the children's hospital at Westmead

DISABILITY NURSING

THE NEW FRONTIER

OBJECTIVES

- Nursing Pathway
- Skills and abilities
- Project Background
- What do I bring to team and service
- Where to now?

CAREER PATHWAY

- 1989 Auburn Hospital New Graduate
- 1989 Paediatric Ward
- 1993 Karitane
- 1995 Liverpool Health Service
- 2001 Northern Sydney Health Service
- 2003 Children's Hospital Westmead

OPPORTUNITIES

- Progression to CNS level of Nursing
- Progression to CNC level
- Nurse Management
- Project Work
- University
  - Writing Distance education modules
  - Teaching
  - Student supervision

OPPORTUNITIES

- Community vs Hospital experience
- Learning Opportunities to broaden my nursing practice

SO WHAT IS THIS NEW SERVICE ALL ABOUT?

TIER 4 PILOTS

Background

- 2007 *Service Framework to improve health care for people with intellectual disabilities* - developed by NSW Department of Health and Aging, Disability and Home Care, Department of Human Services NSW in collaboration with the NSW Council for Intellectual Disability
  - Tiered model of care
  - Aims to reduce health inequalities children, adolescents and adults with ID
    - Specialised ID health services
    - Centre for clinical leadership, education and training
    - Enhancing capacity of existing services to meet their health needs
    - Improve access to quality health services

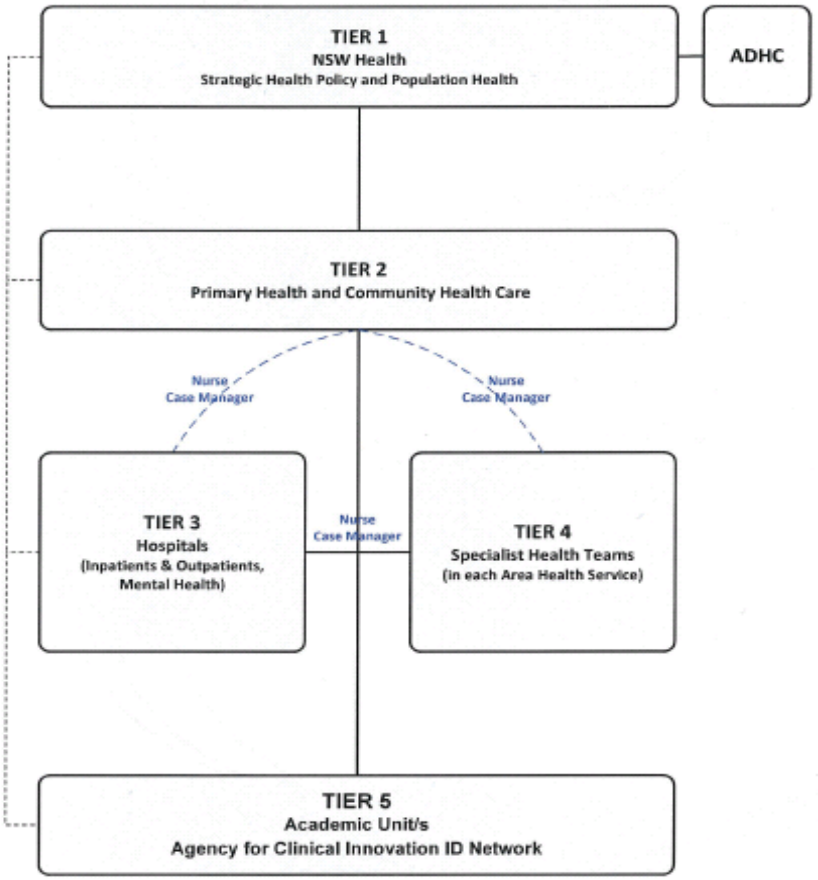
Background

- 2009 NSW Ministry of Health engaged KPMG – economic appraisal of the framework – recommended establishment of specialised services for people with intellectual disabilities and a centre for clinical leadership, research and education
- 2010-2011- NSW Budget allocated funding to Ministry of Health to improve health care for people with ID
  - Utilised to support a Network for ID within the NSW Agency for Clinical Innovation (ACI) to pilot a specialised clinical service for people with ID and complete an evaluation of these initiatives

Background

- The service framework is aligned with the State Plan, supports the State Health Plan and *Stronger Together, Better Together* direction
- This project is targeted at children, young people and adults with ID in Fairfield, Bankstown and Liverpool LGA
- High % of NESB or CALD background (44-66%)
- High unemployment and SES disadvantage
- High rates of disability 4.4% severe or profound
- Clients with ID may be known to ADHC, but how many require specialist health services is unknown

NSW Health Service Framework for People with Intellectual Disability and their Carers



TIER 1:

- NSW Government policy frameworks including State Plan, State Health Plan, Stronger Together, Better Together, Disability Action Plan, Youth Health Plan as well as interagency agreements and escalation processes
- Evaluation and quality assurance (incl. Ombudsman's Reports)
- Partnerships including FACS, ADHC, DEC, Mental Health, Drug & Alcohol, Justice Health, NGOs, Carers and Advocates

TIER 2:

- Generic health services, public and private
- GPs/ Specialists, Allied Health and Nursing
- Early detection, primary intervention and health promotion (e.g. regular health checks, universal hearing and vision checks)

TIER 3:

- Emergency presentations
- Inpatient Hospital care: pre and post admission and discharge planning
- Specialist Outpatient clinics
- Mental Health services

TIER 4:

- Service Type: Multidisciplinary Specialist Health Resource Team/s
- Age Groups: Paediatric, Adolescent, Youth, Adult & Geriatric
- Target Group: People with developmental/ intellectual disability & their carers
- Functions: Diagnosis and Assessment; ongoing medical management of complex health needs in shared care with GPs and other clinicians; liaison, support, collaboration with other services and agencies; leadership and capacity building for other Tiers; health promotion; consultation for acute hospital presentations; staff education, training, carer support programs and research; quality assurance, clinical database management and evaluation; escalation processes
- Medical: Developmental Paediatrician, Psychiatrist, Physician (incl. Rehabilitation, GPs with interest in ID) and other Specialists (incl. Neurologist, Geneticist, Dentist & Trainee Registrars
- Nursing: Clinical Nurse Consultant
- Allied Health: Social Worker, Psychologist/ Neuropsychologist, Dietitian, Occupational Therapist, Physiotherapist, Speech Pathologist

TIER 5:

- Sharing multidisciplinary expertise across resources to improve patient care
- Facilitating the development of Tier 4 units and support early intervention, prevention and health promotion across all age groups
- Supporting evidence-based and cost-effective models to improve access to specialised and mainstream services (incl. acute hospital care) across NSW
- Facilitating strong links with other services and agencies such as ADHC, DEC, Mental Health, GP Networks, NSW Kids, Justice Health and the Academic Units
- Facilitating collaborative clinical research, staff education and development of patient resources
- Aligning with National Disability Strategy and the NSW Implementation Plan, and the United Nations Convention on the rights of people with Disabilities

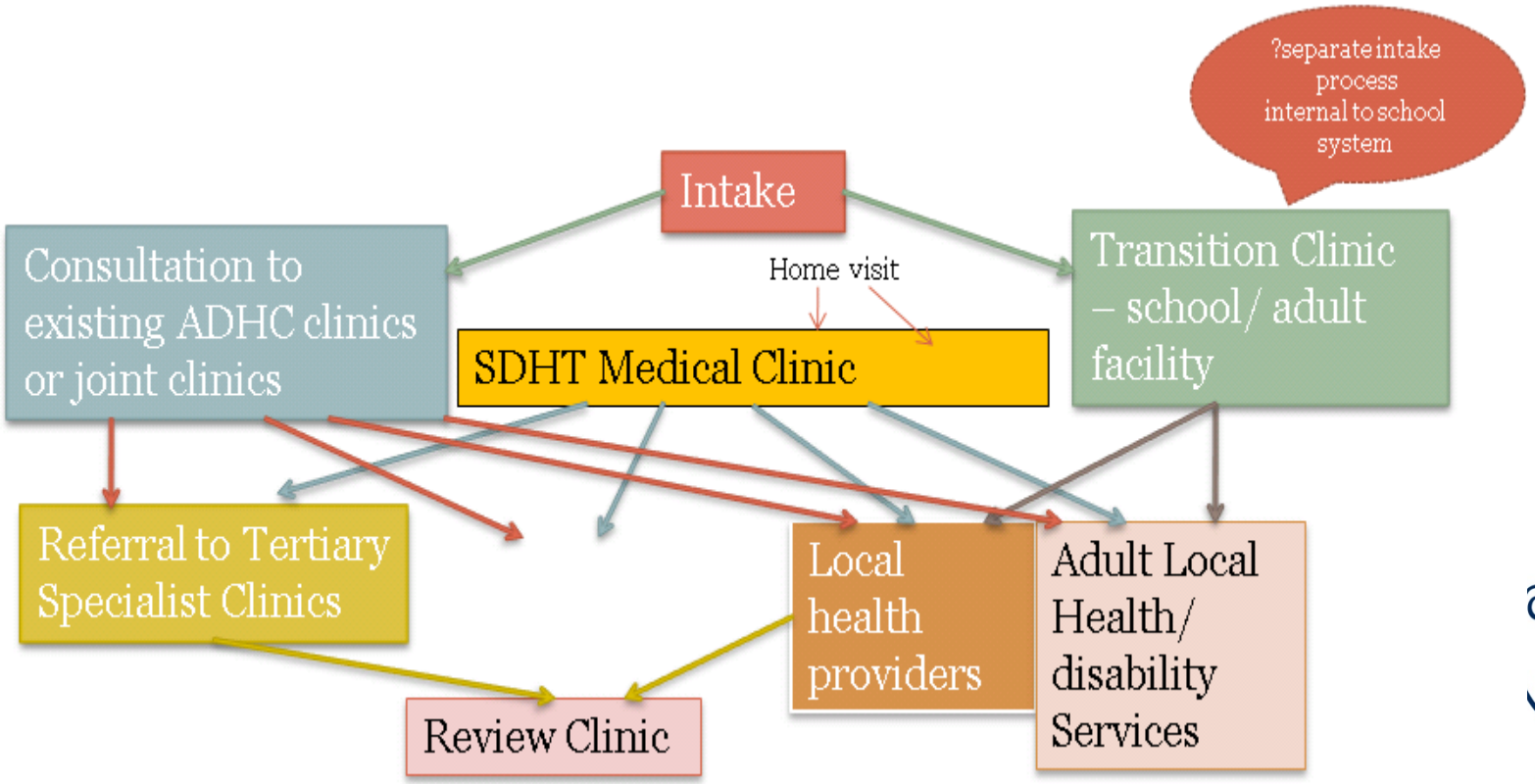
Specialist Disability Health Team

- Core clinical team
  - Dr Natalie Ong
    Paediatrician (Thurs/Fri)
  - Gail Tomsic
    Clinical Nurse Consultant (Wed/Thurs/Fri)
  - Ekta Balu
    Social Worker (Mon/Wed/Fri)
  - Katherine Barlow
    Administration Assistant (Tues/Thurs/Fri)

PROJECT AIMS AND OBJECTIVES

- Identify Current services and pathways
  - Streamline referral pathways
  - Improved care coordination
- Access to specialist health services
  - Collaborate with existing govt and non-govt programmes
  - Development of new models of tertiary health care - better meet the needs of people with ID
  - Capacity building
    - Provision of clinical health services and education
      - Identification of health issues and appropriate referral
      - Enhancement of disability focused clinical skills with regards to health
      - Identify existing and extend professional and interagency networks
      - Development of support service and carer networks eg Health Forums

SERVICE MODEL



REFERRAL CRITERIA

- ID
- Age 6-16
- Lives in Liverpool, Fairfield, Bankstown LGA
- Anyone can refer
- School referrals – school principal/ counsellor to do 'needs assessment'?
- Complex medical problem not addressed or currently addressed but gaps or access issues OR 2nd opinion
- GP referral letter required

TYPES OF CLINICS

- **Medical Clinic** – carer/family, ADHC/ NGO clinician/ case manager +/- medical specialist ? Parallel clinic
- **School Medical** – carer/ family, school staff, ADHC clinician/ CM/ CNC ? Parallel dental, psychiatry, nutrition, sports medicine
- **School Transition** – same as SMC but also transition coordinator, adult physician
- **Home Clinic** – ADHC/ NGO
- **Tertiary Clinics** – CNC or SW or ADHC CM to accompany
- If interpreter required – info from intake

OUTCOMES

- Assessment of health, educational/ vocational and psycho-social issues of client and family and provision of recommendations

  (ADHC CM/ key therapist present)
- Referral to tertiary or support/ therapy services
- Refer back to GP or Paediatrician ongoing support

KEY TARGET AREAS

- Obesity and Weight Management
- Gynaecological issues
- Behavioural Management
- Sports Medicine and Physical Activity
- Oral and Dental Hygiene
- Adolescent Issues
- Transitioning

CASE STUDY

- **CLIENT:** James a 18 year old Intellectually disabled boy with Cerebral Palsy
- **REFERRED BY:** Park House Counselling Psychologist
- **REASON:** Transitioning and Respite
- **ISSUES:**
  - ***Obsessive Compulsive Behaviour*** Playing with rope for hours & hours, worried about people getting hurt
  - ***Risk taking behaviour*** Jumps out of cars, touch hot stove; eats out of bins
  - ***Unusual Body Movements*** hand flicking, head turning, grunting
- **SCHOOL:** Bossley Park High School
- **SOCIAL HISTORY:** James lives with his Mother and two siblings. Parents are divorced. James still has contact with father. Father and his family have psychiatric history of suicide ideation and depression.

SERVICE INTERVENTION

- **INTAKE:** Telephone interview of mum. Contact main services to access reports eg School, Paediatrician, Allied Health etc.
- Parents complete a questionnaire and Developmental Behavioural Checklist prior to appointment
- **APPOINTMENTS**:
  - Meet with mum and James to get a comprehensive health history
  - Next joint clinic with Park House Team
    - ADOS assessment
    - Psychiatric Assessment
    - Transitioning Clinic

OUTCOME

- Transition Co-ordinator following up on available services for transitioning such as counselling and psychiatric services
- Still to meet with Transition Doctor on 16th November 2012
- Diagnosis with tourettes syndrome and starting medication
- Looking at Respite options
- Expediting referral to ADHC
- Advocating for appropriate post school option program as James continually expresses his desire to be a farmer.

HOW HAS MY EXPERIENCES HELPED?

Setting up Service

- History of setting up new services as a nursing level
- History with Hospital
  - Contacts in IT
  - Sourcing Equipment for clinic
  - Contacting partners
  - Promoting Service to local Paediatric services
  - Forming partnerships

Setting up Service

- Networking with ADHC especially linking with ADHC CNC
- Linking with already established networks for CNC's in tertiary settings
- Develop ID friendly resources and education packages

Reporting

- Setting up NAPOOS
- Setting up EMR

What helped

- Positions held
- Experience as a NUM
- Experience working as a Community Paediatric CNC with SWSAHS
- Experience working at an AREA level within NSAHS

LESSONS LEARNT

- Good contacts
- Established working relationships
- Respect of Peers
- Embrace learning opportunities
- Having an open mind and an attitude that you can use every situation as a learning experience