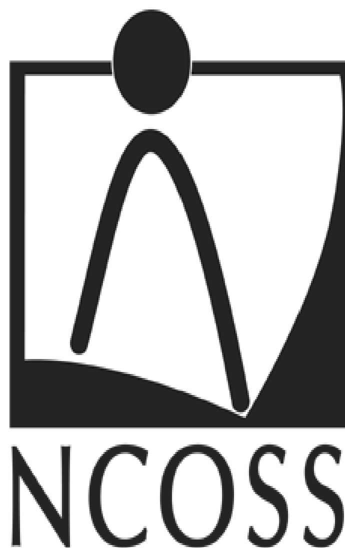
Submission to NSW Health
Discussion Paper

DEVELOPMENT OF A SERVICE FRAMEWORK TO IMPROVE HEALTH CARE OF PEOPLE WITH INTELLECTUAL DISABILITIES



May 2007

Council of Social Service of NSW (NCOSS),
66 Albion Street, Surry Hills, 2010
Ph: 02 9211 2599, Fax: 9281 1968, email: chris@ncoss.org.au
ABN 85 001 797 137

About NCOSS

The Council of Social Service of NSW (NCOSS) is an independent non-government organisation and is the peak body for the non-government human services sector in NSW. NCOSS works with its members on behalf of disadvantaged people and communities towards achieving social justice in New South Wales.

It was established in 1935 and is part of a national network of Councils of Social Service, which operate in each State and Territory and at Commonwealth level.

NCOSS membership is composed of community organisations and interested individuals. Affiliate members include local government councils, business organisations and Government agencies. Through current membership forums, NCOSS represents more than 7,000 community organisations and over 100,000 consumers and individuals.

Member organisations are diverse; including unfunded self-help groups, children's services, youth services emergency relief agencies, chronic illness and community care organisations, family support agencies, housing and homeless services, mental health, alcohol and other drug organisations, local indigenous community organisations, church groups, and a range of population-specific consumer advocacy agencies.

OVERALL COMMENTS:

NCOSS welcomes the opportunity to respond to the Discussion paper on the *Development of a Service Framework to Improve the Health Care of People with Intellectual Disabilities* and appreciates the extension of the consultation deadline.

Preferred Strategy

NCOSS supports a range of strategies in combination, ranging from local initiatives to statewide expertise and leadership. Due to the very poor health outcomes of people with intellectual disabilities in comparison to other people, no single strategy will deliver the necessary population improvements nor equitable access across NSW. NCOSS recommends that all finalised strategies should have performance measures in order to evaluate achievements within the Service Framework.

Person centred approach

In line with other health reform processes, including the patient journey approach and the clinical service redesign project, the person with intellectual disability must be at the centre of any new response system/service framework to address their health needs. While the presence of intellectual disability is the focus for improved health outcomes, it should not be the overriding factor in an individual's care but the emphasis must be on comprehensive and specific care for the whole person rather than the treatment of compartmentalized conditions.

Family and carers
The role of the family is critical to better health for many people with intellectual disability. The care should be person centred, with optimum engagement with the family. Where the person does not want family involved, this should be respected, as for any other adult patient.

Many people with intellectual disabilities do not have close contact with family and rely on support from service providers. Where people with intellectual disabilities have no family carers, health care management plans must specifically attribute responsibility for monitoring and support of treatment and health outcomes. Interagency collaboration is critical in this case, especially including non-government organisations as part of any protocols in this regard.

The Discussion Paper acknowledges that the health outcomes of family carers are often poorer than people without caring responsibilities. This should be addressed as part of overall reforms but is inappropriate to include within the proposed service framework for people with intellectual disabilities.

New Medicare Items for people with intellectual disabilities
NCOSS welcomes the recent introduction of Medicare benefits to doctors for specific treatments for people with intellectual disabilities. The promotion and utilisation of this new benefit should form part of this overall Service Framework.

Links to NSW Health Plan and other policy initiatives
This Service Framework must link with the NSW Health Plan, the NSW Stronger Together Disability Plan, the NSW Better Together Plan and the NSW Carers Action Plan in order to provide specific and deliberate outcomes for people with intellectual disabilities. This Service Framework offers a good opportunity to integrate and coordinate improved health care of people with intellectual disabilities with other related proposals. Currently there is no mention of the State Health Plan, in particular strategic direction two *Create better experiences for people using health services*.

How does this Service Framework link with the clinical service redesign program in Area Health Services?

Access issues
NCOSS is concerned that the access issues for people with intellectual disabilities should be a critical issue in promoting and delivering improved health outcomes to this population. This Service Framework must include access strategies especially assisted and affordable transport, accessible appointment times and low or no cost services. In recognising that people with intellectual disabilities are often reliant only on income supports, the actual cost of the health treatments and coordination must be considered, as well as transport and other access issues.

Aboriginal people and people from diverse cultural backgrounds
The Discussion Paper acknowledges that other strategies may be required to address the specific concerns of people with intellectual disabilities from Aboriginal and Torres Strait Islander communities or culturally diverse backgrounds. NCOSS strongly recommends that these strategies be developed and specifically consulted before any implementation of the Service Framework occurs.

Resources and funding
If there is a genuine commitment to improved health outcomes for people with intellectual disabilities, then proposals for additional funding must reflect this. Expecting that practices will change for people with intellectual disabilities within existing resources is insufficient to create real and lasting results for this population. NCOSS supports targetting the required additional resources with attached outcomes measures to ensure that this group is again not falling to the lowest priority within a pressured health system coping with competing demands.

Models of service
In terms of the most appropriate models there is concern that the decision will fall to Area Health Services (AHS) to decide which model to take up. This decision will be reliant on someone who is interested and can champion the cause, as well as what resources the AHS have and whether it wants to dedicate these to people with intellectual disability. Health services are currently stretched and providing such new service within existing resources will not encourage energetic implementation. However the need is critical for better access and provision of health services to people with intellectual disabilities.

Gender
Gender must also be recognised as a factor when developing service responses to specific needs groups.

Proposed priorities for the health system
NCOSS generally supports these priorities (point 3.4) but suggests priorities also recognise:

- That people with intellectual disabilities as a population are not a homogenous group
- That non-government organisations and Community Health Centres must be included under the Service Framework as part of the networks.

Balance between specialist services and mainstream provision
NCOSS recognises that better health care for people with intellectual disabilities will at times require specialist knowledge, expertise and interventions. There will also possibly be many times when people with intellectual disabilities can be successfully treated by the mainstream system, with better access, communication and understanding.

The development of necessary specialist services must not create bottlenecks for people with intellectual disabilities where they are channelled only to specialist services, instead of receiving treatment via the mainstream in the first instance. It must be clearly reinforced with the mainstream health professionals that the existence of a specialist service does not mean that all people with intellectual disabilities must go to it and can no longer be patients in the mainstream system. This applies to all tiers of the model, except the research tier.

Transport
Transport is a barrier to good health care for many people. It is especially so for many people with intellectual disabilities who may need escorts, assistance during transport and while waiting and who may not be able to access private or public transport. A genuine commitment to improved health outcomes will also address transport issues for this population.

SPECIFIC COMMENTS on the models:

Tier 1 Strategic health policy and population health
This must include non-government organisations as part of this strategy.

The building of continuing relationships with people with intellectual disabilities is essential in improving the health of individuals. In this regard effective communication with people with intellectual disabilities and their personal support systems is critical to the success of proposals in Tier 1.

People with intellectual disability largely rely on the public health system for their health needs. People with intellectual disability also rely largely on the pension as their major income source. This tier of the model must also recognise that access and transport issues are likely barriers to good health care for people with intellectual disabilities. Consequently, people with intellectual disabilities could be forced to make adverse health decisions due to an inability to pay, ie transport too expensive to attend health appointments etc.

The Discussion Paper places a correct emphasis on preventative health treatment and strategies for people with intellectual disabilities.

Tier 2 Primary health and community health care

The Discussion Paper places a correct emphasis on equitable access to overcome the reduced priority often ascribed to people with intellectual disabilities.

Oral health
The Discussion Paper cites the need to "explore options for special dentistry in each AHS". This is a very vague concept which provides no further detail. NCOSS recommends that NSW Health develop an overall strategy with appropriate resourcing and then the implementation is applied to AHS.

In addition to the Australian Dental Council, NCOSS suggests that links could be made with the NSW Health Centre of Oral Health Strategy and also other oral health organisations/ practitioners such as prosthetists, dental therapists etc.

Electronic health records
In relation to "piloting an electronic health record", currently there is the NSW Health electronic health record pilot in two AHS with an evaluation about to begin this year. Does the framework propose a specific pilot for people with intellectual disabilities?

NCOSS has raised concerns about the Healthelink pilot in relation to people with disabilities and capacity to consent and access to information by parents and carers.

There can be significant benefits provided by an electronic health record for people with intellectual disabilities as well as for the health practitioner. Confidentiality and privacy, however, are as important to this population as to any other people. People with intellectual disabilities could require assistance to exercise their rights and entitlements within the e-health system as well.

NCOSS would not support a separate e-health record for people with intellectual disabilities. Healthelink should be accessible and available to all who want it.

Tier 3 Acute care services

NCOSS supports the strategies under this Tier. However, we need to beware of developing a system that adds administrative burden to the health care of people with intellectual disabilities – thereby creating extra barriers or disincentives to care.

Tier 4 Specialist area/local health services

The Service Framework must provide leadership to general practitioners to communicate and respond to people with intellectual disabilities. Additional resources will be required to implement Tier 4.

NCOSS supports the implementation of individual health care management plans. These, however, should build on or coordinate with care plans under Enhanced Primary Care and the new Medicare initiative for people with intellectual disabilities, not duplicate them.

The building of continuing relationships with the people with intellectual disabilities could be essential in improving the health of individuals. In this regard effective communication with people with intellectual disabilities and their personal support systems is critical to the success of proposals in Tier 1.

Under the Intellectual Disability Health Clinics, access appears to be through existing services which could be problematic. Allied health positions not

mentioned that will be expected to provide services are social workers, occupational therapists and physiotherapists. Will there be additional positions to enable appropriate service? Existing service provision from this group of practitioners is inadequate due to demand pressures.

Clinical Nurse Consultants (CNCs)
Where the need is more of a coordination and educative role, NCOSS questions whether this must be provided by clinical nurse consultants. CNCs must not, by design or default, become the sole entry point for people with intellectual disabilities into the public health system. Again, beware bottlenecks.

Resources
With the already strained resources (money, time, staff, ability to attract and retain staff, accommodation), the risk with the three model options is the AHS will be develop the cheaper, simpler and easier to recruit options rather than necessarily the most appropriate solutions.

Tier 5 Specialist regional/state-wide support and clinical leadership

NCOSS supports an approach that maintains a centre of expertise, excellence and research for improved health treatment and outcomes specifically for people with intellectual disabilities. This Tier must operate in addition to strategies at local and regional levels and must not form a single channel of treatment etc for people with intellectual disabilities.

Transport to any single centre is, as explained, can be very problematic for many people with intellectual disabilities.

- o 0 o -