



FINAL REPORT ON ILLAWARRA TRANSITION PROJECT

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BACKGROUND

During 2005, the Greater Metropolitan Clinical Taskforce (GMCT) Transition Executive identified the Illawarra region as having a high number of young adults with spina bifida. A successful proposal for a six-month pilot project to look at the transition issues resulted in the appointment of a project officer in early 2006.

Medical advances have seen a dramatic increase in survival rates and long-term survival of children with spina bifida into adulthood.¹ Having a job, participation in sport, marriage and raising a family are all possible. Many of these adults will live independently but due to the nature of spina bifida (eg hydrocephalus, incontinence) they may require varying levels of assistance. Cognitive deficits in people with spina bifida are common. Memory, attention, distractibility, planning and comprehension problems can be subtle.² These problems can affect compliance with treatments and adherence to management plans. Verbal skills can be excellent but may disguise significant comprehension issues. Young adults with spina bifida have special needs and require a streamlined transition process to assist in “graduating” from the paediatric hospitals.

AIMS OF PROJECT

The main aims of this project were to:

- gather data on current and future numbers of young people with spina bifida living in the Illawarra Area Health Service
- provide a snapshot of numbers of young people with chronic and complex physical disabilities in the Illawarra region.
- perform a needs analysis of what these young people and their families require from health services and develop appropriate resources such as fact sheets
- look at the gaps in health services for this group with particular focus on spina bifida
- develop a proposal for an adult spina bifida clinic with a multidisciplinary referral base at Port Kembla Hospital

The South Eastern Sydney and Illawarra Area Health Services (SESIAHS) Clinical Services Plan³ encourages provision of services at the closest appropriate facility. Identifying a model that would also suit those young people with other complex physical needs eg cerebral palsy or muscular dystrophy was planned.

Goals included educating health professionals about the needs of young people with spina bifida and increasing awareness of the transition process community wide. Resources specific to young adults with spina bifida were developed to assist in improving their independence with own health management.

OUTCOMES

1. Data

Table 1 contains data on the current number of young people with spina bifida and other physical disorders aged 12-24 living in the Illawarra AHS plus projected numbers for the next 5 years

Transition Service Needs	Spina Bifida	Physical Disabilities [^]	Total
Now (2006)	25*	15#	40
Next 5 years (2006 – 2011)	10	43	53
Total Transition Needs Illawarra			93

[^] Physical Disabilities includes disorders such as cerebral palsy, muscular dystrophy, arthrogryposis, and amputees.

* Does not capture current people with spina bifida aged 24+ years (approximately 15)

Reflects only current clients from occupational therapy database at Port Kembla Hospital. No reliable data exists to reflect number of young adults with CP discharged from other paediatric services (eg physiotherapy, paediatricians)

These numbers do not include young adults who are eligible for services through Department of Aged, Disability and Home Care (DADHC). DADHC services are available only to those children and adults with global developmental delay, or intellectual disability, or functional deficits in two or more areas (Appendix 1). DADHC provides case management and has review processes in place for their clients.

- Currently young people with spina bifida are offered appointments at Prince of Wales Hospital (POWH), Royal Prince Alfred Hospital (RPAH), or Westmead Hospital on leaving the paediatric services.
- There is no formal process for transfer of information regarding previous test results and health information to adult service provider.
- Attendance for regular health monitoring as an adult at POWH, RPAH or Westmead is poor with a low percentage of young people attending a hospital or their general practitioner (GP) for regular checks.
- Current service providers are geographically distant requiring extended travel times and difficulty accessing information.
- No accurate data exists on numbers of young people aged 18 – 24 with cerebral palsy or other complex physical needs however it is known to be significant and growing. These young people have no case management service.
- Spina bifida incidence is decreasing but cerebral palsy remains constant, and is increasing in the premature birth population. Survival is now extending far into adulthood. These young people have increased independence due to medical advancements, but also have corresponding increased health needs as adults.

2. Needs analysis from interviews with young people and their families

- 40 families with a person with spina bifida living in the Illawarra region were contacted and offered personal interviews. Age range was 11 – 54 years.
- 18 out of 40 families responded.
- Respondents included the age range 10 – 30yrs with 85% between the ages of 17 – 30 years and 75% of respondents in the transition age range 16 – 24 years of age.
- Thirteen other children or young adults with spina bifida have since been identified following a notice in the Spina Bifida Association magazine, Torque and by word of mouth.
- Ratio Female / Male: 50/50%
- All families reported little or no information available on transition to adult services from paediatric services.
- Transfer to POW hospital adult clinic was reported as difficult.
- There is no system in place to monitor or track loss to follow up with the majority of respondents reporting that they have not seen any specialist between 2 – 10 years.
- Adherence to treatment regimen was initiated and maintained by parents / carers with 99% of appointments made by parent / carer.

- None of the young adults were aware of more than four or five signs or symptoms for problems areas.
- Whilst in paediatric care, the majority of patients did not access services of a local GP. Finding a GP on leaving was reported as extremely difficult.
- 100% families indicated they would prefer to attend a local clinic.

3. Development of transition resources

- A personal alert checklist and emergency wallet card has been developed and is being considered by the Spina Bifida Association for use nationwide.
- Resources relevant to spina bifida and transition from paediatric to adult services for young people and their families, and clinicians have been compiled.

4. Development of links with relevant organisations

- Close links have been established with a number of government and non-government organisations, and information on transition process has been provided to them.

5. Education

- Education of professionals in many clinical areas has been completed or scheduled, including remote and rural areas (eg Shoalhaven Hospital).

6. Trial of Illawarra Adult Spina Bifida Clinic and proposal for ongoing funding

- The first Illawarra Adult Spina Bifida clinic was held in May 2006. Clinics were almost fully booked until December 2006.
- A rehabilitation physician and a Clinical Nurse Consultant (CNC) from Spinal Clinic have been allocated to the clinic.
- A clinic assessment tool has been produced to assist with smooth transition to the Clinic and a checklist has been produced for physicians and CNCs to allow quick recognition of areas covered and potential future needs, and immediate follow up required.
- A proposal has been sent to SESIAHS for ongoing funding of this new clinic

REFERENCES

1. Hunt, G & Oakeshott, P. (2003). Outcome in people with open spina bifida at age 35: prospective community based cohort study. *BMJ* 2003; 326; 1365-1366
2. Spina Bifida Clinicians Manual (2002) *Australian Family Physician* Vol 31, No 1 January: Special Feature
3. South Eastern Sydney and Illawarra Area Health Services (SESAHS) Clinical Services Plan, 2006

APPENDIX 1

DIFFERENCES BETWEEN THERAPY SERVICES in the ILLAWARRA HEALTH and DEPARTMENT OF AGED, DISABILITY AND HOME CARE (DADHC)

CLIENT POPULATION	DADHC	HEALTH	ISSUE
Children of Early Intervention Age	All therapies available to children with global developmental delay or at risk of developing such	Usually ONLY physical issues – SP / PT – but minimal service available. Large waiting lists. Children with cerebral palsy unable to obtain occupational therapy treatment.	Gap - service availability in all therapy areas. Children who have received a DADHC service for a period and deemed no longer eligible may not be able to access OT prior to their entry into school, even if they have equipment or environmental access needs.
Children of School age	All therapies available to children with intellectual disability and functional deficits in two or more areas.	Do not provide services to DADHC population, except dietetics. Provide service to all mainstream school age children with chronic and / or complex needs.	Some children with a mild / borderline I.D. and functional deficits can fall through gaps.
Adults	All therapies available to adults with intellectual disability and functional deficits in two or more areas.	No transition service. No clinics. Referral for outpatient services possible on as needs basis / crisis. **No longer provide dietetic services to adults with intellectual disabilities.	Issues sometimes arise for older clients with intellectual disability who previously may have accessed health rehabilitation services (due to an age related deterioration).