Partnerships: Together for Life
Bloorview Kids Rehab and CNIB
Toronto, Ontario, Canada

Building Bridges to Adult Care Through Collaboration:
A new transition model of care for young people with Spina Bifida

Lynne Brodie
GMCT / ACI Transition Care Network Manager
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NSW Agency for Clinical Innovation
Overview:

- Development of a Spina Bifida Model for NSW
- Background about GMCT/ACI
- Achievements and challenges of the Transition Care Network
Evolution of the Greater Metropolitan Clinical Taskforce

March 2000 - NSW Health Council Review

June 2001 - Report released

November 2001 - GMTT

November 2004 - GMCT

Jan 2010 - GMCT / ACI

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GMCT / Agency for Clinical Innovation (ACI)

GMCT / ACI – a state wide approach:

- Clinician and Consumer involved in 22 networks
- Transparency
- Equity of access and equity of outcome with services based on clinical need

Transition Care Network structure:

- Transition Executive
- Network Manager, 3 Transition Coordinators and 3 support workers
- Part-time project positions (workforce, mental health, allied health)

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NSW Chronic Care Unit

Children and Young People’s Health Priority Taskforce

Non government organisations
eg Spastic centre, spina bifida,
+ other relevant services eg DDHAC

Data / IT Working Group

Diabetes Working Group

Emergency dept Working Group

Workforce Education & Training Group

Resources Working Group

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NSW Child Health Networks
Extent of the problem:

• 300,000 Australian children aged 12-24 live with chronic illness or disability\(^1\)

• In NSW, our focus is on those young people aged 12-24 with complex chronic illness arising in childhood and estimates are approx 30,000

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\(^1\) Australia’s Children: Their Health and Wellbeing, 2007
Main objectives: Transition Network

Adult services
Aim for long term retention

Children’s Services
Aim to prepare well

Prevent rebound

Prevent falling through the gaps
Paediatric hospitals aren’t good at:

- dealing with adolescent concerns and risk taking behaviours
- encouraging independence
- providing contraception advice, fertility and family planning
- providing information on allowances / entitlements
- providing advice on post school options
- involving GPs; communicating with adult colleagues
Adult hospitals aren’t good at:

• providing youth friendly services – environment, activities, communication

• recognising inexperience of young people and providing support

• following up and reminding young people about appointments

• acknowledging the vital role of families
Special needs of young people with Spina Bifida

- Not enough adult services
- Drop out rates were high
- First presentation to an adult service was often when there was a crisis – pressure ulcers, renal problems, blocked shunt
- Self management and poor health literacy was a significant problem
Special transition needs of young people with spina bifida

- Preparation needs to be adapted to take in any intellectual disability and needs lots of time
- Family support is often required and not catered for in adult settings
- Executive functioning issues impact significantly on self-directed responsibilities
- Challenge to find right adult service
- Practical issues such as attending clinics, specialists room, transport can be a problem
- Have specialised and specific health needs that are poorly understood by generic adult services
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 that that. It is society which handicaps me, far more seriously and completely than the fact that I have Spina Bifida.
Implications of poor health literacy

- Problems completing medical forms
- Understanding instructions for prescriptions/treatment
- Ability to provide medical histories
- Provide accurate responses to health questionnaires/surveys
- Links with poorer health outcomes
- Higher use of health services and higher health care costs
- Poorer communication with health professionals
- Limited participation or benefit from health education programs

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Stage 1: Spina Bifida Model of Care
The Illawarra Pilot 2006

- Project position for 6 months to look at numbers of young people with spina bifida in the Illawarra Area and their needs
- Identified and surveyed 40 young people and their families
- Preferred service Port Kembla (local rehab hospital) – pilot established
- Proposal submitted to NSW Health but no funding

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Data from Illawarra: Young people 12-24 yrs

2006 (total = 40)
• Spina bifida = 25
• Disabilities = 15

2007-2011
• Projected that there would be 93 young people who could potentially access local service
Top 5 chronic conditions for NSW by age group in 2007

<table>
<thead>
<tr>
<th>Condition</th>
<th>12-16 years</th>
<th>16-24 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes</td>
<td>1880</td>
<td>1109</td>
</tr>
<tr>
<td>Endocrine</td>
<td>836</td>
<td>514</td>
</tr>
<tr>
<td>Neurology (CP)</td>
<td>1271</td>
<td>953</td>
</tr>
<tr>
<td>Gastroenterology</td>
<td>173</td>
<td>372</td>
</tr>
<tr>
<td>Spina Bifida</td>
<td>254</td>
<td>385</td>
</tr>
</tbody>
</table>

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Stage 2: Workforce study 2007/8

Aims:

- To obtain baseline data on the number of young people aged 12-24 years attending paediatric or adult outpatient clinics in NSW in 2007

- Estimate numbers transitioning to adult clinics in 2007

- Determine service, workforce and education gaps and predict workforce needs
Spina Bifida Data (from workforce study)

- Total = 714; 254 aged 12-18 yrs; 460+ aged > 18;
- 3 main paediatric centres, 3 adult services (gradually increasing)
- No multidisciplinary approach
- Evidence of emergency admissions for pressure areas / renal failure
- Significant numbers falling through the gaps
Common problems associated with neural tube defects

Medical problems
- Paraplegia / Reduced mobility
- Renal impairment
- Hydrocephalus
- Neurogenic bladder and bowel
- Skin problems

Cognitive problems
- Memory
- Attention
- Distractibility
- Planning
- Comprehension
Stage 3: Proposal for state-wide model

- GMCT Spina Bifida working group

- Meetings with State-wide Spina Bifida Collaborative

- Proposal developed for a spina Bifida Adult Resource Team (SBART) was costed and submitted to NSW Health

- A presentation by key members of the working group was given to the NSW Health Department in February 2008
Model of Care (modified Wagner)

• Preparing and empowering young people to manage their health and healthcare

• Delivering effective efficient care and self management support

• Promoting care that evidence based and consistent with patient preferences

• Using a community based approach

• Creating a culture that promotes safe, high quality care
Model of Care Across the Age Span

Model of Care for Spina Bifida

Lifestyle Impact

GOAL: Happy, healthy, competent, independent adult.

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Spina Bifida Adult Resource Team (SBART)

- State-wide community based model

- MOU with Non Government Organisation (Northcott Disability Services)

- Commenced in August 2009

- Team leader Joanne Brady

- Senior Occupational Therapist Jaie Thomson
Aims of SBART:

- To facilitate and coordinate effective transition of young people with neural tube defects throughout NSW
- Reconnect those who have fallen through the gaps
How are aims being achieved?

- Attending adult spina bifida clinics as well as Outreach clinics in rural centres
- Collating data for patients moving from each paediatric facility to adult health care services.
- Developing transition plans and pathways for every young person referred.
- Developing best practice guidelines for hospital care of adults with spina bifida.
- Surveying patients making the transition to the adult health care system to assess any problems with transition and unmet needs.
Snapshot to date

The bar chart shows the following data:

- **Aug-Dec 09**:
  - **18-25** category has a value of around 40.
  - **Over 25** category has a value of around 30.

- **Jan-10**:
  - **18-25** category has a value of around 10.
  - **Over 25** category has a value of around 10.

- **May-10**:
  - **18-25** category has a value of around 60.
  - **Over 25** category has a value of around 20.
Identified gaps in service

- Gaining access to and receiving appropriate respite care
- Support needs of those in employment eg catheterisation
- Need for multidisciplinary adult services for this group
- Lack of supported accommodation or accessible housing
- Discharge with no services in place
- Costs change – orthoses, wheelchairs etc
J’s story: 26 yr old male referred by community service

- Spina bifida, incomplete paraplegia, VP shunt, right below knee amputation due to osteomyelitis
- Single, living at home with parents – very poor social history
- Very independent, uses wheelchair, drives, currently unemployed on disability pension
- 12 admissions in past 12 months with pressure ulcers, cellulitis and osteomyelitis. Sacral pressure ulcers x 3
- Being showered 3 times per week at local hospital by community nurses as his parent’s bathroom and laundry are being renovated
Continued: Role of SBART

- Arranged medical review and renal ultrasound
- Organised continence products/ wheelchair repairs
- Addressed health issues – self care, diet, continence issues
- Referred to ‘burn rubber burn’ program for exercise and socialisation
- Worked with case manager to assist with applications for emergency housing, home care and employment
Challenge to engage young people
Tips to help engage young people and build a relationship based on trust

• Foster adolescent independence while still dependant. START EARLY! Early referral with the Transitional Care Co-ordinator

• Develop a youth friendly environment, adaptable, flexible

• Promote listening between adolescents, clinicians and parents – set parameters and expectations

• Early referral to peer support eg ChIPS and other safe youth friendly groups eg Northcott ‘Face book type’ site

• Designate case manager on discharge – ensure continued engagement

• Adapt existing resources – eg brain injury wheel

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Transition Wheel:
Adapted from the NSW North Coast Head Injury Service
Where are we up to in NSW?

- identification of service gaps and development of models of care
- resources: guidelines, fact sheets, CD, webpage, position statements
- GP liaison, service directories, education, research
- tracking the patient journey via questionnaires, interviews,

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Graduations 2009:
Sydney Children’s and Westmead Children’s Hospitals

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- **Jaie Thomson**, Senior Therapist SBART
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