America*, 50(6).
5. Tuffrey, C., Pearce A., (2003). 'Transition from Paediatric to Adult Medical Services for Young People with Chronic Neurological Problems'. *Journal Neurology, Neurosurgery, Psychiatry*, 74 1011-1013.
6. Reiss J, Gibson R. (2006). Workshop on Disability in America: A New Look- Summary and Background Papers