



Council of Social Service of New South Wales

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National Disability Strategy
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The Council of Social Service of New South Wales (NCOSS) is the peak body for the social and community services sector in New South Wales. NCOSS works with its members on behalf of disadvantaged people and communities towards achieving social justice in this State.

We welcome the Government's decision to develop a National Disability strategy. We note that people with disability continue to face discrimination and significant systemic barriers to full inclusion and participation in Australian communities as well as the social, economic and cultural life of the nation. NCOSS supports the position of the Australian Coalition for the Ratification of the UN Convention on the Rights of Persons with Disabilities, which forms the basis of our submission. NCOSS appreciates the opportunity to provide a submission to the development of a National Disability Strategy.

Should you require further information, please contact Christine Regan, Senior Policy Officer, on 02 9211 2599 ext 117 or chris@ncoss.org.au

Yours sincerely,

Alison Peters
Director
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NCOSS Submission to

***The National Disability Strategy
Discussion Paper***



December 2008

**Council of Social Service of NSW
66 Albion Street, Surry Hills NSW 2010**

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What do you think should be included in the National Disability Strategy?

The National Disability Strategy should be based on the United Nations (UN) Convention on the Rights of Persons with Disabilities and other important UN Conventions.

NCOSS strongly endorses the Government decision to base the National Disability Strategy on the UN Convention on the Rights of Persons with Disabilities.

The UN Convention provides a clear framework for the changes that are needed to make sure that the human rights for people with disability in Australia are protected, respected and fulfilled. It also gives us the opportunity to improve our knowledge about how well the rights of people with disability are respected in Australia.

However, there are other important UN conventions that can also be applied to protect the rights of people with disability. Under the International Covenant on Civil and Political Rights, Australia must ensure that the civil and political rights of people with disability are immediately respected, protected and fulfilled. We are aware that there is substantial work to be done in this area.

There is also a great deal of work to be done to ensure that the economic, social and cultural rights of people with disability are respected, protected and fulfilled.

The National Disability Strategy gives us the opportunity to translate these UN Conventions into an action plan relevant to Australia.

What are the greatest barriers that people with disability face to participating fully within the community

Supported Living

The main facilitators and barriers to successful provision of accommodation support identified in the research are: effective and supportive legislation and agreements; beneficial and compatible building legislation; effective and streamlined interagency coordination; the nature of the supported living arrangements; funding and demand management; staffing quality including training and management; discrimination, including the specific interests of Aboriginal and Torres Strait Islander peoples and people with diverse cultural and linguistic interests; levels of flexibility and choice in service types and levels; and support for the involvement of families and carers.¹

NSW Government Model of Cluster Housing

Researchers have criticised clustered, rather than dispersed, community living as providing an overall poorer quality of life. EIDRN argue that cluster housing disrupts family and community ties even with more progressive cluster community living

¹ 'Effectiveness Of Supported Living In Relation To Shared Accommodation' University of New South Wales Consortium Social Policy Research Centre Disability Studies and Research Institute, City Futures June 2007 p iv

arrangements, which are considered reminiscent of institutional services.² Epstein-Frisch et al suggest that many of the features of institutional living are also risks in cluster models, including: a whole of life umbrella approach to the delivery of services; a custodial and impersonal nature of care; segregation from the community; inability to provide a home-like environment; and their difficulty meeting the physical, emotional, social and skill development needs of the groups of people living there.³ Propagation of the cluster model constitutes a mumpsimus similar to the continuation of disability institutions or large congregate care in New South Wales.

Bigby (2006) suggests that often the primary focus is on day-to-day care by staff and managers, with little weight being given to planning and vision for the quality of life of the people.⁴

The four main goals of supported living identified in the research are

- (i) human rights concerns for people with disability and the equalisation of their position in society to that of the general population, with a focus on empowerment;
- (ii) quality of life, including social participation;
- (iii) independent living with a focus on self-determination and choice; and
- (iv) cost effectiveness for the person using accommodation support and the most effective use of limited funding.⁵

Strategies to bring about appropriate supported living for people with disability include increasing the individualisation of funding allocations, increasing the flexibility of potential living arrangements in ordinary housing which is dispersed within the community and having a more rigorous performance management of services based on the actual outcomes to be achieved for people with disability.⁶

Devolution from congregate care

NCOSS strongly advocates the closure of all disability institutions and/or large residential centres for people with disability, as announced and planned under NSW Minister Lo Po' in 1998. The NSW Government has since resiled from this commitment and is now actively re-developing its large residences under the Stronger Together Disability Plan. People with Disabilities Australia advises that 1162 people with disability remain in 10 large residential centres in NSW as at December 2008. NCOSS believes that, following successful devolution initiatives to dispersed community living in other states, NSW should facilitate improved life

² European Intellectual Disability Research Network (2003) *Intellectual Disability in Europe: Working Papers*, University of Kent at Canterbury, United Kingdom.2003.

³ 2006 Epstein-Frisch, B., Van Dam, T. and Chenoweth, L. (2006) *Presenting the Evidence: Accommodation and Support for People with a Disability*.

⁴ Bigby, C. (2006) Shifting Models of Welfare: Issues in Relocation from an Institution and the Organisation of Community Living, *Journal of Policy and Practice in Intellectual Disabilities*, 3(3), pp. 147-154.

⁵ 'Effectiveness Of Supported Living In Relation To Shared Accommodation' University of New South Wales Consortium Social Policy Research Centre Disability Studies and Research Institute, City Futures June 2007 p iv

⁶ Emerson, E. (2006) *Presenting the Evidence: Accommodation and Support for People with Disability*, Institute for Family Advocacy and Leadership Development, Epping.

outcomes for people with disability by devolving large institutions into small supported living in community locations, tailored around the needs of each person with disability.

People with disability who live in large institutions must be included in the National Disability Strategy, and the Commonwealth should hold the NSW Government accountable so they continue the process of deinstitutionalisation.

Support Services

People with disability have limited access to services to support their independence in the tasks of daily living. Particularly in NSW, support is delivered according to which service types have vacancies, rather than targeted to individual need.

There is also a lack of accessible information for people with disability and their carers around the type of support that is appropriate and/or available.

There are massive workforce issues in providing support services, with huge shortages of available and skilled staff.

Equipment, aids and appliances

Access to essential equipment is limited, with long waiting times of several years for assistance from the PADP (Program of Aids to Disabled People) administered by NSW Health.

Transport

Lack of accessible public transport is a major issue for people with disability, given their income levels. For example, in Western Sydney private buses, which form the majority of public transport, have no timetabled regular accessible buses. There are also major issues in accessing wheelchair accessible taxis and high costs to adapt vehicles.

Subsidised transport in rural and remote areas is essential to enable opportunities for people with disability to participate in economic and social activities taken for granted by non-disabled people.

Physical Community Infrastructure

Lack of accessible physical infrastructure in communities: footpaths, buildings, leisure/recreation facilities impacts on the ability of people with disability to participate in the community and access services. Local Government must develop and implement a program of:

- continuous improvement in the accessibility of existing local infrastructure,
- consistent and mandatory accessibility requirements for
- new buildings/developments and
- development applications,
- town planning

- incentives for progressing the accessibility of local commercial premises eg banks, specialists offices, optometrists etc
- transparent accountability and progress via public reporting

Accessible adaptable housing

NCOSS advocates for a universal standard of housing in Australia that is adaptable and accessible.

Financial Security

Many people with disability are dependent on the disability support pension, which means they are living below the poverty line. In Australia, the median gross income per week of people with disability aged 15-64 was \$255 (AUD), compared to \$501 (AUD) for those without a disability.⁷ Adults with significant disability (particularly intellectual disability) are three times more likely to live in poverty.⁸

Inadequate health care for people with intellectual disability

Poor health care is one of the greatest barriers to participation in the community.⁹ If a person is unwell, then it is much harder to lead a full life in the community. Life expectancy is much lower for people with intellectual disability than the general population, approximately twenty years lower for people with very high support needs.

Issues for people with intellectual disability related to inadequate health care include:

- Communication issues between professional and patient – capacity to communicate, training of professionals in communication techniques.
- High rates, and often complex ranges, of health problems.
- Health professionals have to spend more time with people with intellectual disability but the health system often does not allow for this.
- Diagnostic overlay – mistakenly assuming symptoms are related to the disability.
- Poverty and inadequate supply of free and subsidised health services.
- Inadequate multidisciplinary focus on health problems.
- Few health professionals having a special interest in intellectual disability.
- Many members of society attaching less value to people with disability.
- Health promotion, campaigns and research tending not to focus on people with intellectual disability.
- Limited carer skills in recognising and acting on health problems.

⁷ ABS Survey of Disability, Ageing and Carers, 2003

⁸ ABS Measuring Wellbeing, 2003; Surgeon General: Closing the Gap, 2002

⁹ *The Health Of People With Intellectual Disabilities*, National & NSW Councils For Intellectual Disability & Australian Association Of Developmental Disability Medicine October 2008

- Inadequate cooperative action within and between governments.

Recommended strategies to improve health care for people with intellectual disability include:

1. Specify that all health reform initiatives will incorporate and respond to the health care needs of people with intellectual disability.
2. Work with the States and Territories to develop a network of specialist intellectual disability health teams and clinical nurse consultants who can back up mainstream health services. For most mainstream health services, people with intellectual disability are only 2% of their patients and they often struggle with the challenges to diagnosis and good treatment. Mainstream services require readily available advice and training if they are to provide good health care to people with intellectual disability. Specialised services can also be leaders of the widespread health reform that is needed.

Communication

Almost 60% of people with intellectual disability have severe communication limitations. People with intellectual disability are also highly likely to have severe limitations in all three core activities of daily living: self-care, mobility and communication.¹⁰ This distinguishes intellectual disability from other major disability groups for which severe limitations are more concentrated in self-care and mobility. Additionally, some people with physical and other disability can require appropriate aids and time for communication where necessary.

Participating in society

Many people with intellectual disability function well in familiar environments and routines, and can be independently mobile. Some people with intellectual disability can have considerable difficulty in managing emotions and relating to other people. It is therefore important to consider the level of support required to participate in society, especially in making friendships, maintaining relationships and interacting with others.¹¹

Stigma is a very significant barrier for people with disability; particularly intellectual disability, people with severe behavioural issues, people with autism and people with mental health issues. Australian society generally has a focus only on someone's inability, rather than their abilities and strengths. NCOSS advocates for improved public education, supported by greater opportunities for people with disability to participate in the community, to improve opportunities for the general public to know people with disability and therefore improve understanding. This will lead to a change of attitude focussing on the talents and attributes of people with disability rather than on incapacities.

Accordingly, support to enable the participation of people with disability in the arts and film should increase, to provide an opportunity to for people with disability to tell

¹⁰ Bulletin 67 November 2008 'Disability in Australia: intellectual disability' Australian Institute of Health and Welfare p2

¹¹ Bulletin 67 November 2008 'Disability in Australia: intellectual disability' Australian Institute of Health and Welfare p2

their stories and thereby improve understanding and interactions within the general community.

The exemption of the Migration Act from the Disability Discrimination Act must be removed.

Education

In Australia only 30% of people with disability have completed year 12 and 13% had completed a bachelor degree or higher; corresponding rates for those with no disability were 49% and 20%.¹²

School students with intellectual disability typically require additional support at school in order to learn and successfully participate in the school environment. This is reflected in their lower rate of participation in ordinary classes, compared to students with other disabilities. In 2003, 45% of students with intellectual disability attended ordinary school classes, compared to 95% of students with physical or diverse disability. For this group of students, learning and social difficulties were far more common problems than other sorts of problems that people with disability often encounter, such as participating in sport or physical access barriers. Around 28% of school students with intellectual disability in 2003 did not receive additional educational support for their disability.¹³

The lack of understanding by teachers of different types of disability can lead to inappropriate responses, for example, behavioural issues.

People with physical disability can face difficulties finding appropriate and local education due to inaccessibility of buildings and infrastructure. This limits their ability to be part of the local community if schools are not appropriate locally.

Transitions can be difficult from primary to high school and high school to tertiary education for students with disability and their families. These critical times may require additional support for successful and smooth progress.¹⁴

Employment

On finishing school, people with intellectual disability are far less likely to move into post-secondary education or the labour force than their age peers without disability. In 2003, the labour force participation rate of people with disability who were aged in their 20s was around 60% and between 34% and 46% for those aged in their 30s, well below the 85% participation by young adults without disability.¹⁵

When people acquire a disability whilst in work, they are encouraged to leave, rather than give the person long term leave, like maternity leave, to come to terms with their disability. Long periods of unemployment at this time can create barriers to re-employment.

¹² ABS Survey of Disability, Ageing and Carers, 2003

¹³ Bulletin 67 November 2008 'Disability in Australia: intellectual disability' Australian Institute of Health and Welfare p2

¹⁴ *Critical Bridges: Transitions in Education*. A resource developed by Dept Education & Disability Council of NSW 2007.

¹⁵ Bulletin 67 November 2008 'Disability in Australia: intellectual disability' Australian Institute of Health and Welfare p2-3

There is a need to improve funding of assistive technologies, which can enable employment but can be prohibitively expensive prior to employment. For example, government funding and subsidies for hearing aids discontinue when a person turns 21 years.

Transitions from the Disability Support Pension to paid employment can incur significant financial costs for people with disability, including transport and increased fees for support services. This can lead to decreased income, and hence a disincentive to employment.

Criminal Justice System

There is an over-representation of people with disability in the criminal justice system. NCOSS advocates for appropriate diversionary programs as well as timely and sustainable post-gaol support services. NCOSS further acknowledges the first steps under the *Stronger Together* (NSW Disability Plan) for support services in this regard.

People with disability from culturally and linguistically diverse backgrounds (CALD)

People with disability of CALD backgrounds are three times less likely to use government disability services. The NSW Government Department of Ageing, Disability and Home Care have implemented strategies for more proportional use of disability services by people from CALD backgrounds. NCOSS recommends urgent and renewed attention to this vulnerable population, especially a balance between generic and specialised services, outreach services, tailored culturally appropriate services all with a focus on outcomes for the person and family as well as the local population.

People living in rural & remote areas

People with disability who live in rural and remote areas have significant barriers to fully participating in their community, with poorer access to transport and support services. Longer distances can often mean

- higher access costs to the person with disability and family,
- greater imposition on the person and family to obtain disability support and other necessary services,
- a smaller range and fewer available localised services
- reduced access to quality of life interactions within the community

NCOSS recommends the development of specific strategies to overcome access and availability issues for people with disability in rural and remote areas.

... and what specific local or national actions could be taken to overcome these barriers?

Outcomes & goals for quality of life of people with disability

There is a greater need to focus on the quality of life of people with disability rather than the current government attitude of whether they are adequately 'cared for'. For people with disability, this focus involves goals which describe a quality of life that:¹⁶

- “Achieves, encourages and facilitates overall well-being
 - Physical (eg. physical health, nutrition, exercise and general physical appearance)
 - Psychological (eg. psychological health, adjustment; cognition; feelings, self-esteem, self-concept, self-control)
 - Spiritual (eg. personal values; personal standards of conduct; spiritual beliefs)

- Achieves and facilitates personal goals, hopes and aspirations
 - Practical (eg. domestic activities; paid work; education or volunteer activities; seeing to health or social needs)
 - Growth (activities that promote the maintenance or improvement of knowledge and skills; adapting to change)
 - Leisure (eg. activities that promote relaxation and stress reduction)

- Achieves and facilitates connection with one's environment
 - Social belonging (eg. intimate others; family; friends; co-workers; neighbourhood and community)
 - Community belonging (eg. adequate income; health and social services; employment; educational programs; recreational programs; community events and activities)
 - Physical belonging (eg. home; workplace/school; neighbourhood; community)”

Funding that supports individual choice and priorities

NCOSS recommends the implementation of individualised funding mechanisms, also known as person centred funding or self-directed support. In a departure from regular or traditional funding mechanisms involving block funding to disability providers to service as many people as possible, individualised funding or self-directed support is a new vision that enables people with disability to control their own funding budget and support priorities. Using this approach, funding would be provided for direct decision-making by the person with disability. NCOSS maintains that adequate

¹⁶ 'Effectiveness Of Supported Living In Relation To Shared Accommodation' University of New South Wales Consortium Social Policy Research Centre Disability Studies and Research Institute, City Futures June 2007 p 18 referencing the University of Toronto Quality of Life Profile

support for the service industry is a necessary and critical element to this new approach. Self-directed funding can be

- provided to and managed by the person, and/or if necessary by their family/advocate or administered by an intermediary body of the person's choice (eg. for employment and financial accountability etc)
- spent according to a regularly reviewed plan centred on the person's needs and individual goals/priorities based on the strengths, talents, interests and attributes of the person with disability rather than the deficits
- assisted in planning and programming if required by professionals and social educators,
- allocated by the person to existing disability services or used to initiate new or specific service supports

There are good models available in both international and national disability practice. Assuming adequate monetary allocations and flexible guidelines/contracting, NCOSS contends that a funding system of self-directed support or individualised funding will

1. provide appropriate accountability for the person with disability as well as for the expenditure of government funds
2. enable improved quality of outcomes and supports to people with disability
3. improve consumer satisfaction with disability services
4. facilitate more accurate data collection on activities and performance for expenditure and more realistic unmet need
5. fulfill all contractual, legal and administrative obligations
6. enhance and expand the existing disability services industry, including the flexibility of supports that the industry often advocates, the range of services and the quality of support delivered to the individual

Accordingly, a self-directed support approach can serve to provide solutions for specific issues because the supports are determined and directed by the individual around their personal needs. Immediate benefits of this approach include

- culturally appropriate support responses that start with the person, including self-determination by Aboriginal and Torres Strait Islander people with disability
- tailored supports using local resources in rural areas, or the ability to initiate new localised solutions
- the introduction of choice for people with disability in the kinds of supports that are important to them as individual people
- real engagement in decision-making by people with disability, not just consultation or participation in external processes
- a reduction in entrenched or inappropriate service models or service types
- ability to innovate within responsive timeframes
- efficiencies in the service system and the elimination of duplication of services and administration costs

- an increase in consumer confidence in the provision of disability supports

Recommended policy actions

1. To ensure that the needs of people with disability are considered in relation to all mainstream policy areas, and to promote Commonwealth-State/Territory co-operation, the National Disability Strategy should require each Ministerial Council to conduct a compliance audit of the UN Convention on the Rights of Persons with Disabilities and to develop an action plan to progress all issues identified.
2. Priority should be given to assessing the compliance against the UN Convention of all national frameworks and strategies, for example, the National Community Crime Prevention Programme and the National Council to Reduce Violence against Women and their Children.
3. The National Disability Strategy should include a commitment to achieving equitable outcomes for priority population groups including women with disability, Aboriginal and Torres Strait Islander people with disability and people with disability from culturally and linguistically diverse backgrounds.
4. The National Disability Strategy should include significantly enhanced resourcing for disability representatives and legal and advocacy organisations to participate in the development and monitoring of implementation actions
5. The National Disability Strategy should include a commitment for each Commonwealth Department and agency to develop a disability strategy based on the UN Convention that addresses each Department and agency's specific responsibilities and also those issues that are common to all agencies, including:
 - a. employment practices, including targets for opportunity and participation by people with disability;
 - b. accessible premises;
 - c. accessible communications;
 - d. accessible procurement; and,
 - e. effective consultation with people with disability

NCOSS contends that the concomitant benefits will greatly improve the access and participation of people with disability as well as many others in society.
6. The National Disability Strategy should also include the same commitment from each State and Territory on behalf of its Departments and agencies.
7. The National Disability Strategy should establish a body with responsibility for ensuring co-ordination within Government. The role of this body would be to work in consultation with disability representatives, legal and advocacy organisations and advisory bodies to:
 - Identify actions needed under the Convention that are cross-departmental;

- Promote information about effective strategies across jurisdictions and to local government, the private sector and other organisations;
- Co-ordinate the development of Australia's initial comprehensive report on its compliance with the Convention (due by August 2010); and,
- Co-ordinate an ongoing process of feedback between reporting under the Convention and the further development of the National Disability Strategy and measures for implementation of the Strategy in all areas.

This year, Queensland Advocacy Incorporated conducted an extensive process of research and consultation to develop a resource entitled *The Human Rights Indicators for People with Disability*. This resource provides a valuable starting point for turning the UN Convention into strategies that can be developed, adopted and monitored in Australia.

What areas of research do you think should be a priority to better inform the National Disability Strategy?

- Research and development on how universally designed goods, services, equipment and facilities can be promoted within the general community and applied through general government policy and expenditure processes.¹⁷
- Research into the benefits and application of individualised funding mechanisms for people with disability towards greater coverage, application and availability across Australia.
- Research and development of technologies that are affordable to persons with disability.¹⁸
- Enhanced research on the health of people with intellectual disability, in both mainstream and specialised research.
- Other successful international models of providing support services to people with disability.

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Should you require further information,
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¹⁷United Nations Convention on the Rights of Persons with Disabilities

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