Specialist Intellectual Disability Health Services .....and Beyond

SeetaDurvasula
seeta.durvasula@sydney.edu.au
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
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
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
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 $\geq 16$ 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
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
Much done, more to do