

Service Framework to Improve the Health Care of People with Intellectual Disability

July 2012



Health

NSW MINISTRY OF HEALTH

73 Miller Street

NORTH SYDNEY NSW 2060

Tel. (02) 9391 9000

Fax. (02) 9391 9101

TTY. (02) 9391 9900

www.health.nsw.gov.au

Produced by:

Inter Government and Funding Strategies & Integrated Care

NSW Ministry of Health

Tel. (02) 9391 9240

Fax. (02) 9424 5816

Email. csumm@doh.health.nsw.gov.au

This work is copyright. It may be reproduced in whole or in part for study or training purposes subject to the inclusion of an acknowledgement of the source.

It may not be reproduced for commercial usage or sale. Reproduction for purposes other than those indicated above requires written permission from the NSW Ministry of Health.

© NSW Ministry of Health 2012

SHPN (PHCP) 120223

ISBN 978-1-74187-737-3

Further copies of this document can be downloaded from the
NSW Health website www.health.nsw.gov.au

July 2012

Contents

Executive Summary	2	The Service Framework	12
Introduction	4	Purpose	
Background	6	Key Objectives	
The definition of Intellectual Disability		Key Outcome of the Services Framework	
Prevalence		Tiered Model	
Legislative and Policy Framework		Governance and Reporting	18
Health care needs of people with Intellectual disability		Performance Indicators and evaluation	19
Health Risks for people with intellectual disability		References.....	20
Current Health Services for people with Intellectual Disability			

The *Service Framework to improve health care of people with intellectual disability* is NSW Health's response to:

- promote a broader understanding of the health needs of people with intellectual disability and their right to effective services and care; and
- improve the quality, range, consistency, accessibility and integration of services necessary to meet the health needs of people with intellectual disability

Executive Summary

People with intellectual disability have poorer health outcomes and greater difficulty obtaining health services in comparison with the general population. They experience a high prevalence of significant medical problems and their health conditions are often unrecognised, misdiagnosed and poorly managed.

The co-existence of multiple and complex health needs impacts on the ability of generic services in primary and secondary care to effectively assess identify and meet the range of needs. Health co-ordination and specialised assessment, interventions and support for primary and secondary care health services are essential.

In 2009, there were 196,047 people in Australia whose main disabling condition was an *intellectual and developmental disorders*. In NSW, there were 65,130 people (0.9% of the population) whose main disabling condition was *intellectual and developmental disorders*. This corresponds with other surveys which report that about one per cent of the total population the need assistance with basic daily living activities, most frequently: self-care, mobility and verbal communication. (ABS 2010, ABS 2012 & Wen 1997)

The target population who would visit specialised intellectual disability health services are those people who have an intellectual disability and complex health needs.

The *Service Framework* aims to 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 existing services to meet their health needs

- improving access to quality health care services.

The Service Framework is based on a tiered model of care.

- Tier 1 strategic health policy promotes better health and well being and focuses on the entire community, including people with intellectual disability.
- Tier 2 Primary and community health services are the first point of contact for most people seeking health care and from where referrals to further health care are made.
- Tier 3 Acute health care services deal with critical or emergency health care needs of patients.
- Tier 4 Specialised intellectual disability health services staffed with experience multidisciplinary clinical teams would be able to better assess, treat and manage the health needs of people with intellectual disability. At the same time these services could provide advice to general primary and secondary health services.
- Tier 5 Clinical leadership, research and education are essential elements for enhancing the capacity of primary and secondary health services to care for and manage the health of people with intellectual disability. A centre of excellence would also provide a focal point for improved clinical practice based of robust evidence through the development of clinical practice and clinical education programs.

The Service Framework would deliver a range of benefits to people with intellectual disability and to health care professionals.

People with intellectual disability, their families and carers:

- have health problems identified in a timely way
- have timely access to the range of health services they require
- are assisted by health professionals who understand and know how to respond to their particular needs
- have a healthier lifestyle, and
- are healthier.

Health care providers:

- understand the needs of people with intellectual disability and their carers
- know how to communicate effectively with people who have an intellectual disability and adapt their ways of working to respond to their needs
- recognise the contribution of carers and support their health care needs
- are proactive in promoting the health and wellbeing of people with intellectual disability and their carers
- promote and facilitate interagency co-ordination and collaboration.

Introduction

This *Service Framework* has been developed by NSW Health and the Department of Family and Community Services – Ageing, Disability and Home Care in collaboration with the NSW Council for Intellectual disability. An extensive consultation with stakeholders has also helped to shape the *Service Framework*.

Significant changes to legislation and disability service provision over the last three decades has largely resulted in positive outcomes for people with intellectual disability with better access to generic services in the community and a more inclusive society. There has been a clear shift in community attitudes and acceptance.

The institutional model of care was dominated by the medical model, which emphasised illness rather than broader psychosocial goals. Deinstitutionalisation accompanied the phasing out of specialised medical personnel such as doctors, psychiatrists and Mental Retardation Nurses with the expectation that generic health services, and in particular that the General Practitioner (GP) would meet the health care needs of people with an intellectual disability.

In the process of deinstitutionalisation there was a move away from a focus on “illness” of people with intellectual disability to incorporate concepts of health, wellbeing and community participation. However, it is now recognised that people with intellectual disability need special assistance if they are to access generic services, and deinstitutionalisation was not always accompanied by a commensurate recognition of the need to provide this specific support.

Compared to the general population, this group experiences greater prevalence of health problems. Their additional health needs are evident across the life course throughout childhood, adulthood and into old age. However, not infrequently these health problems are either under-recognised or inadequately managed.

Children, adolescents and adults with intellectual disability have a different patterns of health need compared with the general population. The types of health needs they most commonly experience differ from those most commonly experienced by the general population, and some types of health needs are specific to the intellectual disability.

The life expectancy of people with intellectual disability is improving, however it is still below that of the general population. Based on *Australian Bureau of Statistics, Population Projections, Australia – 2006 –2101, (2008)* the mean life expectancy of men and women in the general population are respectively 78.7 years and 83.5 years. A H Bittles et al found in their study, *The Influence of Intellectual disability on Life Expectancy (2000)* that the mean life expectancy for people with moderate and severe intellectual disability are respectively 67 years and 58 years. (ABS 2008; Bittles 2000)

However, substantial increases in life expectancy are occurring across the spectrum of intellectual disability severity and in future there will be more people with intellectual disability across all aged cohorts and level of health service need.

The generic health service system does not always effectively meet the health needs of people with intellectual disability, especially those whose needs are more complex. Changes need to be made to ensure improved access to generic services as well as the development of a more active infrastructure of specialised expertise. It is essential that the infrastructure comprise professionals who are skilled and experienced in the provision of health care to people with intellectual disability and that it can facilitate service delivery whether from generic service providers, such as GPs or from specialised services.

These difficulties in the generic health system are more pronounced for adults than for children.

Children tend to have access to paediatricians and, in metropolitan areas, to specialised developmental disability Diagnosis and Assessment services.

The *Service Framework to improve health care of people with intellectual disability* is NSW Health's response to:

- promote a broader understanding of the health needs of people with intellectual disability and their right to effective services and care; and
- improve the quality, range, consistency, accessibility and integration of services necessary to meet the health needs of people with intellectual disability.

Background

2.1 The definition of Intellectual disability

It is generally accepted that the definition of Intellectual disability refers to that cognitive impairment which arises at birth or in early childhood which continues into adulthood and which leads to the need for support from another person for aspects of higher functioning (eg advice on financial management) or for support for basic activities of daily living.

A person with an intellectual disability will require lifelong support and assistance with basic living and/or functional activities at varying levels depending on individual needs, age, health, lifestyle preferences and living circumstances.

Although it is by no means totally predictable, the tendency is that the need for support of all kinds, including health care, increases as the level of intellectual disability becomes more severe. The “levels” of support that are needed can be defined as follows:

- intermittent support needs – episodic, for example, support may be needed at times of significant change.
- low or limited support needs – minimal support is provided on an ongoing, life long basis.
- medium or extensive support needs – more substantial amounts of support are provided on an ongoing basis.
- high or pervasive support needs – support is ongoing and provided for all daily living activities, including personal care and self maintenance activities such as bathing and eating.

Clinically, a person is described as functioning in the intellectual disability range if they perform at or below 70 on a recognised psychometric test, have

accompanying deficiencies in social and adaptive skills, and acquired the disability before age 18.

Intellectual disability is further categorised from mild to profound, which is also based on IQ assessments. However, in the human services sector it is recognised that knowing a person’s level of support needs is more suitable and appropriate for identifying relevant service requirements.

2.2 Prevalence

In 2009, there were 196,047 people in Australia whose main disabling condition was intellectual and developmental disorders and in NSW, there were 65,130 people or 0.9% of the population. This corresponds with other surveys which report that about one per cent of the total population the need assistance with basic daily living activities, most frequently: self-care, mobility and verbal communication. (ABS 2010, ABS 2012 & Wen 1997)

In 2008–09 of people who used disability support services provided under the CSTDA and the NDA the most common reported primary disabilities was ‘Intellectual’ (28%). People who identified ‘Intellectual’, ‘Acquired brain injury’ and ‘Deafblind’ as their primary disability were also the most likely to experience the greatest number of other significant disabilities, with an average of more than two disability types per service user. (AIHW 2011)

The target population who would visit specialised intellectual disability health services are those people who have an intellectual disability and complex health needs.

2.3 Legislative and Policy Framework

In July 2008, Australia ratified the UN Convention on the Rights of Persons with Disabilities. Article 25 of the Convention states:

States Parties recognise that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

- (a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programs as provided to other persons, including in the area of sexual and reproductive health and population-based public health programs;
- (b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;
- (c) Provide these health services as close as possible to people's own communities, including in rural areas;
- (d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;
- (e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;
- (f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

The National Disability Strategy sets out a ten year national plan for improving life for Australians with disability, their families and carers. It represents a commitment by all levels of government, industry and the community to a unified, national approach to policy and program development

The Commonwealth, State and Territory and Local Governments have developed the Strategy in partnership under the auspices of the Council of Australian Governments (COAG) and was formally endorsed by COAG on 13 February 2011.

The Strategy is a ten year plan that sets out six priority areas for action to improve the lives of people with disabilities, their families and carers. These are:

- Inclusive and accessible communities—the physical environment including public transport; parks, buildings and housing; digital information and communications technologies; civic life including social, sporting, recreational and cultural life.
- Rights protection, justice and legislation—statutory protections such as anti-discrimination measures, complaints mechanisms, advocacy, the electoral and justice systems.
- Economic security—jobs, business opportunities, financial independence, adequate income support for those not able to work, and housing.
- Personal and community support—inclusion and participation in the community, person-centred care and support provided by specialist disability services and mainstream services; informal care and support.
- Learning and skills—early childhood education and care, schools, further education, vocational education; transitions from education to employment; life-long learning.
- Health and wellbeing—health services, health promotion and the interaction between health and disability systems; wellbeing and enjoyment of life.

The *National Disability Strategy* will guide public policy across governments and aims to bring about change in all mainstream services and programs as well as community infrastructure. It is the first time the Commonwealth, State and Territory Governments have agreed to such a wide ranging set of directions for disability.

In NSW, this approach is underpinned by the *Anti-Discrimination Act 1977*, *Commonwealth Disability Discrimination Act 1992* and the *NSW Disability Services Act 1993*.

NSW 2021: a plan to make NSW Number one is a 10 year plan to rebuild the economy, return quality services, renovate infrastructure, strengthen our local environment and communities and restore accountability to Government. The goal is to restore confidence in the public health system by rebuilding hospitals and health infrastructure, re-engaging clinicians, and giving communities and health care providers a strong and direct voice in improved local patient care.

By focusing on illness prevention, (including a strong focus on mental health) this can reduce the burden of chronic disease on the health system and keep our community active and healthy.

In regard to health the specific key goals are:

- Keep people healthy and out of hospital
- Provide world class clinical services with timely access and effective infrastructure

In addition, the *NSW Health and Equity Statement – In All Fairness (In All Fairness)* guides planning and decision making to enable the NSW health system to reduce the gap between those with best and poorest health, while continuing to improve the health of all people in NSW. People with disability were identified as among those groups of people at risk of poorer health outcomes.

The Department of Family and Community Services – Ageing, Disability and Home Care (ADHC) 10-year plan *Stronger Together: A new direction for disability services 2006-2016* are key policy and service frameworks underpinning service provision for people with a disability in NSW. Further, *Better Together: a new direction to make NSW Government services work better* for people with a disability and their families 2007-2011 is a whole of government strategy to improve co-ordination, planning and delivery of services for people with a disability and their families and focussing on improvements to the whole service system. Under this strategy one of the key priorities for action is to make it easier for people to get the therapy services they need. ADHC had lead responsibility for the strategies and actions for both Early Intervention and Therapy Services. NSW Health, the Department of Education and Community and Department of Family and Communities (Community

Services) are part of the core group contributing to the strategies and actions.

2.4 Health care needs of people with intellectual disability

Health care for people with intellectual disability has been characterised by a lack of communication, poor understanding of their everyday and special health needs and poor procedures for the delivery of services. Contemporary research indicates that people with intellectual disability continue to experience poorer health outcomes and have more difficulty in obtaining the necessary health services in comparison with other populations (Krahn & Drum 2007). They experience a high prevalence of significant medical and mental health problems compared to the general population as well as conditions often being unrecognised, misdiagnosed and poorly managed. (AIHW 2008; Lennox & Kerr 1997).

Many causes of intellectual disability have associated additional health problems which are often multiple and complex. For example, people with Down Syndrome experience increased prevalence of early onset Alzheimer type dementia and congenital heart disease. Epilepsy is also a commonly associated condition with intellectual disability with a prevalence rate of 22% (Welsh Office, 1996) compared to prevalence rates for the general population of 0.4%-1% (Chadwick, 1994).

People with intellectual disability across all age groups are more at risk of developing mental illness than the general population. The likelihood of psychiatric disorders increases with the severity of the intellectual disability. 30–42% of children require treatment for mental health problems, while as many as 40-50% of adults and 60% of older adults with intellectual disability may have mental health problems (Cooper, S-A. Bailey, N.M. 2001).

Knowledge of these associations is important to prevent problems occurring and to improve the early identification of health needs to enable appropriate treatment and management. This may reduce unnecessary pain and illness as well as prevent long term irreversible damage to health and functioning or premature death.

It has been found that people with intellectual disability in Australia had higher rates of obesity, nutritional problems, vision and hearing impairment, epilepsy, dermatological problems, endocrine disorders, hypertension, psychiatric disorders compared to the general population. Dental disease was found to be the most frequent health problem occurring in 86% of the population sample (Beange et al:1995).

Studies have shown that people with mild and borderline intellectual disability who come in contact with the criminal justice system have high rates of alcohol and drug problems. (Kenny et al 2006)

It has also been established that people with intellectual disability do not access preventative health care and health promotion programs to the same extent as others in the community and there is a lack of health promotion material available in formats that are accessible to people with an intellectual disability.

In addition as life span is increasing, the disease patterns and risk factors for diseases that are present in the general community are increasingly being seen in people with intellectual disability. For example the incidence of cancer, which has traditionally been lower in people with intellectual disability, is rapidly increasing (Cook, 1997; Duff et al, 2001). As are the rates of coronary heart disease due to increased longevity and lifestyle changes associated with community living (Turner & Moss, 1996; Wells et al, 1997).

Family carers are generally the major contributors to the care and support of people with intellectual disability. Their health is also important as many people with intellectual disability depend on their family to initiate and facilitate access to all health care, making them one of the very few groups in society to be so dependent.

Many adults with Intellectual disability continue to live with elderly family carers. McGrother et al (1996) reported that these carers had 40% more limiting health disorders compared to the general population, with depression almost four times more common among female carers. Back problems are particularly prevalent in carers of people with significant physical disabilities, and stress related illnesses are common.

Exclusion from or lack of availability of services causes additional strains on health and wellbeing. Effective support for family carers is crucial to ensure that their own health needs are recognised.

2.5 Health Risks for people with intellectual disability

There are a number of reasons why the health care of people with intellectual disability is challenging and why, with undiagnosed and untreated conditions the health status of people with intellectual disability is much lower than that of the general population.

As with the general population, the life expectancy of people with Intellectual disability has increased over the past fifty years. A West Australian database has information on people with Intellectual disability who have been registered with services since 1953 (approximately 0.4%) Study of this cohort indicates a life expectancy of

- 74 years for people with Mild Intellectual disability,
- 67 years for people with Moderate Intellectual disability' and
- 58 years for people with Severe-Profound Intellectual disability.

(Bittles et al 2000)

Medical and social literature review suggests that

- For most people with Intellectual disability there are low levels of smoking, alcohol abuse and illicit drug use though the opposite case for people in contact with the criminal justice system.
- For most people with Intellectual disability there are high levels of overweight status and obesity, and low levels of physical activity;
- People with Mild Intellectual disability are surviving to face the risk factors and disease patterns of old age eg thyroid disease, arthritis, falls, early dementia;
- People with moderate and severe-profound Intellectual disability experience greater prevalence of preventable health-related problems than their age matched peers, particularly dental disorders, skin breakdown and osteoporosis;
- People with Intellectual disability do not use preventative health care and health promotion

- programs to the same extent as others
- Many causes of Intellectual disability lead to associated additional health problems which are often multiple and complex;
- People with Intellectual disability across all age groups are more at risk of developing mental ill health than the general population;
- Approximately 25% of people with Intellectual disability presenting to Clinics are taking high levels of psychotropic medications for behaviour and psychiatric disturbances;
- Approximately 30% of people with Intellectual disability presenting to Clinics are taking long term anti-epileptic medications; and
- The health of family carers is often negatively affected by their caring responsibilities.

2.6 Current Health Services for People with intellectual disability

Diagnosis and Assessment Services

Diagnosis and Assessment services are primarily located in metropolitan NSW. In some cases, these services are provided by teams which function predominantly for the diagnosis and assessment of developmental/intellectual disability in children and in other cases by teams in which this forms a smaller part of their service provision.

Existing DA services are an example of Tier 4 services for people with intellectual disability who require diagnostic assessment. However, even though there are elements of these services in many areas, even they do not represent a comprehensive network of services for children requiring diagnostic assessment. Some services are without psychologists, others without medical practitioners, and others focus on only the very early years of childhood. Many of these services contribute little to the ongoing needs of children with complex developmental disabilities, or adolescents who require diagnostic assessment. While many of these services have well established links to early childhood services, their linkages to other services for children with developmental disabilities or to services for adults with intellectual disability are less well developed.

The Commonwealth Medicare Benefits Schedule

The Medicare Benefits Schedule (MBS) primary care items support primary care services including: general attendances, after-hours attendances, health assessments, nurse practitioners, midwives, chronic disease management and mental health care. Some of these services provide particular target groups with preventative health care or improve coordination of multidisciplinary care for people with chronic (or terminal) conditions and complex care needs.

For patients with a chronic (or terminal) medical condition and complex care needs

The Chronic Disease Management (CDM) Medicare items on the Medicare Benefits Schedule (MBS) enable GPs to plan and coordinate the health care of patients with chronic or terminal medical conditions, including patients with these conditions who require multidisciplinary, team-based care from a GP and at least two other health or care providers. The items are designed for patients who require a structured approach to their care.

A 'chronic medical condition' is one that has been or is likely to be present for at least six months, including but not limited to asthma, cancer, cardiovascular disease, diabetes mellitus, musculoskeletal conditions and stroke.

Whether a patient is eligible for CDM services is a clinical judgement for the GP, taking into account the patient's medical condition and care needs, as well as the general guidance set out in the MBS.

GP Mental Health Treatment Plans apply to patients with mental disorders.

Patients who have a chronic medical condition and complex care needs and are being managed by their GP under a GP Management Plan (item 721) and Team Care Arrangements (item 723) are eligible for Medicare rebates for certain allied health services on referral from their GP.

Children with Disability initiative

From 1 July 2011, the Better Start for Children with Disability initiative provides new items in the Medicare Benefits Schedule to provide early intervention

services from eligible allied health professionals (audiologists, occupational therapists, optometrists, orthoptists, physiotherapists, psychologists and speech pathologists) for children diagnosed with sight and hearing impairment, cerebral palsy, Down syndrome and Fragile X syndrome.

Medicare items are available for:

- Specialists, consultant physicians and general practitioners to diagnose and develop a treatment plan for children aged under 13 years;
- audiologists, occupational therapists, optometrists, orthoptists, physiotherapists, psychologists and speech pathologists to provide up to four services in total per child per lifetime, to collaborate with the referring medical practitioner on the diagnosis, where required;
- audiologists, occupational therapists, optometrists, orthoptists, physiotherapists, psychologists and speech pathologists to provide up to 20 early intervention treatment services in total per child per lifetime following the diagnosis of an eligible disability, and consistent with the treatment and management plan prepared by the referring medical practitioner.

These services must be provided before the child's 15th birthday, provided a disability treatment and management plan was in place before the child's 13th birthday.

Mental Health Care

The Better Access to Psychiatrists, Psychologists and General Practitioners through the MBS (Better Access) initiative aims to improve outcomes for people with a clinically-diagnosed mental disorder through evidence-based treatment. Under this initiative, Medicare Benefits Schedule (MBS) rebates are available to patients for selected mental health services provided by GPs, psychiatrists, psychologists (clinical and registered), eligible social workers and occupational therapists.

An intellectual disability is not a mental disorder but many people with intellectual disability also have mental disorders such as a psychosis, mood disorder or anxiety disorder.

Allied Health Group Services under Medicare for patients with type 2 diabetes

Medicare rebates are payable for group services provided by eligible diabetes educators, exercise physiologists and dieticians for people with type 2 diabetes, on referral from a GP.

Dental Services under Medicare for People with Chronic and Complex conditions.

Some patients may be able to receive dental services under Medicare.

Under the Medicare chronic disease dental scheme, Medicare benefits are available for most services provided by a dentist, dental specialist or dental prosthetist in private dental surgeries. Benefits are not available where services are provided to a person who has been admitted to a hospital.

For most people, this involves the preparation of a "GP Management Plan" and "Team Care Arrangements". For residents of aged care facilities, it involves the GP contributing to a multidisciplinary care plan prepared for the resident by the facility.

The Service Framework to Improve the Health Care of People with Intellectual Disability

3.1 Purpose

The *Service Framework* recognises that people with intellectual disability have the same right to good health and quality health care as others in the community. Its purpose is to:

- improve the health outcomes and reduce the health disparities experienced by people with an intellectual disability; and
- support and resource generic service providers to better meet and understand the complex and multiple health needs of people with an intellectual disability and their carers.

3.2 Key Objectives

The *Service Framework* aims to improve overall health and well-being for children, adolescents and adults with an intellectual disability.

By establishing specialised services for people with intellectual disability and complex health problems, the *Service Framework* will:

- ensure the every day health needs of people with intellectual disability are met, effective health promotion is delivered, and complex health needs are addressed
- deliver high quality accessible health care
- respond more appropriately to health care needs

The establishment of a centre for clinical leadership, research and education will:

- build workforce capacity to facilitate the inclusion of people with intellectual disability in mainstream health services
- enhance capacity for continuous improvement within specialised and general services

3.3 Key outcomes of the *Service Framework*

People with intellectual disability, their families and carers:

- have health problems identified in a timely way.
- have timely access to the range of health services they require.
- are assisted by health professionals who understand and know how to respond to their particular needs.
- have a healthier lifestyle, and
- are healthier.

Health care providers:

- understand the needs of people with intellectual disability and their carers.
- know how to communicate effectively with people who have an intellectual disability and adapt their ways of working to respond to their needs.
- recognise the contribution of carers and support their health care needs.
- are proactive in promoting the health and wellbeing of people with intellectual disability and their carers.
- promote and facilitate interagency co-ordination and collaboration.

3.4 Tiered Model

The *Service Framework* is based on a tiered model of care:

- Tier 1: Strategic health policy and population health
- Tier 2: Primary health and community health
- Tier 3: Acute health care services

Tier 4: Specialised area/local health services
Tier 5: Specialised regional/state-wide support and clinical leadership.

There is considerable expertise already in the field as well as examples of best practice. The *Service Framework* will foster strong partnerships so that best practice can be replicated instead of implemented from a start position.

Tier 1: **Strategic health policy and population health**

Better promotion of the general health and well being of all people with intellectual disability and their carers in all settings in the community is needed. This includes working with communities, local councils, NGOs, specialised disability services and local health services to promote involvement of people with intellectual disability and their carers, social inclusion and raise awareness of health issues.

Strategies include:

- Issue a policy directive requiring all NSW Health strategic plans, action plans, policies and programs, including models of care, to actively consider the needs of people with intellectual disability.
- Include the needs of people with intellectual disability in the revised policy directive: *People with disability; Responding to their needs during hospitalisation*.
- Develop targeted workforce strategies to increase the skills of the health promotion workforce and build NSW Health's capacity to review and adjust health promotion initiatives in response to the needs of people with intellectual disability.
- Increase accessibility of health promotion, health screening and wellness programs in formats appropriate to the communication needs of people with intellectual disability, their families and carers.
- NSW Oral Health Promotion Network (facilitated by Centre for Oral Health Strategy) could be engaged to meet health promotion and education needs around oral health.

Tier 2: **Primary health and community health care**

Primary health care is, by definition, the first point of contact with health services and the pathway to further treatment, if required. Regular health screening and checks can improve the health care of people with intellectual disability.

Recent national primary care initiatives such as the introduction of GP extended care Item Numbers specifically for attendances by people with Intellectual disability, and capacity for Allied Health interventions for people with chronic disease have been welcomed by the sector.

Strategies include:

- Work with the General Practice NSW to:
 - promote Medicare Items: an annual health check for people with intellectual disability
 - better utilise the Medicare items to promote multidisciplinary case co-ordination and management plans.
- Incorporate issues into the integrated primary and community health services planning process at Local Health District level
- Develop targeted workforce development strategies to build primary health care providers' capacity to provide appropriate chronic disease prevention interventions to people with intellectual disability.
- Promote the use of the Personal Record Book (PRN), more commonly known as the "The Blue Book" to record childhood developmental milestones that can be used as a screening tool to identify areas for early intervention strategies for children with developmental disabilities/ Intellectual disability.
- Increased responsiveness by health care professionals to the needs of women with Intellectual disability who are victims of domestic violence needs by screening clients for abuse histories.

Tier 3: **Acute health care services**

This tier focuses on improving the capacity of the secondary health care system to care for and

manage the additional health care needs of people with intellectual disability who need to access both hospital-based inpatient and outpatient services. This includes pre and post admission planning.

Recent initiatives have included the development of Local Health District Disability Action Plans and training programs on NSW Health policies on hospitalisation of people with disability.

Most public oral health services are provided from community based care settings, along the lines of an outpatient service. Ensuring that oral health services have the capacity for managing the additional needs of people with intellectual disability would require the development of generalist oral health clinicians' capacity to manage the care of people with mild Intellectual disability.

Strategies include:

- Exploring feasibility of establishing a service plan for specialised mental health services similar to the Specialist Mental Health Services for Older People.
- Making available reference guides to assist staff such as *Hospital Care for People with a Disability*.
- Reviewing current models of care developed for their applicability for people with disability eg Community Acute/Post Acute Care, Geriatric Rapid Acute Care Evaluation and Compacts models of care.
- Developing systems for day patient admissions of people with intellectual disability who require multiple investigations or treatments to be done under general anaesthetic. (Some people with intellectual disability require general anaesthetic due to their lack of understanding of the need for medical interventions)
- Enhancement of services for adults with ID should include advocacy around workforce issues such as re-implementing general physician training and a general physician workforce.
- Promoting *Policy Directive: People with a Disability Responding to needs during hospitalisation*.

Tier 4: Specialised area/local health services

These services would work to support primary care services and others by providing advice, assessment, interventions and treatments for complex specialised intellectual disability health needs. Those health professional would provide advice and practical support to people with an intellectual disability, their families, carers, community health, GPs, other health and allied professionals, disability services and non-government service providers.

People with an intellectual disability will often require investigation and treatment across a range of health services. Access, co-ordination and support are important issues.

As it is not possible for all nurses and health professionals to develop the full range of skills necessary to work with all people with an intellectual disability, it is important to ensure that specialised health professionals are available locally and are accessible. This should not be optional and clear pathways for access need to be in place.

The principal aims, key elements and core functions of a specialised health care service for people with intellectual disability should be consistent and be used to determine the most appropriate option in each Local Health District.

Tier 4 services are needed for both adults and children. However, the current gap in these services is greater for adults than for children. General paediatricians and developmental disability Diagnosis and Assessment Services tend to be available to children with Intellectual disability.

The principal aims of Tier 4 services are to:

- Provide multidisciplinary specialised health care assessment and clinical services to people with moderate or severe Intellectual disability and people with mild Intellectual disability who in addition have significant complex health care needs.
- Ensure continuous, comprehensive and co-ordinated health care by facilitating collaboration and co-operation within the health

care system as well as between the health and disability support systems.

- Increase the capacity of GPs and other medical and disability practitioners to meet the health needs of people with intellectual disability and their carers through the provision of education, training, specialised clinical support and consultancy.

The key elements of Tier 4 services are:

- Provision of clinical services to children, adolescents and adults with an intellectual disability whose health needs are not met by primary or other specialist health services
- Multidisciplinary and multidimensional team structure and staffing - to provide multidisciplinary and comprehensive diagnosis, assessment, and clinical services to people with moderate or severe Intellectual disability and people with mild Intellectual disability who in addition have significant complex health care needs.
- Multidisciplinary and multidimensional team structure and staffing - to provide multidisciplinary and comprehensive diagnosis, assessment, and clinical services to people with moderate or severe Intellectual disability and people with mild Intellectual disability who in addition have significant complex health care needs.
- To encourage specialised staff to act as role models and educators to other health professionals in particular in their behaviour towards people with intellectual disability, treating them as equal and fully participating members of society.
- Health promotion - to facilitate access to health promotion, preventative health, immunisation and health screening activities.
- Health facilitation - working across primary, secondary and tertiary health care to enhance access to mainstream services.
- Education - of health professionals familiar with how to support and assist to meet the health care needs of people with intellectual disability.
- Health care coordination - for those people whose needs are complex and cannot be met by the generic system alone.

- Service development – to contribute knowledge of specialised health issues to service planning and improvement.
- Interagency and intersectoral collaboration – across the health and disability support systems.
- A specific focus on Aboriginal people and people from Culturally and Linguistically Diverse (CALD) backgrounds through collaboration with Aboriginal health services, the Diversity Health Institute and Transcultural Mental Health Centre.
- Primary health care responsibilities remain with the general practitioner.
- An oral health assessment could be conducted as part of a broader health assessment to generate a referral to a specialist oral health clinician.

Specialised intellectual disability teams

Multidisciplinary specialised health teams including clinical nurse consultants at Local Health District level will be established to achieve the key elements above. Clinical leadership of each team would be provided by a doctor with expertise and interest in intellectual disability. This may be a general practitioner, developmental physician or rehabilitation specialist. These teams would include medical, nursing, allied health (i.e. dietitians, speech pathologists, psychologists, occupational therapists), psychiatric expertise, alcohol and other drug (AOD) worker and access to oral health expertise and would provide outreach services. The team would be the point of contact in each area, working in close cooperation with general practitioners, dental services, specialist diagnosis and assessment services, primary and community health services, mental health services, drug services and disability services.

The locations of the teams may vary across the Local Health Districts depending on available clinical resources, expertise and special interests as well as some measure of demand. Possible sites include co-location with Rehabilitation and Aged Care Services, co-location with existing Diagnosis and Assessment and other specialist intellectual disability/developmental disability services. Consideration will also be given to co locating with a HealthOne Clinic.²

² HealthOne NSW model of care is where General Practice and Community Health staff work together as a multidisciplinary team to provide coordinated and integrated services for a local community that encompasses health promotion and illness prevention, early detection and intervention and continuing care for people with chronic & complex conditions..

The functions underpinning a multidisciplinary Team includes:

- Comprehensive medical evaluation and preventative medical screening including follow up investigations and trialling medications.
- The development of individual health care management plans with recommendations, in conjunction with patients, their families and/or support workers. The plan will include co-ordinated multidisciplinary advice based on all investigations, assessments and referrals that have been undertaken.
- Assistance to GPs and other professionals providing mainstream services in the care of their patients, and
- To encourage specialised staff to act as role models and educators to other health professionals in particular in their behaviour towards people with intellectual disability, treating them as equal and fully participating members of society.
- Utilise existing health care resources and expertise based on negotiated agreements with AHS for designated clinician and allied health hours and positions.
- Provision of transitional services for clients moving from Children's to Adult services.
- Specialised advice provided by clinical psychologists, dieticians, occupational therapists, dental therapist and alcohol and other drug officers.
- A health care case coordination role, in particular in collaboration with other agencies such as the Department of Ageing Disability and Home Care, Department of Education and Training and Department of Community Services.
- Primary health care responsibilities remain with the general practitioner.
- Foster the development of better local networks of GPs and other primary health workers, health specialists and disability support workers

There is a need for the formal organisation of regional Tier 4 services for people with Intellectual disability with identified teams of clinicians staffed to levels commensurate with need, who will provide

- Population based secondary and tertiary clinical services:
 - Diagnosis
 - Assessment of functional needs
 - Specialist management and advice
- Subspecialty medical services:
 - Developmental paediatricians
 - Neurologists with an interest in epilepsy
 - Psychiatrists with training or expertise in Intellectual disability
 - Rehabilitation physicians
 - General Practitioners with specialty interest in Intellectual disability
 - General physicians, geriatricians, respirologists, gastroenterologists, endocrinologists etc with an interest in Intellectual disability
- Liaison Nurses with mental health and/or disability training
- Allied health professionals with special interest
 - Psychologists
 - Occupational therapists
 - Physiotherapists
 - Speech pathologists
 - Dieticians
 - Exercise scientists
 - Social Worker
- Training sites for undergraduate and postgraduate clinicians
- Local educational activities for general community, carers, other clinicians
- Clinical research activities integrated with Tier 5 programs

The proposed clinics provide support for general and other medical practitioners through:

- Telephone and email advice service
- Multidisciplinary team advice by telephone, telemedicine or in person

Tier 5: **Specialised regional/state-wide support and clinical leadership**

The complex and lifelong nature of the health problems of the population and some of the specific physical and psychiatric health problems often require a special knowledge, a familiarity with the population and links with the system that supports them to be dealt with effectively.

A recognised state-wide specialised centre would underpin and support the local specialised service infrastructure to provide specialised clinical advice and support to generalist primary and secondary health care services and to provide a focal point for teaching, evidence based research and advocacy initiatives. There is also a need to have better systems in place to monitor health outcomes.

The establishment of a Tier 5 specialised model would be the second stage in the implementation of a Service Framework.

Specifically the proposed function of the centre would:

- Undertake research itself and foster research by tier 4 and others to enhance the evidence base for best practices.
- Identify linkages with whole of government research priorities and other clinical research networks to advance better prevention, early diagnosis and treatment of health problems experienced by people with intellectual disability.
- Establish state-wide clinical leadership role, a clinical governance framework and expert clinical resources.
- Promote interdisciplinary collaboration and integration in health care and support services for people with intellectual disability.
- Support continuous improvement in the quality and effectiveness of health care provision.
- Link with current workforce planning initiatives in NSW Health.
- Provide expert support, education and training for health care professionals at all levels of health care.
- Develop options for a web based state-wide information and resource service for health professionals the provision of care to people with intellectual disability.
- Identify how the ADHC funded Chair in Dual Diagnosis will be linked to other clinical leadership strategies.
- Develop a triage approach to identify how the client's health care needs are initially assessed, by whom and how they are directed into the broad health care service areas such as health maintenance, health promotion and illness.
- Review best practice of specialised intellectual

disability management, reference guidelines and other management and resource tools with a view to disseminating relevant material to professionals across the Tier.

- In conjunction with the Centre for Oral Health Strategy identify strategies to ensure that dentists in the public system have appropriate training in understanding the needs of people with intellectual disability.
- Be linked into a Faculty of Medicine or perhaps a Faculty of Health Sciences with the director of the Centre having at least Associate Professor status.
- Be linked to an LHS and major teaching hospital.
- Expect to have close working relations with Tier 4 services.

As with Tier 4 services, it is essential that the Tier 5 Centre have staff with appropriate expertise and staff advocating people with intellectual disability as equal and fully participating members of society.

Governance and reporting

NSW Ministry of Health will lead the planning and implementation phases of the *Service Framework*, working in close collaboration with the Department of Family and Community Services – Ageing, Disability and Home Care.

During the initial planning phase an Advisory Group was established to undertake more detailed analysis for the implementation of the *Service Framework*. Consideration was given to issues such as the location of new services, whether existing services should be enhanced, funding allocations for services to children, adolescents and adults and how new services will be evaluated.

The Advisory Group included representatives from NSW Ministry of Health, NSW Department of Family and Community Services – Ageing, Disability and Home Care, clinicians who specialise in Intellectual disability and advocates for people with intellectual disability.

During the implementation phase existing governance mechanisms will be used to monitor and report progress, these include:

- Health and Ageing, Disability and Home Care Senior Officer Group meetings and Health and Family and Community Services Chief Executive Officers meetings
- NSW Health's Disability Action Plan identifies strategies from the *Service Framework* and implementation will be detailed in the Annual Report.

Performance indicators and evaluation

An evaluation strategy for the Service Framework will be developed. This will include:

- The development of key milestones and performance indicators for the Service Framework as a whole, and
- Mechanisms for consistent regular reporting against these performance indicators that can be incorporated into existing NSW Health and ADHC reporting requirements

References

- Australian Bureau of Statistics (2010) Disability: Ageing and Carers Australia: Summary of Findings, Ageing and Cares: Summary of Findings 2009, Cat no. 44300
- Australian Bureau of Statistics (2012) 4430.0 - Disability, Ageing and Carers, Australia: Summary of Findings, 2009 44300 DO001_2009 Disability, Ageing and Carers, Australia: State tables for New South Wales
- Australian Institute of Health and Welfare (2011), Canberra, Cat. no. DIS 58. Disability support services 2008–09. Report on services provided under the Commonwealth State/Territory Disability Agreement and the National Disability Agreement. January 2011.
- Australian Institute of Health and Welfare (2008) "Disability in Australia: intellectual disability" 67pp 11-12.
- Beange, H. & Bauman, A. (1990) Caring for the developmentally disabled in the community.
- Bittles, A.H et al. (2002) The influence of intellectual disability on life expectancy.
- Cooper, S-A. Bailey, N.M. (2001) Psychiatric disorders amongst adults with learning disabilities – Prevalence and relationship to ability level.
- Cumella S & Martin D (2000) Secondary Healthcare for People with a Learning Disability.
- Davis, R. Phillips & A. Nankervis, K. (2002) Service Delivery to people with an intellectual disability in Victoria and Australia – A report to the Scottish National review of the Contribution of Nurses to the Care and Support of People with a Learning Disability.
- Department of Health UK (2001) Valuing People: A new strategy for learning disabilities for the 21st century.
- Dovey, S.& Webb, O.J. (2000) General practitioners' perception of their role in care for people with intellectual disability.
- European Manifesto (2003) Basic Standards of Health Care for People with intellectual disability.
- Evenhuis, H. Henderson, M. Beange, H. Lennox, N. & Chicoine, B. (2000) Healthy Ageing – Adults with Intellectual Disabilities Physical Health Issues.
- Hogg, J. (2001) Essential healthcare for people with learning disabilities: barriers and opportunities.
- International Association for the Scientific Study of Intellectual disability (2002) Health Guidelines for Adults with an Intellectual disability.
- Irish College of Psychiatrists Dublin. (2004) Proposed model for the delivery of a mental health service to people with intellectual disability.
- Janicki, M. P. Dalton, A.J. Henderson, C.M. & Davidson, P.W. (1999) Mortality and Morbidity among older adults with intellectual disability: Health services consideration.
- Jansen, D.E.M.C., Krol, B. Groothoff, J.& Post, D. (2006) 'Towards improving medical care for people with intellectual disability living in the community: possibilities of integrated care' Journal of Applied Research in Intellectual Disabilities 19 (2), 214- 218.
- Kenny, D.T., Nelson, P., Butler, T., Lennings, C., Allerton, M., and Champion, U. (2006). NSW Young People on Community Orders Health Survey 2003-2006: Key Findings Report. The University of Sydney.

- Krahn & Drum (2007) "Translating Policy Principles into Practice to improve health care access for adults with intellectual disability" *Mental Retardation and Developmental Disabilities Research Reviews* 13: 160-168.
- Leonard & Wen (2002) "The Epidemiology of Mental Retardation: Challenges And Opportunities In The New Millennium" in *Mental Retardation And Developmental Disabilities Research Reviews* 8: 117-134.
- Lennox, N.G. & Kerr, M.P. (1997) Review: Primary health care and people with an intellectual disability: the evidence base. *Journal of Intellectual disability Research*, 41:5, 365-372.
- Lennox, N.G. (1999) *Comprehensive Health Assessment Programme*. University of Queensland: Brisbane.
- Lennox, N. G (2002) *Issues Paper – National Health Priority Targets for Adults with Developmental Disability*. Unit.
- Lennox, N. G. Diggins, J.N. & Ugoni, A.M. (1997) *The general practice care of people with intellectual disability: barriers and solutions*.
- Lennox, N. G & Beange, H. (2000) *The health needs of people intellectual disability*.
- Martin, D.M. Roy, A. & Wells, M.B. (1997) *Health gain through health checks: improving access to primary health care for people with intellectual disability*.
- McConkey, R. (February 2006) *Accessibility of healthcare information for people with a learning disability A Review and Discussion Paper*.
- McGrother, et al. (1996) *Community care for adults with learning disability and their carers: needs and outcomes from the Leicestershire register*.
- Ouellette-Kuntz, H. et al (2004) *Addressing Health Disparities through Promoting Equity for Individuals with Intellectual disability* Canadian Institutes of Health Research.
- Royal College of Nursing, UK (2006) *Meeting the health needs of people with learning disabilities – guidance for nursing staff*.
- Scott, A. Marsh, L & Stokes, M.L. (1998) *A survey of oral health in a population of adults with developmental disability: comparison with a national oral health survey of the general population*.
- Scottish Executive (2001) *The Same as You? A review of services for people with learning disabilities*.
- University of Glasgow (2002) *Training Pack for Practice Nurses to Support the Health of People with Learning Disabilities*.
- US Department of Health and Human Services (2002) *Closing the Gap: a national blueprint to improve the health of persons with mental retardation*.
- Webb, O.J & Rogers, L (1999) *Health Screening for people with intellectual disability: the New Zealand experience*.
- Welsh Assembly Government (2002) "Inclusion, partnership and innovation": *A framework for realising the potential of learning disability nursing in Wales*.
- Wen, X. (1997) *The Definition and Prevalence of Intellectual disability in Australia*. Australian Institute of Health and Welfare.

