NSW HEALTH

# 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

GMCT TRANSITION

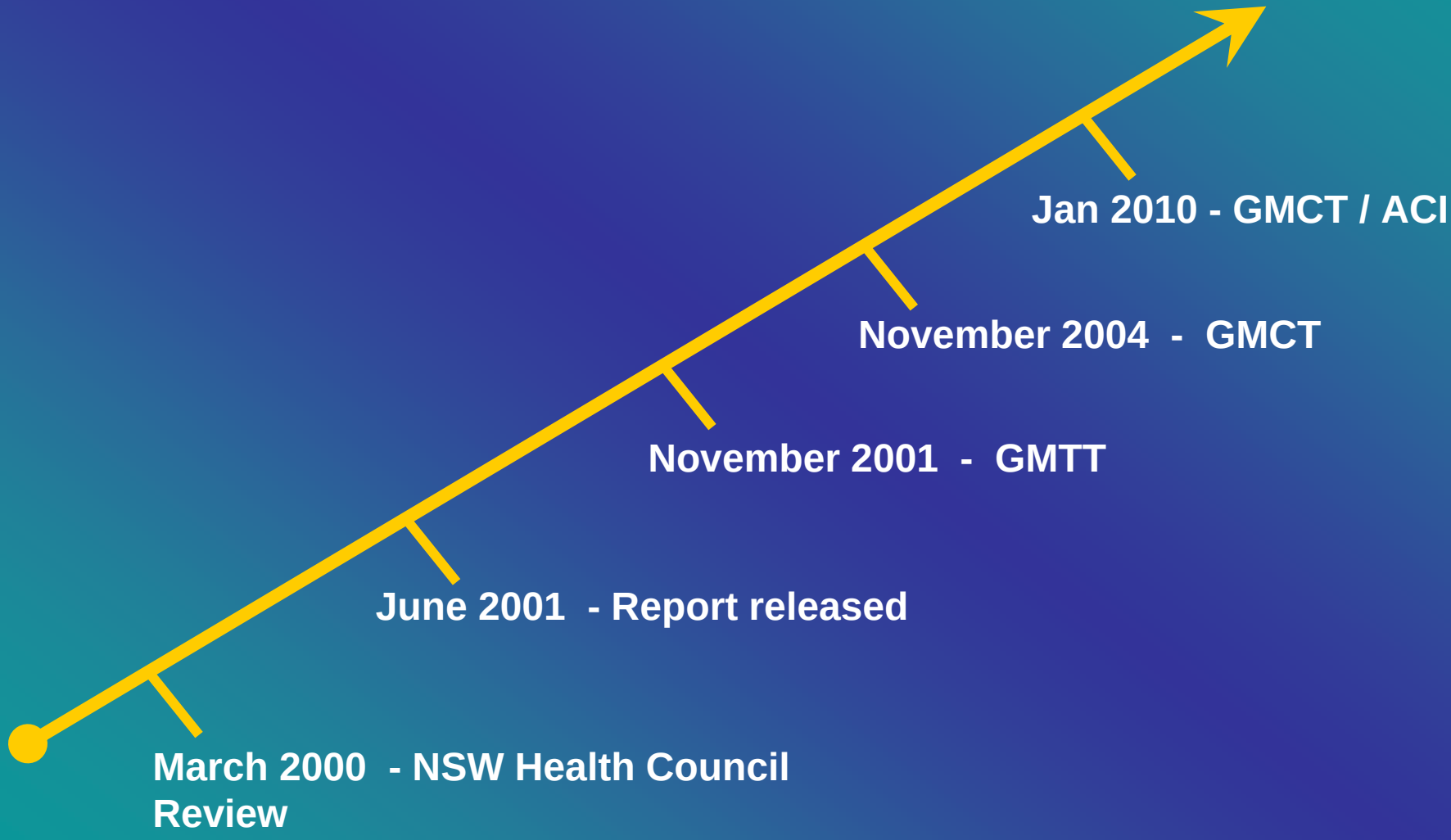
NSW Agency for Clinical Innovation

**Lynne Brodie**
**GMCT / ACI Transition Care Network Manager**
**March 2010**

# 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



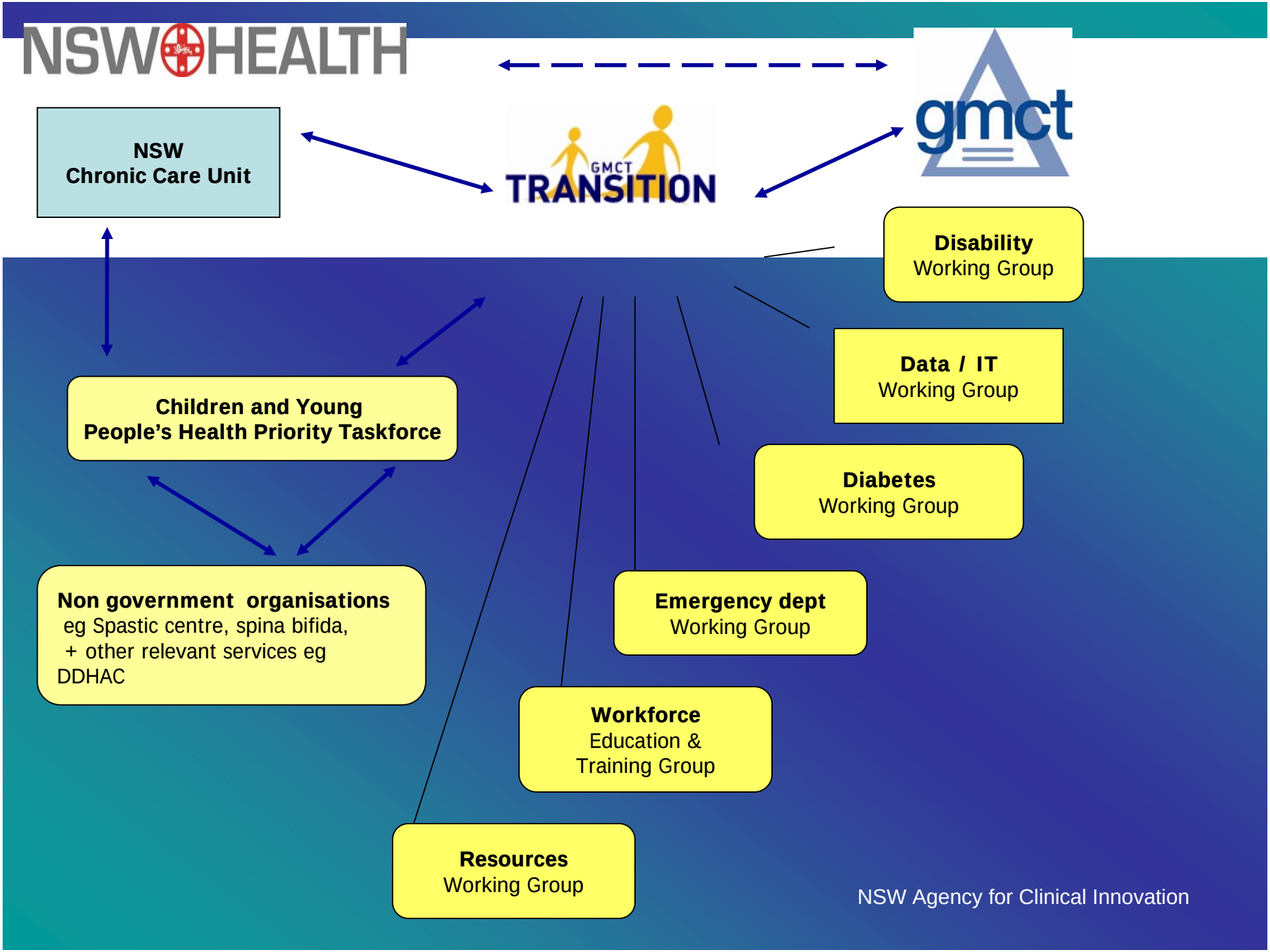
# GMCT / Agency for Clinical Innovation (ACI)

**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

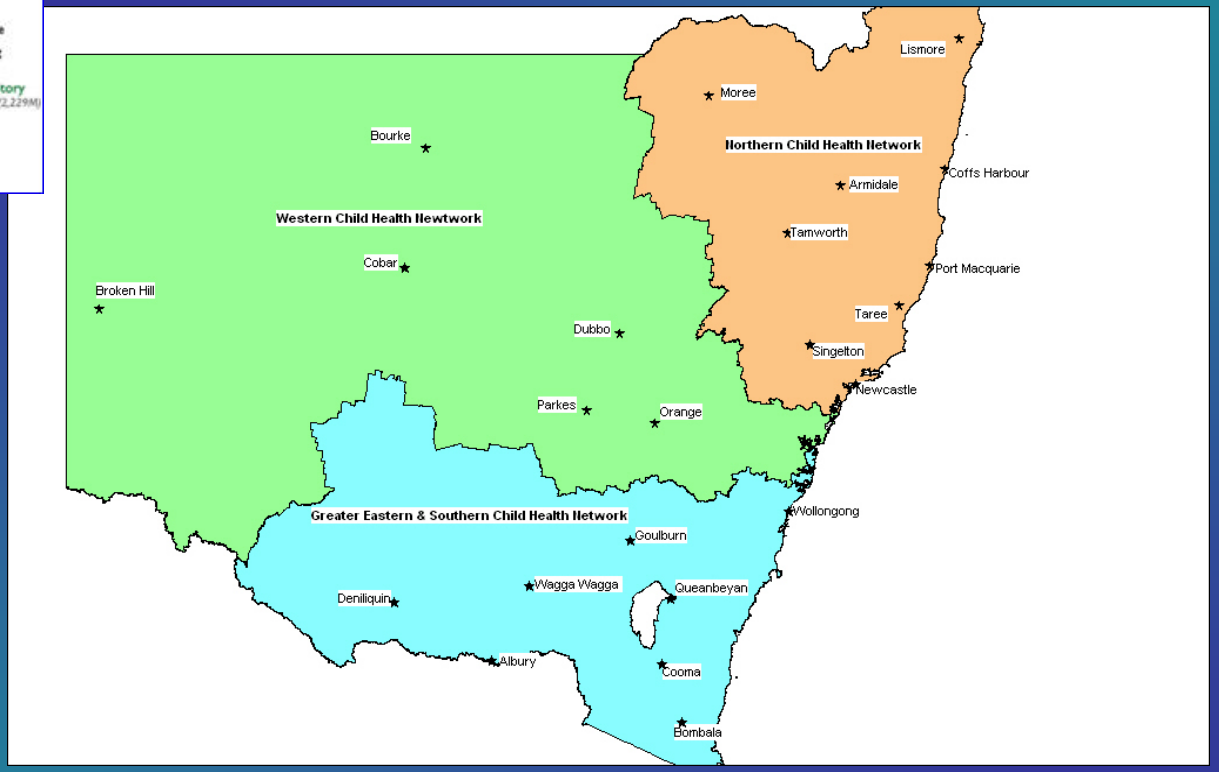
**Transition Care Network structure:**

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


NSW HEALTH
NSW
Chronic Care Unit
GMCT
TRANSITION
gmct
Disability
Working Group
Data / IT
Working Group
Children and Young
People's Health Priority Taskforce
Diabetes
Working Group
Non government organisations
eg Spastic centre, spina bifida,
+ other relevant services eg
DDHAC
Emergency dept
Working Group
Workforce
Education &
Training Group
Resources
Working Group
NSW Agency for Clinical Innovation

# Transition Coordinators

# NSW Child Health Networks



# Extent of the problem:

- 300,000 Australian children aged 12-24 live with chronic illness or disability[1]

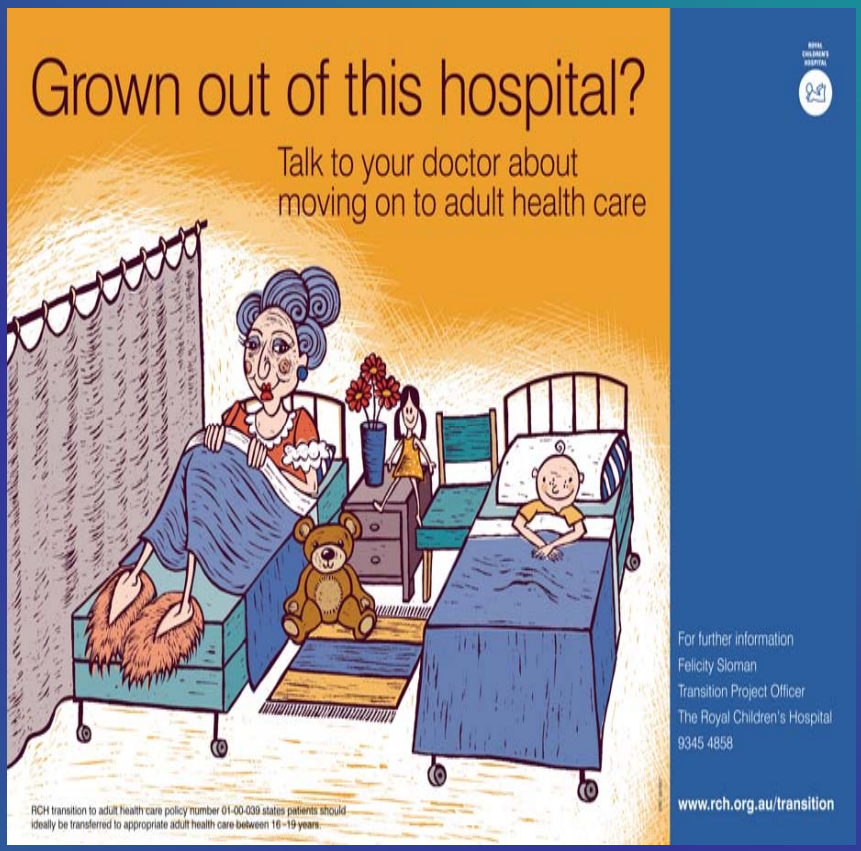
- In NSW, our focus is on those young people aged 12-24 with complex chronic illness arising in childhood and estimates are approx 30,000

1. Australia's Children: Their Health and Wellbeing, 2007

# Main objectives: Transition Network

# 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

# Quote from Shut Out: The experience of People with Disabilities and their Families in Australia

*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*

**Shut Out: The experience of People with Disabilities and their Families in Australia**
**National Disability Consultation Report 2009**

# 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

# 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

# Data from Illawarra: Young people 12-24 yrs

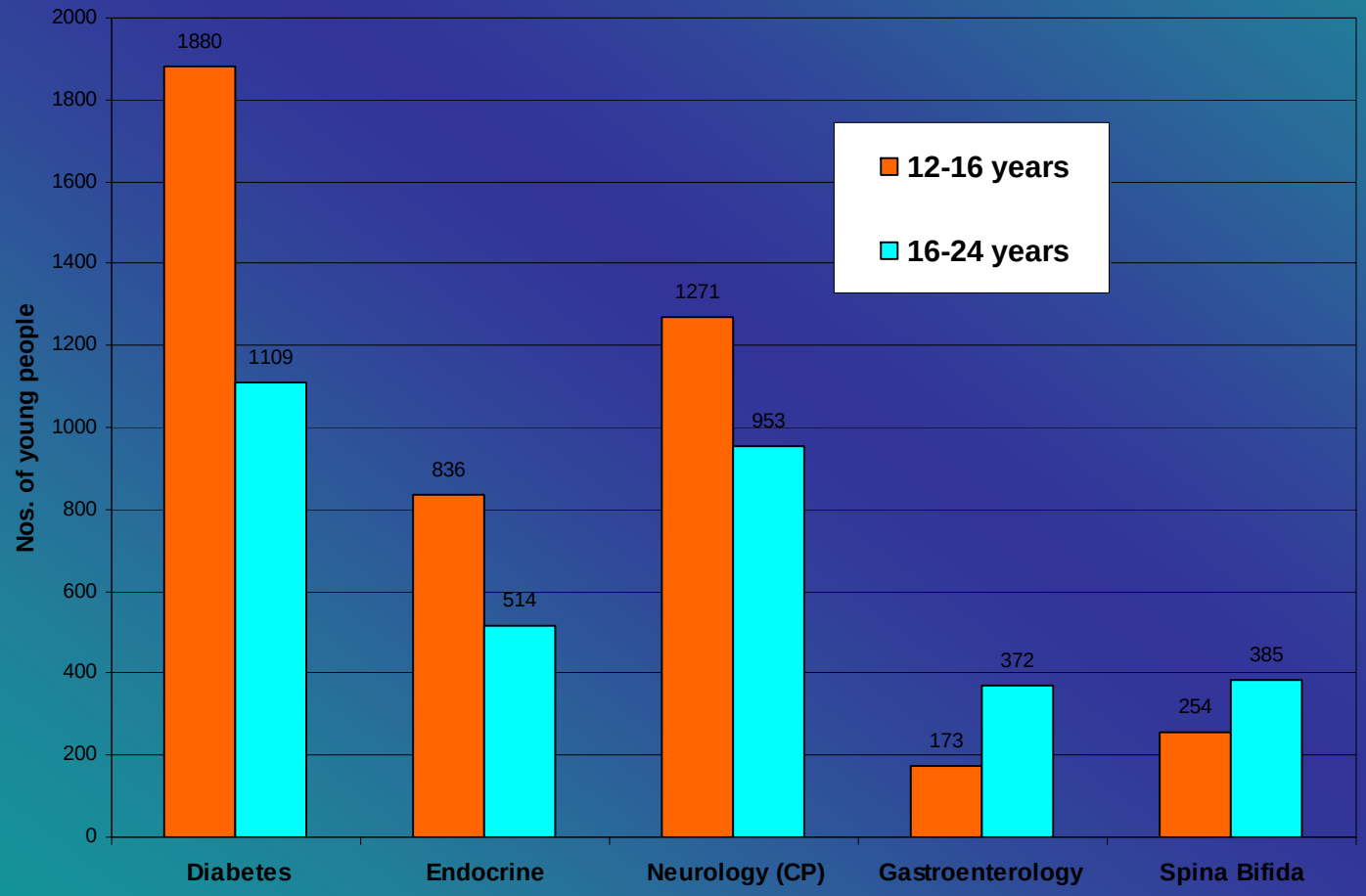
**2006 (total = 40)**

- 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

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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

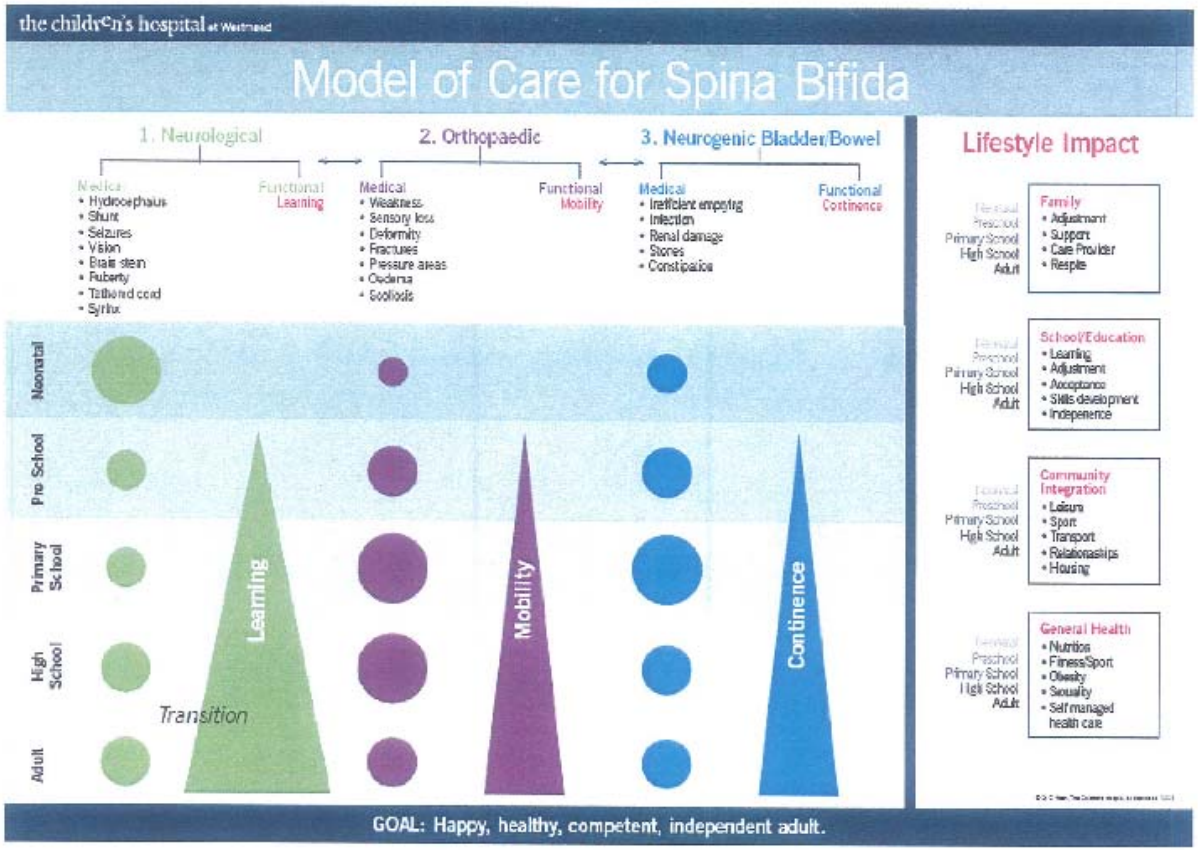
# Stage 3: Proposal for state-wide model

- 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

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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

Spina Bifida
Adult Resource Team

northcott disability services

## Introducing the new Spina Bifida Adult Resource Team.

Spina bifida is a neural tube defect caused by the incomplete development of the spinal cord and/or its protective coverings. It can result in muscle paralysis and sensation deficits. People with spina bifida are affected in a variety of ways including walking difficulties, bowel and bladder problems and hydrocephalus. Hydrocephalus is when the fluid surrounding the brain and spinal column is not draining effectively and applies pressure on the brain. Hydrocephalus can affect a person's cognitive abilities, particularly in areas of memory, problem solving, attention and concentration.

The Spina Bifida Adult Resource Team is a new initiative funded by NSW Health and commenced in August 2009. The team, which consists of a Clinical Nurse Consultant and a Senior Occupational Therapist, aims to provide clinical consultation, education, support and preventative health strategies to adults with spina bifida across NSW health services.

The need for this service was established as clinical data indicated a significant reduction in adults with spina bifida attending hospital clinics and an increase in health issues for these adults after they have left paediatric care. Evidence has shown that giving these individuals increased support to manage their condition would benefit both their health and quality of life.

The team will focus on facilitating and coordinating the effective transitions of young people with Spina Bifida from paediatric to adult health services and aim to reconnect any adult who has been lost to adult health services after moving on from paediatric services.

If you would like to contact the team you can reach them by phone or email - details below.

L to R: Clinical Nurse Consultant Joanne Brady and Occupational Therapist Jaie Thomson

Contacts

Joanne Brady
Team Leader/CNC
Ph: (02) 9472 5214
Mobile: 0418 429 960
Email: joanne.brady@northcott.com.au

Jaie Thomson
Senior Occupational Therapist
Ph: (02) 9472 5215
Mobile: 0418 408 738
Email: jaie.thomson@northcott.com.au

www.northcott.com.au

# Aims of SBART:

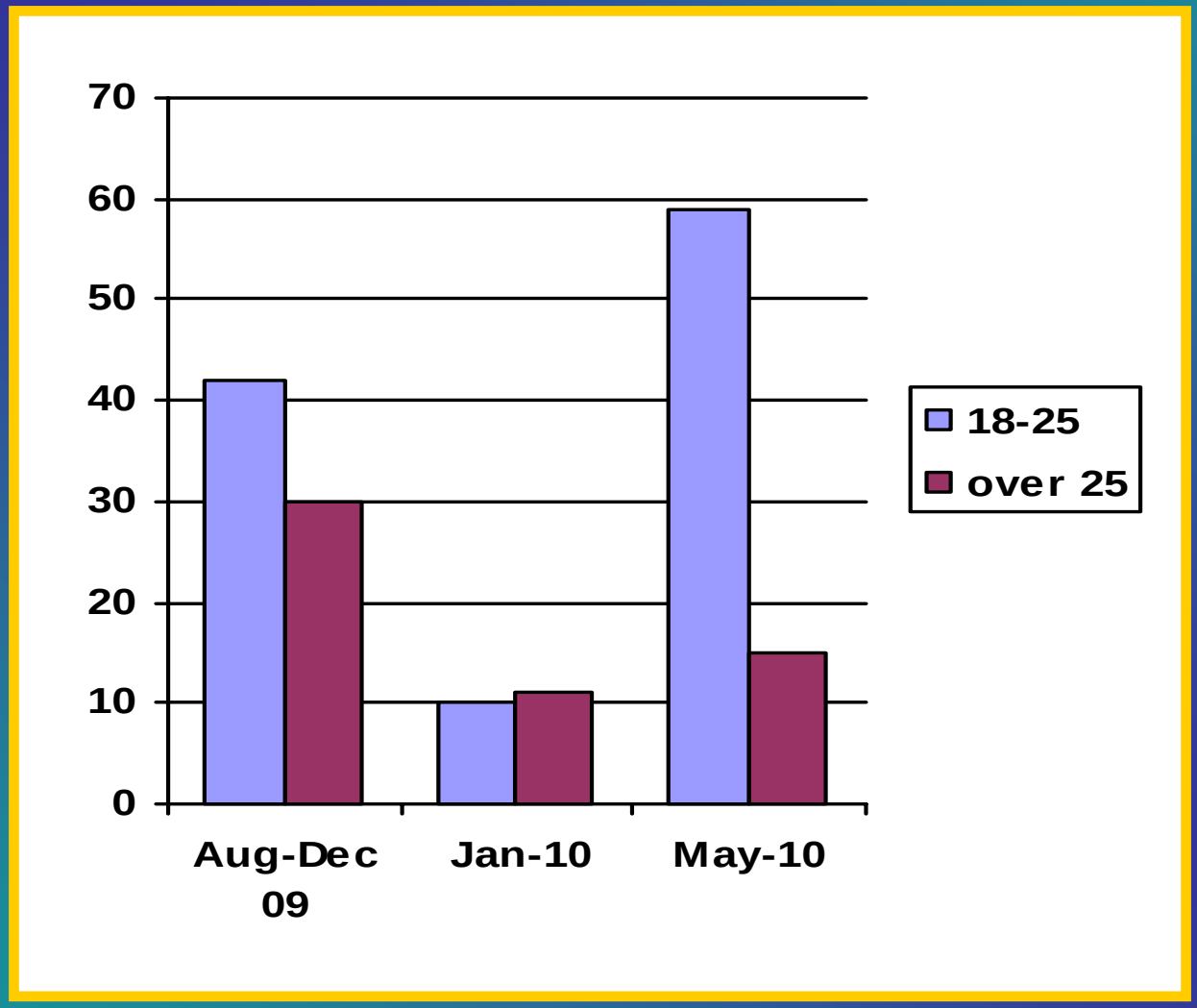
- To facilitate and coordinate effective transition of young people with neural tube defects throughout NSW

- 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



# 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

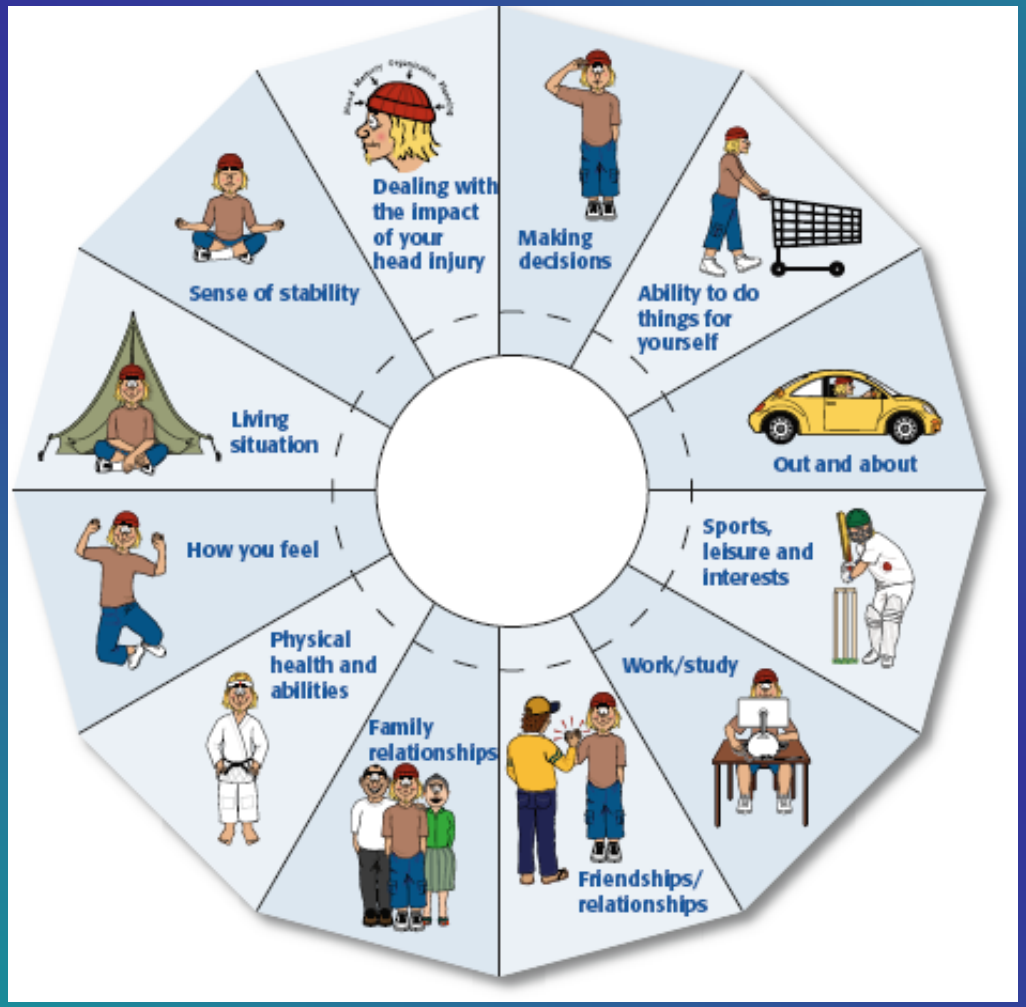
# Challenge to engage young people

# 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

# Transition Wheel:

## Adapted from the NSW North Coast Head Injury Service

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# 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,

# Graduations 2009:

## Sydney Children's and Westmead Children's Hospitals

# Acknowledgements


- **Dr Carolyn West,** paediatrician and Head of the Spina Bifida Team , The Children's Hospital at Westmead (CHW)
- **Julie Dicker**, CNC Spina Bifida, CHW
- **Joanne Brady**, Head of SBART NSW
- **Jaie Thomson,** Senior Therapist SBART
- **Members** of the NSW Spina Bifida Collaborative
- **Professor Kate Steinbeck,** Foundation Chair in Adolescent Medicine Sydney University

email: lbrodie@nsccahs.health.nsw.gov.au
phone: +61(02) 98875578

www.health.nsw.gov.au/gmct/transition

Greater Metropolitan Clinical Taskforce
Postal Address: PO Box 6314
North Ryde
NSW 2113, Australia