



Specialist Intellectual Disability Health Servicesand Beyond

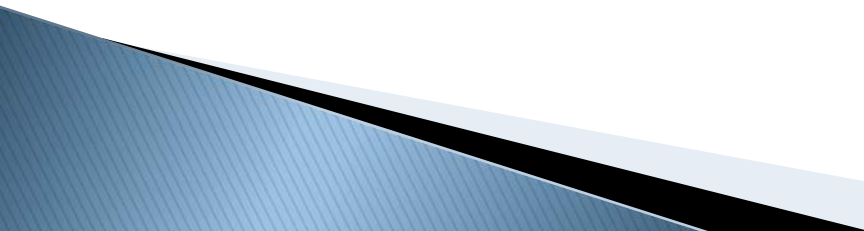
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NSW Framework for Health Services for People with Intellectual Disability

- ▶ Aim – reduce health inequalities for children, adolescents and adults with intellectual disability by:
 - Establishing specialised intellectual disability health services
 - Creating a centre for clinical leadership, education and training
 - Enhancing the capacity of the generic health system to meet the needs of people with intellectual disability
 - Improving access to health services

Service Framework Tiered Model

- ▶ Tier 1 – Strategic health policy – promote health and wellbeing in the community
 - ▶ Tier 2 – Primary and Community Health Services
 - ▶ Tier 3 – Acute health services – emergency, inpatient services
 - ▶ **Tier 4 – Specialised intellectual disability health services**
 - ▶ Tier 5 – Clinical leadership, education and research
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Specialised Intellectual Disability Health Services

- ▶ Existing services e.g.
 - Diagnostic and Assessment Teams
 - NSW Developmental Disability Health Unit
 - Clinics at Concord and Westmead Hospitals
 - Specialist clinics – e.g epilepsy, dysphagia, psychiatry, neuropsychiatry
- ▶ Three new clinical pilot multidisciplinary services funded by NSW Health for 3 years
 - Northern Sydney
 - Illawarra–Shoalhaven
 - Fairfield (Paediatric)
 - External evaluation of all pilots by KPMG

Northern Intellectual Disability Health

- ▶ Joint project of Northern Sydney Local Health District (NSLHD) and Centre for Disability Studies(CDS)
 - NSLHD funds and oversees project
 - CDS delivers clinical services
 - CDS
 - Education, research and clinical services
 - Affiliated with University of Sydney Medical School
- ▶ NGO Model
- ▶ Based at Cremorne Community Health Centre

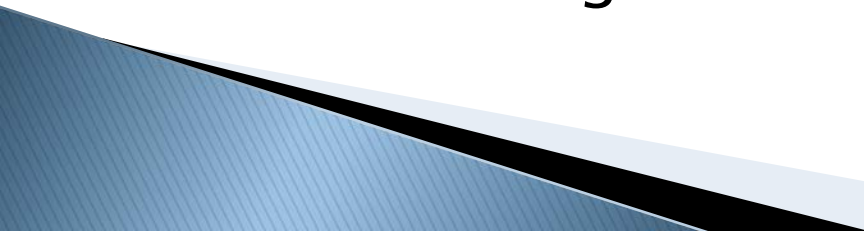
Areas of focus of NIDH

- ▶ School age children / School clinics
- ▶ Transition clinics with paediatric and adult clinicians and transition coordinator involved
- ▶ Comprehensive health assessments
 - Assess current concerns, general health, mental health and behaviour, screening, preventive health, medication review
- ▶ Psychology counselling and therapy
- ▶ Health Promotion – nutrition, physical activity
- ▶ Group sessions
- ▶ Education – clinicians, undergraduates, disability support staff
- ▶ Seminars for families

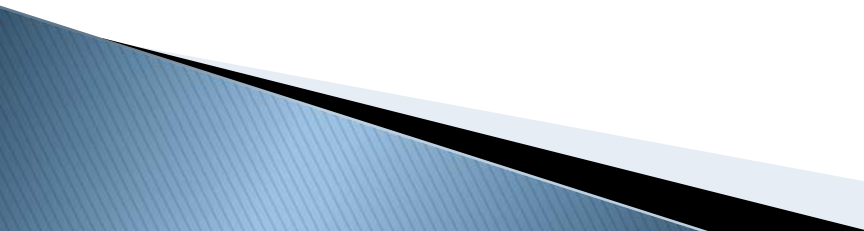
Clinical services

- ▶ Multidisciplinary team
- ▶ Clinics
 - Paediatric, adult medical assessment
 - Paediatric, adult psychology
 - Psychiatry
 - School
 - Transition
 - Nutrition
- ▶ Health care planning, coordination and referral with CNC input
- ▶ Detailed reports to individuals/families, general practitioners, support staff etc.

Other activities

- ▶ Referral pathways e.g.
 - Special needs dental service
 - Exercise physiologist
 - ▶ Group CBT for adults with mild intellectual disability and anxiety
 - ▶ Parent support group with CBT to reduce parental stress
 - ▶ Seminars /workshops for families, disability support staff
 - Physical activity, ageing and health, medication management
 - ▶ Undergraduate teaching – medicine, dentistry, pharmacy
 - ▶ GP and GP registrar workshops
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Client characteristics

- ▶ Majority live with family
 - ▶ Just under half have behaviours of concern
 - ▶ Just under half have mental health conditions
 - ▶ About quarter have epilepsy
 - ▶ More than a third have hearing and / or vision impairment
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Identification of new conditions

- ▶ Comprehensive health review and assessment identified:
 - New diagnoses/ health risk factors in just over one fifth of those seen – e.g.
 - Dementia
 - Anxiety
 - Anaemia
 - Gastro–oesophageal reflux disease
 - High cholesterol
 - Iron deficiency
- Investigations/ referrals/ recommendations for management

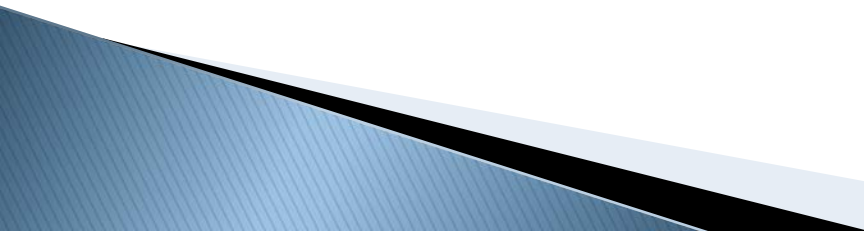
Preventive health

- ▶ Identified through comprehensive health assessment
 - Only one third had up to date dental checks
 - One third had up to date hearing assessments as recommended by standard guidelines
 - Just under half had vision/eye checks as recommended by standard guidelines
 - One third were not fully immunised according to National Guidelines
- ▶ Referrals made
- ▶ Recommendations to general practitioners

NSW Developmental Disability Health Unit

- ▶ Funded by NSW Health
- ▶ Operated by Centre for Disability Studies
- ▶ At Royal Rehab
- ▶ State wide
 - Across Sydney metro, regional and rural areas
 - e.g. South Western Sydney, Blue Mountains, Central Coast, Lithgow, Bowral, Griffith
- ▶ Adolescents and adults ≥ 16 years
- ▶ Medical assessment and psychology clinics
- ▶ Dental assessments
- ▶ Some Outreach clinics
- ▶ Specialised clinics for people with Down, Fragile X or Cornelia de Lange syndromes

Specialised health teams

- ▶ Different models of service to address local needs, but
 - Provide specialised multidisciplinary health assessments and interventions
 - ▶ Few if any outside metropolitan areas
 - ▶ Small number of metro teams see people from outside metro areas
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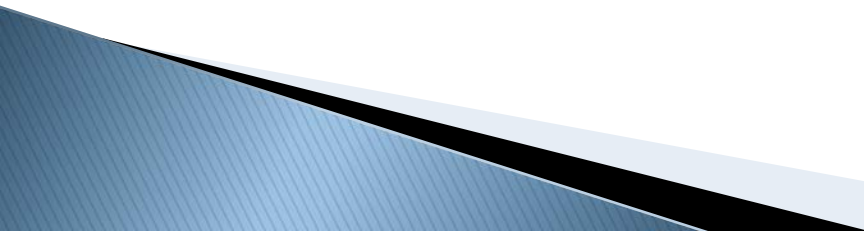


Where to now?

Future development of specialised health teams

- ▶ Continue specialised assessment, consultation
- ▶ Facilitate integration of health care and disability support
- ▶ Further increase capacity in main health system
- ▶ Jointly develop and evaluate models of care and evidence based health interventions
- ▶ Impact of NDIS
 - Working with disability services
 - Decline of ADHC funded services
 - Quality of health care provision
 - NDIS providers of allied health services?

Increasing capacity in health system

- ▶ Referral pathways
 - ▶ Guidelines, Resources
 - ▶ Education
 - ▶ Joint consultations / case discussion
 - ▶ Shared care models
 - ▶ Peer support, clinical supervision
 - ▶ Hub and spoke
 - Community of Practice
 - Outreach clinics combined with above to increase capacity in regional, rural areas
 - Telehealth consultations
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Much done, more to do

