

## REHABILITATION IN PRACTICE

# Development of health support services for adults with spina bifida

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### Abstract

**Purpose.** To describe, within a state-wide transition framework, the pathway to improved health support services for adults with spina bifida. Our aim was to achieve adult care that addressed adult health issues, despite significant budgetary restraints and competition for the public health dollar.

**Method.** A pilot clinical service project in one of the Area Health Services and a transition workforce study were carried out in the state of NSW in Australia. The advocacy skills of clinicians were harnessed.

**Results.** A regional adult spina bifida clinic was successfully created and patient resources were developed. Ongoing funding was not granted. A transition workforce study identified the poor clinic attendance of adult spina bifida patients and the high costs of hospital admissions for spina bifida related complications. Through advocacy and data provision, health funding was provided for two health support workers for a new service, the Spina Bifida Adult Resource Team.

**Conclusions.** An effective transition to adult care is essential for chronic childhood illness, but young people with chronic illness often have no significant voice. Advocacy for public health spending requires compelling evidence which we were able to provide and which could be a model for other service providers.

**Keywords:** *Spina bifida, transition, adult*

### Introduction

The New South Wales Agency for Clinical Innovation (ACI) Transition Network, previously the Greater Metropolitan Clinical Taskforce (GMCT) is one of 22 clinician led networks funded by the State of New South Wales (NSW) in Australia [1]. The Transition Care Network was established in 2004, and funds a Network Manager, three full-time Transition Care Coordinators (TCCs) and three part-time TCC support positions. The overall aim is to facilitate the transition of young people with ongoing medical conditions from paediatric services to relevant and appropriate adult services across the state.

One of the Transition Network's first projects was to identify the numbers of young people in NSW who required transition from specialist to specialist care. Spina bifida was identified as the fifth most common transitioning condition [2.] There were

multiple case reports of young people with spina bifida dropping out of services once they left paediatric care only to later re-present to adult emergency departments in crisis, often with severe preventable problems such as infected decubitus ulcers and renal failure.

### Disability in spina bifida

Spina bifida is the most common, complex, congenital condition affecting the development of the brain and the spinal cord. It is a neural tube defect and this condition occurs in 1 in 1000 pregnancies. These patients have multifaceted health care needs and disability, resulting in paresis or paralysis limiting mobility, sensory deficits in the lower limbs causing pressure areas, burns and fractures, hydrocephalus requiring a shunt and compromising cognition and complex spinal complications. Neuro-

genic bladder and bowel present in up to 95% of patients with spina bifida [3] and incontinence of bladder and bowel is a major management issue. Australian morbidity data from 2007 described the first cohort of adult patients surviving childhood with complex spina bifida and hydrocephalus requiring shunting, and who were above 18 years of age. Of 29 known deaths over a period of 25 years, 33% were from chronic renal failure, 14% died from pressure area associated sepsis, 10.4% from chronic respiratory failure and 7% from acute shunt dysfunction (Personal communication, Dr Carolyn West, Head, Spina Bifida Services, The Children's Hospital at Westmead, Sydney, Australia).

### Transition to adult services

Many patients with spina bifida and hydrocephalus have an IQ in the low average to borderline range. However, the majority have executive functioning difficulties which vary from patient to patient and which impact on many areas of day-to-day functioning [4]. These include planning and organising, problem solving, goal-directed behaviour, motivation and drive and mental flexibility. These functional deficits may impact on planning daily activities, dealing with a novel situation, switching between tasks, setting personal goals and altering behaviour to achieve these goals. Many of the cognitive deficits impact on health care and access to health services and result in a lack of health care, in acute medical issues requiring hospitalisation, and in problems with access to and maintaining of equipment, when they transition to adult care. Adult health services, in contrast with the developmental, family centred approach of paediatric services, are frequently problem orientated and individual patient focused and may not be aware of the specific needs of spina bifida patients. There are a few adult physicians who specialise in the care of adults with spina bifida and the three adult spina bifida clinics are in the Sydney metropolitan area. Access to specialist services for rural and regional patients becomes difficult and expensive.

As with many chronic childhood disabilities, it is harder for spina bifida youth to achieve autonomy from parents or carers [5–7]. Parents and carers tend to continue responsibility for the daily activities of living rather than act as facilitators to independence. These learned dependencies reinforced from an early age, require high levels of assessment and interventions in self-management training and support to enhance self-management and achieve behaviour change [8]. There is evidence that young people with spina bifida are significantly disadvantaged in all areas of life studied, and suffer much higher levels of discrimination, social exclusion and isolation than

their able bodied peers [9,10]. Adverse health outcomes contribute significantly to their inability to find work, form relationships and live independently. Health care professionals involved with young people with spina bifida in NSW, and like many around the world, have long recognised the need for health support services for this group to maximise health care, reduce hospitalisation and enable access to appropriate equipment.

The aim of this article is to describe the approach taken in NSW, Australia (which has a population of close to seven million) to develop a health support network for this group of patients within the constraints of the current adult health system, which is non-expansionary. Several unsuccessful proposals to government to fund support services had been made over the last 10 years. The overarching health goal was to provide quality health care, reduce acute hospital admissions and facilitate active lifestyles in the community for all adults with spina bifida.

### A methodology to achieve change

A clinical project and a transition workforce study which produced clinically useable data were integral to the final outcome. The aspects of the study which involved patient contact were approved by the Institutional Ethic's Review Committee.

#### *The Illawarra Project [11]*

The Illawarra Area Health Service is a 2 h drive south of Sydney, the capital of NSW and was identified as having a relatively high number of young adults with spina bifida with no local services. A data collection took place in 2006. Numbers of spina bifida subjects over 12 years of age were obtained from local clinicians, including general practitioners and cross correlated with those obtained from the two metropolitan tertiary paediatric hospitals, the occupational therapy database at the regional acute care facility and from non-government organisations. Twenty-five young people aged 11–24 years with spina bifida were identified and 15 consented to be interviewed about their transition experiences. Expert clinicians were invited by the project manager to have input into development of resources. A directory of local and more distant services and resources was developed.

#### *The Transition Workforce Study [12]*

Data collection to identify service gaps took place throughout NSW in 2007. Spina bifida was one of

the chronic conditions previously identified as one of the top five chronic conditions in NSW [2] and was therefore targeted by the Transition Workforce Study. Liaison and consultation with stakeholders and other relevant agencies in workforce management and planning, acute and chronic care facilities and education and training occurred over a 12-month period. There were three stages to the data collection: (i) outpatient (ambulatory) clinics – patient and workforce data; (ii) inpatient and Emergency Department data; (iii) workforce planning and training for transition care. As part of the Transition Workforce Study questionnaires were sent to all known outpatient and outreach clinics managing young people with spina bifida in NSW and baseline data were collected on the numbers of young people aged 12–24 years with spina bifida attending paediatric and adult services in 2007. The age group 12–24 years is consistent with that used by the national Australian Institute of Health and Welfare (AIHW) [13].

## Results

### *The Illawarra Project*

The majority of spina bifida patients had not seen a specialist for more than 2 years, with the longest duration being 10 years. The parents or carers were still identified as being responsible for monitoring therapy and making appointments. No respondents older than 16 years of age were able to identify important spina bifida related signs or symptoms necessitating urgent medical review. Fourteen subjects did not have a local general practitioner (primary care physician) while in paediatric care, and found it difficult to identify one on discharge from paediatric care. All respondents stated that they would prefer local specialist spina bifida adult care. Thirteen more young people with spina bifida came forward directly as a result of publicity for this project.

The pilot regional adult spina bifida clinic ran from May 2006 to December 2006, staffed by a physiotherapist who was the pilot programme manager, a rehabilitation physician and a clinical nurse specialist from the established Spinal Clinic at the regional acute care hospital. Specific transition resources were developed from the generic ones developed by the GMCT Transition team [14]. In addition, a personal alert checklist and an emergency wallet card were developed with input from young people (Appendix). Table I outlines the human resources negotiated for the pilot clinic. Clinicians from existing clinics were diverted to the pilot project. The costing of the clinic in Australian dollars

Table I. Staffing for pilot regional spina bifida service.

Staff proposed for clinic	Hours required
Rehabilitation/Spinal Clinical Nurse Specialist (CNS)	<b>0.3 Full Time Equivalent (FTE): CNS</b> (1 clinic/month and case management of patients > 24 years)
Transition Care Coordinator (TCC)	<b>0.8 FTE CNS*</b> (2 clinics/month, case management 12–24 years)
Physical disability case manager	<b>0.2 FTE CNS**</b> (> 16 years)
Occupational therapist	<b>0.2 FTE OT/Allied Health</b> (> 16 years)

\*Attend monthly clinic/re-arrangement of work schedule (not extra).

\*\*Position could also be undertaken by an allied health professional (physiotherapist or occupational therapist).

per annum was \$80,200.00 (1 \$AUD = 1.1 \$USD). A proposal was presented to the local Area Health Service for continuing funding of 10 adult spina bifida clinics per annum but this was not successful.

### *The Transition Workforce Study*

In 2007, 288 patients aged 12–18 years were registered with the three tertiary paediatric spina bifida clinics in NSW. The largest clinic had 195 registered, but of these 50 were considered lost to follow-up because they had not been in touch with the service in any manner and were unable to be contacted. The remaining 238 patients aged 12–18 years attended a paediatric service at least once during 2007. An additional 31 patients over 18 years also attended paediatric clinics in the same year. Seventeen young people were transitioned to adult care in the 12 months. There were 549 patients aged 16–24 years registered with adult clinics, although only 40% attended appointments in the year of the data collection and none of these were less than 16 years.

In 2007 there were 740 inpatient admissions in NSW for young people aged 16–24 with spina bifida, with an average length of stay of 5 days. The commonest causes for admission were chronic renal failure, pressure areas/sepsis, chronic respiratory failure and acute shunt dysfunction. Anecdotal evidence suggests that many of these admissions were unplanned through the emergency departments. The AIHW reported in 2006 (from figures obtained 2004–2005) that the average cost to the health system per patient separation was \$AUD3410.00 (with an estimated per annum increase of nearly 5%) [15]. Annual spina bifida admission costs conservatively were thus estimated at over \$AUD 2.5 million.

The key advocacy strategies which we used evolved from the work of two groups, the spina bifida collaborative which was a longstanding advocacy group of health professionals and the GMCT spina bifida working group which was set up with the specific aim of seeking resources for adult spina bifida patients. This working party was made up of four physicians, three specialist spina bifida nurses, two transition nurse co-ordinators, three social workers, three physiotherapists, one occupational therapist, one education researcher and three key staff from the facility which was planned to host the Spina Bifida Adult Resource Team (SBART). A further 15 members of the spina bifida collaborative, who were not on the working party, received all working party documents for review and comment. These strategies were as follows:

1. To engage tertiary paediatric and adult spina bifida clinicians as supporters for a health plan that transcended single hospital services.
2. To use the financial argument that the SBART costs would be covered by an 8% reduction in hospitalisation rates which would seem eminently feasible given that the majority of hospitalisations was preventable.
3. To ensure that government health officers understood about the neurocognitive defects in spina bifida. For instance there was a misconception in some that folic acid improved these defects.
4. To acknowledge that spina bifida subjects are not always strong advocates for themselves and that health professionals may have to take on a formidable advocacy role on their behalf.

After negotiations and discussions around the specific needs of young adults with spina bifida, the proposed service, the SBART in NSW was funded by NSW Health in 2008, for \$AUD 210,000 per annum. The major identified needs were (1) the cognitive difficulties inherent to the condition which interfere with self-management, (2) the increased personal health care costs when young people leave the heavily subsidised paediatric system and (3) pathways to avoid avoidable acute hospitalisations.

The principles of the SBART proposal were (1) affordable easy access to a specialist multidisciplinary team, (2) continuity of care with close collaboration between paediatric and adult health services during the transition period and (3) a case manager/co-ordinator to liaise with young people and their families, to provide support and education to help them to remain engaged with appropriate health services. In practical terms, the SBART team has a complex brief which includes numerous responsibilities as summarised in Table II.

This service commenced in August 2009 with two staff – a full time Clinical Nurse Consultant and a 0.8FTE occupational therapist. A single contact person was appointed from current human resources to represent NSW's three tertiary paediatric hospitals, for the purpose of any negotiation of targets, resources and issues (currently Author CW). The two SBART professionals are physically located at Northcott Disability Services in Sydney. This is a non-government organisation, first established as The NSW Society for Crippled Children in 1929 by the Rotary Club of Sydney to deal with the outcomes of polio and tuberculosis. Northcott Disability Services now provides support and services for more than 6000 people with disabilities, their families and carers living in NSW and the Australian Capital Territory.

In the first 6 months a total of 132 patients aged 18 years and over were referred to SBART and of these 51 were over 25 years of age.

Key outcomes for the first 12 months of SBART will be documentation of service gaps, development of transition plans and pathways, reporting of individual patient data, including successful engagement in the adult service, number of appointments attended and unplanned hospital admissions at all monthly Adult Spina Bifida clinics in metropolitan, regional and rural centres in NSW. Validated measures of health and lifestyle and the development of evidence based, best practice guidelines for hospital and community care of adults with spina bifida will also be developed. The Transition Network has secured funding from the Agency of Clinical Innovation to support a project officer to collect data on key outcomes.

The following case summary highlights the benefits of the SBART service in addressing individual

Table II. Responsibilities of the SBART team.

- |  |
|--|
| <ol style="list-style-type: none"> <li>(i) Facilitating access to general practitioners, spina bifida clinics, specialists (including urologists and neurosurgeons)</li> <li>(ii) Improving the young person's ability to access equipment provision and equipment maintenance (wheelchairs, pressure cushions, toileting aids, continence equipment, modification to the home and work place, post surgery equipment needs)</li> <li>(iii) Assisting in the adaptation to changes in life situation (pregnancy, parenthood, deterioration in mobility, change in accommodation status and support services where elderly parents become unable to provide the level of necessary care).</li> <li>(iv) Playing an educative role and providing information specific to the needs of patients with spina bifida to health professionals in more generic services who may be able to provide the care closer to home.</li> <li>(v) Developing a directory of appropriate services able to provide care eg equipment supplies and maintenance, government benefits, continence assistance schemes and programmes of aids for disabled persons.</li> <li>(vi) Improving access to respite services, identifying supported accommodation and educating new carers.</li> </ol> |
|--|

needs, helping to prevent unnecessary hospital admissions and advocating for those who are unable to advocate for themselves.

### Case study: 26-year-old male referred to SBART by community service

- Spina bifida, incomplete paraplegia, ventriculo-peritoneal shunt, right below knee amputation (osteomyelitis)
- Single, living at home with parents - social isolation
- Relatively independent, uses wheelchair, drives, currently unemployed on disability pension
- 12 hospital admissions in past 12 months with pressure ulcers, cellulitis and osteomyelitis. Sacral pressure ulcers  $\times 3$
- Being showered 3 times per week at local hospital by community nurses as his parent's bathroom and laundry are being renovated

### SBART team

- arranged medical review and renal ultrasound
- organised continence products/wheelchair repairs
- addressed health issues – self-care, diet, continence issues
- referred to 'burn rubber burn'\* programme for exercise and socialisation
- worked with previous case manager to assist with applications for emergency housing, home care and employment

\*A community-based fitness programme for spinal cord injured individuals in wheelchairs.

### Discussion

This article is the first identifiable, prospective report in the literature which describes the evolution of a spina bifida adult service, based on assessment of need. An earlier publication from Australia described the transition experiences of 10 young people with spina bifida [16].

In 2007, Binks et al. published an in-depth review of the spina bifida transition literature between 1990 and 2006 [16]. Overall, the authors identified limited empirical evidence related to optimal service provision, while noting that there were more studies concerned with functional and social status, and morbidity and mortality. In their conclusion the authors call for prospective studies: 'It is time to use emerging theoretical models to develop transition interventions and to evaluate them using controlled

trial methods that consider both medium and long-term health'. This is how an evidence base should be created, but raises new issues around standard (control) care *versus* more intensive care models. There remains debate around the optimal service for transition for many conditions and spina bifida is an example where condition focussed service has advantages compared to a general rehabilitation service [8,17]. Young people with spina bifida and their parents continue to experience lack of support during the transition, professional's lack of knowledge and lack of adult services [18]. Parents continue to have a highly supportive and practical role in self-management, to a degree which is greater than many other chronic diseases and in part reflects the specific cognitive issues that young people with spina bifida have [19]. Working memory becomes less reliable with high information load and prospective memory about future tasks can be impaired, particularly in those who have experienced a number of shunt revisions [3]. Any prospective transition studies should ideally control for cognitive and parental factors, and also incorporate specific community exposure and intensive work around self-management [20].

In Australia, prior to SBART there had been no state or national health funding to develop or even maintain the status quo, let alone respond to the increasing demand as the numbers of young spina bifida patients reaching adult life increase. There have been very limited positions to coordinate these services and no way of tracking and following up those who do not attend.

The key findings of the development of health support services for adults with spina bifida are first the confirmation of a clinical need that is best addressed at a local level, moving away from the traditional paediatric centralised hospital-based service. Secondly, that the attendance rate for spina bifida patients is low for paediatric services and falls further over the age of 18 years. This adult finding is similar to other chronic illnesses such as diabetes and congenital heart disease [21,22]. In spina bifida cognitive function that makes it difficult for the young person to organise their care independently and the fact that life threatening complications can appear in early adulthood increase the urgency to provide a consumer friendly service. Our data provide a baseline for service assessment. Thirdly, it is well documented that chronic conditions represent the most prevalent problem and place the greatest strain on health care systems today in developed countries [23]. This article outlines both a local clinic option, and modestly costed state wide option. The latter has the additional ability to track young people in the health care system and potentially reduce the loss to follow-up. It is condition focused and acknowledges that professional expertise does not need to always be medical or co-located with major

hospitals – both of which make a service more attractive to those who fund public health.

There is clinician evidence that young people with spina bifida can be managed in a variety of settings by a variety of health professionals, including dedicated spina bifida clinicians and rehabilitation experts, but these models are yet to be evaluated [8]. There are other potential, non-health benefits to co-ordinated management, an example of which would be an improved ability to undertake vocational training as a result of better health and resultant higher potential for employment. Initial referrals to SBART suggest both a willingness for young people to transition, and a group of older adults who were not well serviced.

In conclusion, we have presented an evidence-based process for the management of adult spina bifida patients after they leave paediatric care. We believe that the solution proposed has a universal application and could be modified to suit established health care systems.

There is a great demand for the service and further initiatives will be developed as SBART expands. Good communication between the resource team, paediatric and adult spina bifida services, adult hospitals and community care is essential to good service provision. A clear work plan allows the evaluation for the numerous aspects of spina bifida care and will be a platform for more formal clinical trials in the future.

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‘If I lived in a society where being in a wheelchair was no more remarkable than wearing glasses, and if the community was accepting and accessible, my disability would be an inconvenience and not much more than that. It is society which handicaps me, far more seriously and completely than the fact that I have Spina Bifida’ [24].

### Declaration of interest

Both the Illawarra Project and the Transition Workforce Study were funded by internal, competitive GMCT grants.

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**Appendix**

SHUNT/ HYDROCEPHALUS	CHIARI MALFORMATION	BLADDER & BOWEL SKIN	CORD TETHERING
<p>Potential Issues:</p> <ul style="list-style-type: none"> <li>● Headaches</li> <li>● Vomiting</li> <li>● Vision problems (cross-eyed, double vision)</li> <li>● Tired – more than usual</li> <li>● Easily upset/moody</li> <li>● “Just don’t feel right”</li> <li>● Pass out or collapse</li> <li>● Memory problems</li> <li>● Balance altered</li> <li>● Head and neck pain</li> <li>● Numbness in arms</li> <li>● Gagging/swallowing problems</li> </ul>	<p>Potential Issues:</p> <ul style="list-style-type: none"> <li>● Difficulty swallowing/ choking problems</li> <li>● Things go down wrong way</li> <li>● Wheezing</li> <li>● Arching of the head</li> <li>● Stiffness and spasms in neck, arms or hands</li> <li>● Head and neck pain</li> <li>● Turned eye</li> <li>● Loss of feeling in hands or arms</li> <li>● Loss of coordination or balance</li> </ul>	<p>Potential Issues:</p> <p><b><u>Urinary Tract Infection/Bladder</u></b></p> <ul style="list-style-type: none"> <li>● Chills and fever</li> <li>● Cloudy or dark/bloody urine</li> <li>● Nausea or vomiting</li> <li>● Back pain</li> <li>● Change in urinary continence</li> </ul> <p><b><u>Bowels</u></b></p> <ul style="list-style-type: none"> <li>● Increased difficulty at home</li> <li>● Unusual/unexplained changes</li> <li>● Bowel accidents</li> </ul> <p><b><u>Skin/Pressure Sores</u></b> (Remember to check skin daily)</p> <ul style="list-style-type: none"> <li>● Redness one hour after clothing or shoes removed</li> <li>● Sore, ulcerated or broken skin</li> </ul>	<p>Potential Issues:</p> <ul style="list-style-type: none"> <li>● Altered walking ability</li> <li>● Pain</li> <li>● Progressive changes bowel/bladder</li> <li>● Foot deformities</li> <li>● Headaches</li> <li>● Muscle weakness/wasting</li> <li>● Curved spine</li> <li>● Altered sensation in genital regions and during sex</li> <li>● Impotence</li> <li>● Any motor or sensory deficits</li> </ul>

**Some of the issues can be URGENT! Please discuss with your specialist.**

**CONTACTS**

Norcott Spina Bifida Group  
Ph: 02 9890 0990  
Email: subgroup@northcott.com.au

National Continence Hotline:  
1800 330 066

Useful Websites  
www.asbha.org.au  
www.ifglobal.org  
www.northcott.com.au  
www.health.nsw.gov.au

**MY INFORMATION NAME:**  
Emergency Contact  
Name  
GP:

Spina Bifida Clinic  
Nurses:  
Neurosurgeon:

Medicare No:  
Private Health Fund/No:

Notes:

Please note that this health checklist is for information only not medical advice. If you notice anything different or are concerned, don’t hesitate to call your GP or specialist straight away.

**MY EMAILS:**  
Ph:  
Mobile:  
Ph:  
Address:  
Ph:  
Fax:  
Ph:  
Address:  
Pension No:

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