

a note from David Dossetor...



Better Health Services for People with Intellectual Disability in NSW: The Agency of Clinical Innovation Disability Network.

Associate Professor David Dossetor, Child Psychiatrist with a special interest in Intellectual Disability and Autism, Area Director for Mental Health, The Children's Hospital at Westmead.

This article describes the health needs for people with intellectual disability in Australia, and describes the developments in NSW to establish a health framework for better health services for people with intellectual disability. Brief comparison is made to the initiatives to tackle the health disadvantage of this population in the UK.

The context and the evidence of health need in people with intellectual disability

There are approximately 200,000 people in Australia whose main disabling condition is intellectual and developmental disorders, and in NSW there are 65,000 or 0.9% of the population and this corresponds with surveys which report 1% of population need assistance with basic daily living activities: self-care, mobility, and verbal communication. Such people require lifelong support and assistance, and the levels of support have been defined as intermittent, limited or high/pervasive support needs. In NSW of those of adult age it has been "guestimated" that 0.2% or 15,000, with intellectual disability also have complex health needs, but this could be an underestimate.

There is good evidence that people with intellectual disability are disadvantaged in their health status compared with a mainstream population. People with intellectual disability are characterised by communication difficulties, poor understanding of their everyday and special health needs and poor procedures for the delivery of health services. They have poorer outcomes and have more difficulty in obtaining the necessary health services (NSW Health: Service Framework to improve the health care of people with intellectual disability, 2012). Whereas the mean life expectancy of men and women in the general population is 78.7 and 83.5 years respectively, for people with mild, moderate and severe intellectual disability mean life expectancy are 74, 67 and 58 years (Bittles et al, 2000). This data derives from Western Australia, which is the only state to have an intellectual disability register, which is a key tool to evaluate the health needs and outcomes.

Although there have been substantial increases in life expectancy across the spectrum of intellectual disability, health services are ill prepared for the special health needs of this growing ageing population. Further the NSW Ombudsman (McKenzie K, Reviewing the deaths of people with disability in care, 2011. www.ombo.nsw.gov.au) has reported on the number of deaths of people with intellectual disability in boarding houses, accommodation provided by Non-Government Organisations and by NSW Disability Services, often from readily preventable and treatable problems such as recurrent respiratory infection and aspiration pneumonia in the context of swallowing problems. Also reported were the co-existing chronic health problems including incontinence, dysphagia (swallowing or drinking problems), epilepsy, constipation, weight concerns, gastro oesophageal reflux and helico bacteria infection, osteoporosis, diabetes, hypertension and asthma. Most had other disabilities such as physical disability (eg Cerebral Palsy) sensory impairment (almost half, mainly sight impairment) and psychiatric disability (almost a quarter, mainly psychosis). Most also required a substitute decision-maker or person responsible for providing consent to mental or dental treatment on their behalf.

Contemporary research indicates that people with intellectual disability experience a high prevalence of significant med-

ical and mental health problems as well as conditions often being unrecognised, misdiagnosed and poorly managed (Lennox & Kerr, 1997). For example Helen Beange the NSW medical practitioner and advocate found higher rates of medical disorders in an unselected or random sample of people with ID aged 20-50 living in North Shore of Sydney (Beange et al, 1995) (see table). Only 15% had been seen as patients, 10% had visited the Health Promotion Clinic for people with intellectual disability at Royal North Shore Hospital, and 5% had presented because of symptoms. Despite a mean of 5.4 health problems per patient, when interviewed 65% reported no symptoms and 24% of carers said there were no problems.

Accordingly, even those without recognised problems still need a thorough health check-up. People with intellectual disability across all ages are at greater risk of developing mental illness: 40% of children require treatment of mental health problems and as many as 50% of adults and 60% of older people with intellectual disability. Studies show that people with mild and borderline intellectual disability are vastly over-represented in the criminal justice system (35%) and have high rates of alcohol and drug problems (Kenny, 2006).

Table of Rates Medical Disorders	
Medical Disorder	Rate in %
Dental	86
Ocular	68
Dietry	57
Neurological	53
(Incl Epilepsy)	29
Skin	96
ENT	40
(inc deafness)	25
Orthopaedic	35
Endocrine	29
Cardiovascular	24
Psychiatric	24
Gastrointestinal	17
Haemopoetic	12
Iatrogenic	11
Renal	11
Respiratory	10

Table of Summary of Health Impairments	
Type of Problem	Mean #/person
Major Problems	2.5
Minor Problems	2.9
Total Problems	5.4
Not previously diagnosed	2.3
Not adequately managed	2.7
Specialist care needed	4.0

(Beange et al, 1995)

Note: *Iatrogenic means problems caused by medical intervention

**A major problem was a health problem that significantly added to health handicap or performance.

As life span is increasing the disease patterns and risk factors for diseases are increasing with increasing rates of cancer, coronary heart disease, diabetes, thyroid disease, arthritis, falls, and early dementia. In addition, people with intellectual disability do not use preventative health care and health promotion programs to the same extent as the general population?. Many of the causes of intellectual disability are also complex with associated problems. 25% of people presenting to health clinics are taking psychotropic medications for behaviour and psychiatric disturbances, often several at a time.

Family carers are the major contributors to the care and support of people with intellectual disability, so their health is as important as for those dependent on them. Yet this population of carers have marked increased limiting health problems compared to the general population, such as depression (4 times more common), back problems and stress related illnesses. Numerous surveys have found that both general practitioners and other specialists lack confidence in meeting the health needs of people with intellectual disability and believe current training is inadequate (Cook & Lennox, 2000). This also applies to undergraduate medical and allied health training or post graduate training for doctors and nurses (Lennox & Diggins, 1999).

The NSW Health initiative to develop a framework for better health for people with intellectual disability

How was the framework developed?

The deinstitutionalisation and the demedicalisation of the care of people with intellectual disability in the 80s, left a government led service that was inadequate for the support of people with intellectual disability in the community, and a lack of investment in a specialist health system to support them (Parmenter, 1988). Further, there has been a lack of collaboration between the two underfunded services. In this context NSW Department of Health and ADHC commissioned a draft service framework to improve the health care for people with intellectual disability in 2007 and in 2009 I was a member of the advisory group to consider various options to improve health services. This in turn led to the Consultancy report by KPMG for NSW Health: "Analysis of costs and benefits of specialised intellectual disability health services and enhanced clinical leadership" (See Below).

NSW Health introduced a Service Framework of 5 tiers:

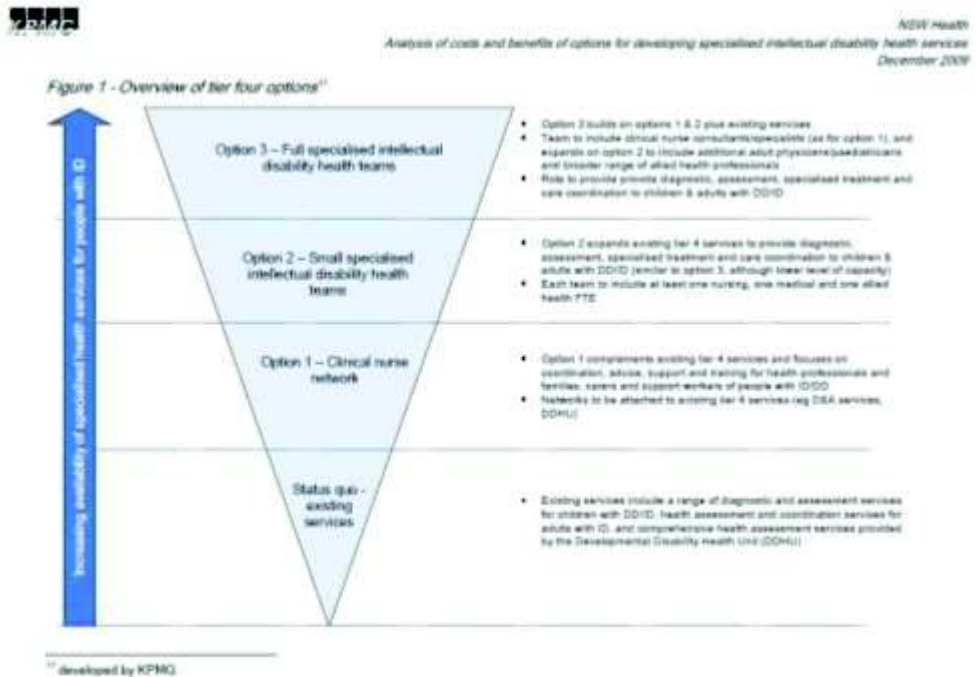
- Tier 1.** Strategic health policy and population health;
- Tier 2.** Primary health and community health care;
- Tier 3.** Acute health care services;
- Tier 4.** Specialised intellectual disability

mated cost of a sample of clinical cases that illustrated the additional cost incurred through inadequate or inefficient health and mental health provision for those with complex and special needs. They estimated the costs that might be saved through the provision of multidisciplinary expertise, particularly from saving lengthy hospitalisation or through maintaining care in the family as opposed to long term community care, not to mention the improved health and quality of life which was not costed. They also looked at costing different specialist service models to improve tier 4 specialised health services:

Three options for enhancing tier 4 were costed to provide a service throughout the state:

1. A Clinical Nurse Network:
 - a. one CNC per area health service: \$1.364M.
 - b. one CNC/CNS per 450,000 population: \$4.575M.
2. Small intellectual disability teams: \$14.488M.
3. Full intellectual disability health teams: \$37.146M.

It was felt that having specialist services



health services which provide specialised assessment, intervention and treatment for people with intellectual disability and complex health needs and facilities development of the health systems capacity to meet the needs of people with intellectual disability generally;

Tier 5. State-wide clinical leadership, research, education and training.

in some area health services that provided outreach to others was unacceptable, but that was before this number was increased by breaking up area health services into the 15 local health districts (LHDs) that we now have.

They also estimated recurrent costs of implementing tier 5: \$0.287M to support a clinical leadership network and \$1.26M to fund 3 university chairs in intellectual

In the absence of epidemiological and health economic data, KPMG did an esti-

disability medicine, nursing and allied health.

What does the framework look like?

This report was followed by NSW Health establishing and funding in 2011 the **Disability Network of the Agency of Clinical Innovation (ACI)**, and three pilot specialised health services for people with intellectual disability of \$450,000 each. The ACI was established in 2010 to drive continuous improvement in the way care is provided to patients in NSW health system and supports 29 different clinical networks. The ACI is one of the 6 pillars of reform recommended by the Garling Inquiry into Acute Care Services in NSW Public Hospitals (2008). Its core aims are: promoting innovation, giving consumers a say and using evidence. The other 5 pillars are: 1. The Clinical Excellence Commission with an overview of clinical governance, 2. The Bureau of Health Information to provide information on activity and outcomes, 3. the Health Education, and Training Institute (HETI) managing training not just for clinicians, undergraduates and vocational training but also non-clinical leadership and management, 4. NSW Kids and Families, and 5. Rural Health. The 3 3-year pilot specialist health services are:

1. **The Metro-Regional ID network (MRID.net)** based at St Georges Hospital in Kogarah, which provides local and regional multidisciplinary outreach clinic to the Illawarra and other parts of NSW.
2. **The Fairfield Specialist Intellectual Disability Health Service** is an community based team of the Children’s Hospital at Westmead, co-located with disability services, extends its service to Western Sydney, with a focus on young people with intellectual disability facing transition to adult health services and considers added complexity from multicultural diversity.
3. **North Sydney Intellectual Disability Health Team** is based in Cremorne, which promotes a specialised General Practitioner service run by the Centre for Disability Studies. Its outreach will extend to the Central Coast LHD. The 3 pilot projects have oversight and support from steering committees but also meet to compare processes and report to the ACI Disability Network through the Models of Care Subcommittee. These pilot projects are developing formative evaluation processes. KPMG have also been appointed to provide an external evaluation of the benefits of these pilot projects and the Intellectual Disability Network of the ACI which will take place between October 2012 and April 2015.

The ACI Disability Network was founded in 2011 under the chairmanship of Professor Les White, the Chief Paediatrician of NSW and a parent of a young person with intellectual disability and initial scoping sessions encouraged attendance of all interested clinicians, parents, carers and advocates for people with an intellectual disability, representation from NSW Health, Disability Services Partners, Non-Government organisations, and anyone with an interest in improving the services.

These initial discussions led to a framework of 4 Subcommittees whose two chairmen are also members of the Executive Steering Committee, along with other senior stakeholders. The Executive Steering Committee is co-chaired by Les White and Maria Heaton, a parent of a child with intellectual disability and winner of the parent of the year award 2012; all committees are supported by the network manager, Tracey Szanto. Each subcommittee has now been asked to define strategic aims for the next 6 and 12 months.

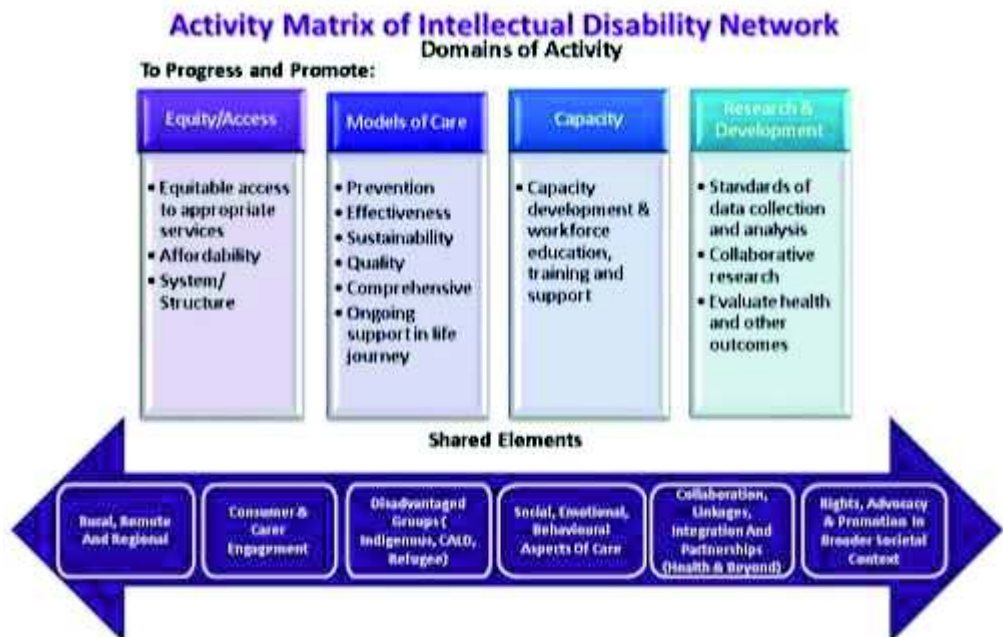
The following are a sample of the initiatives of each of the **subcommittees**:

- **Access and Equity** are drafting a survey to identify specialist health services and gaps.
- **Research and Development** are drafting a survey of current research and have a project looking at linking data systems between **Health and Disability Services** to understand and monitor health usage by people with an intellectual disability.
- **Workforce and Capacity** is mapping current workforce development processes and developing strategies to change attitudes and improve communication of health employees around people with intellectual disability.

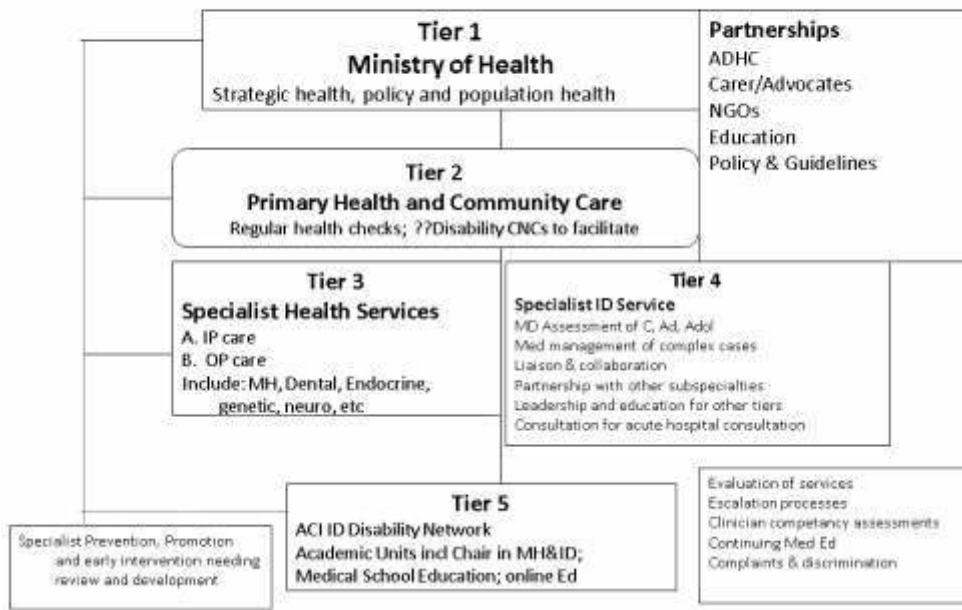
- **Models of Care**, of which I am co-chair with Dr. Robert Leitner, are working on how to better understand the different components of the tiered structure of services and what each tier is doing to consider the special needs of people with an intellectual disability and how to improve the interaction between each tier. This involves holding forums on different components of the services, such as Corrective Services and Forensic Mental Health Services Initiatives, and in the near future General Practice and Medicare Locals.

It is also important to help people with an intellectual disability and their carers and advocates to better understand and use the health system. We have produced a draft document on the “Responsibilities and Rights for Carers and Advocates of People with an Intellectual Disability to enable equity of access to Health Services in NSW” which is reproduced later in the newsletter as part of the consultation process, and “Pathways to Care for Children and Adolescents with Intellectual Disability Challenging Behaviour and Mental Health Problems” which we shall present in an edition later this year.

The network had a successful first annual half day workshop on November 15, 2012, which enabled a wider participation particularly of consumers and carers to how different components of the network are developing. Prof Eric Emerson of Lancaster and Sydney Universities gave a notable keynote presentation on “Improving health and lives: The Learning Disabilities Observatory” on how the same issues of health inequality and access to health care are being tackled in UK. On a background of socially inclusive intellectual disability specific policies, increasingly



NSW Service Framework for People with ID and their carers



ambitious legislation regarding disability equality and accumulating evidence of poorer health of people with intellectual disability and institutional discrimination in health care systems, the UK government set up the National Specialist Public Health Observatory (LDO) in 2010 with 1 million pounds annual budget for 3 years (www.improvinghealthandlives.org.uk).

The LDO has established important partnerships, and has provided an evidence based approach to examining the access of people with intellectual disability to health care. The LDO has summarised the evidence on current health status and the multifactorial determinants to health. It has worked to make the risk factors and the service usage data localised. With General Practice data extracts they have charted a rise in general health check-up for people with intellectual disability, with details of investigations performed, whether they have a stable home, are in employment, and receive social and or community care. The LDO has audited the extent to which each local administrative district have made “reasonable adjustments” (legal terminology for health service adaptations for people with intellectual disability) to enable access to services including dental, ophthalmology services and cancer screening. The LDO has developed audit tools for Autism health and employment services and disseminated a Royal College of Psychiatry Report on practitioners enabling people with mild intellectual disability and mental health problems to access mental healthcare services. The LDO has reported on rates of unnecessary admissions to hospital due to inadequate management of chronic conditions in the community

and reviewed the quality of care of in-patient services for challenging behaviour.

Currently, there is a further confidential enquiry into deaths of people with learning difficulties. The LDO is promoting positive messages and information on the positive contributions people with an intellectual disability can and do make to our communities and the barriers to that participation (Fulfilling Potential: building a deeper understanding of disability in UK today, 2013). The LDO has demonstrated that major health institutional change can be achieved with political will, serious academic leadership and funding, and the strength of the National Health Service of UK (NHS) data systems.

What is the future for the Framework for Health Services for people with Intellectual Disability?

Compared with the NHS, I think the ACI Disability Network of clinicians and services and Specialist Health Pilot Studies start from a weaker service and academic base for people with intellectual disability. However, there is a wealth of motivation, concern and professionalism to make a start to the institutional change needed in NSW.

I am impressed with the extent to which I see strong advocacy leading to awareness raising of these health needs for example in the accounts of the pilot projects efforts to get a better deal for their patients from the broader health and disability systems. There is nothing like

experience of a successful service provided to make it happen again.

I am convinced that change requires a strong voice and partnership with consumers and advocates. The health service is a complex system and I feel it is important to educate consumers and their carers and advocates about these service systems and how to get the best out of this network of clinicians. Evidently data is important as it speaks directly to managers on the effectiveness of a service but currently our data systems are weak on information about people with an intellectual disability, especially across funding structures, state, federal, private, NGOs.

We shall need better training and multi-disciplinary involvement within mainstream services on people with an intellectual disability. It is my view that two other important drivers of change are clinical research and human moral, ethical and legal development (Evans et al, 2012).

As medicine advances, so specialist academic expertise needs to be nurtured to keep abreast of scientific progress which in turn needs to promote the dissemination of advances of knowledge to mainstream services. Despite current financial caution in all governments, there is a growing recognition of the human rights of people with intellectual disability and a political will to make progress in our health and welfare institutions. Hopefully the Disability Network and Pilot Projects will build evidence of their impact and worth and guide future political, clinical and research direction and investment in NSW. ●

Postscript: Opportunity remains for people to contribute to these potential developments and the ACI Disability Network. Issues of mortality and unnecessary fore-shortened life expectancy are emotive concerns. However I feel that chronic health and mental health problems are central to improving the quality of life of people with intellectual disability. In a subsequent article I shall return to report on the developments in NSW for mental health and wellbeing.

References

Please see www.schoolink.chw.edu.au for a full list of references from this article.

