

NSW DISABILITY NETWORK FORUM

NSW Disability Network Forum Submission to NSW Disability Services Act Review February 2013

The NSW Disability Network Forum is pleased to provide this submission to the Review of the NSW Disability Services Act. Member organisations of the NSW Disability Network Forum have contributed to this submission from their areas of expertise as well as including jointly agreed positions shared within the Forum. The NSW Disability Network Forum (the Forum) conducted an intensive discussion workshop using the Issues Paper and the Act itself in February 2013.

Unfortunately, the Forum has been unable to provide more in depth analysis and feedback given the short consultation time available. If you require any further information or clarification, please contact the NCOSS secretariat: Christine Regan chris@ncoss.org.au ph. 92112599 ext. 117.

About the NSW Disability Network Forum

Initiated in June 2011, the **NSW Disability Network Forum** comprises non-government, non-provider peak representative groups whose primary aim is to promote the interests of people with disability. The aim of the NSW Disability Network Forum (the Forum) is to provide a new avenue to build capacity within and across all organisations and groups so that the interests of people with disability are advanced through policy and systemic advocacy. The Council of Social Service of NSW (NCOSS) provides secretariat support to the Forum as part of funding from Department of Family and Community Services, Ageing, Disability and Home Care.

The NSW Disability Network Forum generally meets monthly to co-ordinate issues of significance among people with disability, make representations on disability issues in NSW to Government, advise Government and others on policies affecting people with disability and to promote issues relating to people with disability across the wider society.

More information and current reports from the NSW Disability Network Forum are available at http://www.ncoss.org.au/component/option,com_docman/task,cat_view/gid,367/Itemid,78/

NSW Disability Network Forum Member Organisations:

Aboriginal Disability Network NSW	NSW Consumer Advisory Group - Mental Health
Association of Blind Citizens of NSW	NSW Council for Intellectual Disability
Brain Injury Association NSW	NSW Disability Advocacy Network
Deaf Society of NSW	People with Disability Australia
DeafBlind Association NSW	Physical Disability Council of NSW
Deafness Council (NSW)	Positive Life NSW
Institute For Family Advocacy	Self Advocacy Sydney
Intellectual Disability Rights Service	Side By Side Advocacy Incorporated
Multicultural Disability Advocacy Association of NSW	Council of Social Service of NSW

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The NSW Disability Network Forum considered the questions in the Issues Paper and the Discussion Paper and has grouped the feedback under the following topic headings.

Implementing the existing Act

The NSW Disability Network Forum observed that the NSW Disability Services Act 1993 contained the potential for person-centred approaches to be implemented at any time during the operation of the legislation. The implementation of the Act however, effectively inhibited a more person-centred approach and ensured the Act focused on service provision and funding to organisations and providers.

Clause 8 (2) (b) clearly provides the capacity for funding to be provided directly to persons in the target group and Clause 8 (2) (c) provides that supports can be provided by other persons and bodies. Similarly Clause 10 (1) (a) enables the Minister to approve funding to a person in the target group. However, no terms and conditions are then laid out in the Act for the provision of funding to the person, only to organisations. This may not mean that funding cannot be provided to the person, only that funding can be provided to eligible organisations. Government interpreted the Act as only providing funding to organisations.

Further, clauses 13, 16 and 18 refer to the terms and conditions on which financial assistance may be provided to a person or eligible organisation. This review provides an opportunity for the foresight of the original architects of the DSA to be enhanced and expanded to encompass contemporary thinking surrounding the rights, inclusion and support of people with disability.

UN Convention on the Rights of Person with Disabilities UNCRPD

The Forum was clear that the legislation should be underpinned by the UNCRPD. There are two groups of rights under the Convention; the social, economic and cultural rights that are subject to continuous improvement and staged introduction; and the civil and political rights which can be met immediately.

Objectives in the new legislation

The Forum believes that the new disability legislation should closely reflect the UN Convention on the Rights of Persons with Disabilities. The Act should be explicit about this connection.

The NSW Disability Network Forum contends that the **choice and control** of the person with disability is a primary Object of the new Act.

While the Objects of the current Act are still worthwhile, the language of “services” must be deleted and updated as it implies traditional specialist disability service provision. In the new person-centred environment, people with disability will purchase their supports from a range of options, including mainstream, local, private and commercial as well as specialist disability service providers. The term “supports” is more encompassing than “services”.

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Principles in the new legislation

The Forum considered that the existing Principles and many of the Applications of the Principles are good and can enable a truly person-centred approach, if interpreted to be implemented in that way. However, the Forum recognises the review is an opportunity to upgrade the Principles to include **choice and control** by the person with disability.

The Forum considered that the legislation could contain a principle specifically in relation to Children: as an example refer Disability Services Act 2006 (Vic)

“(I) have regard for the needs of children with a disability and preserve and promote relationships between the child, their family and other persons who are significant in the life of the child with a disability;”¹

The Forum did a short analysis of the Principles contained in the legislation of other jurisdictions and found that several phrases captured concepts that would enhance the Principles in the NSW legislation. These included:

- Flexible and responsive (from Victoria)²
- Individual aspirations (from Victoria)³
- Balance safety with participation and risk (from Victoria)⁴
- Inherent dignity (from Tasmania)⁵

The NSW Disability Network Forum contends that Aboriginal and Torres Strait Islander communities should direct how their communities are represented and be included in the legislation, the Objects and Principles.

Disability definition

Some people with long term disability may be unable to prove their disability is absolutely permanent. This should not be a prohibitive criterion under the existing or new legislation. Therefore, the Forum recommends the word “permanent” be changed to “long term” in the definition of a person in the target group in line with United Nations Convention on the Rights of Persons with Disabilities.

Who is included in the Act?

The Forum understands that the target population of people with disability under the current DSA will not be expanded under the present Stronger Together funding plan for disability services. However, the target groups of the proposed Ability Links Coordinators will already extend supports to more than the traditional target population:

“Ability Links NSW Coordinators will work with individuals and communities...

Group 1 involves the provision of information on community, mainstream and disability services to all people with disabilities and the general population.

¹ Reforming NSW Disability Support Discussion Paper, page 56:

http://www.adhc.nsw.gov.au/_data/assets/file/0020/263252/Reforming_NSW_Disability_Support_Discussion_Paper.pdf

² Reforming NSW Disability Support Discussion Paper, page 58:

³ Reforming NSW Disability Support Discussion Paper, page 58

⁴ Reforming NSW Disability Support Discussion Paper, page 59

⁵ Reforming NSW Disability Support Discussion Paper, page 60

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Group 2 involves working alongside people with disabilities who are not receiving disability services assisting them to expand their networks by building on their assets and networks, and connecting them with mainstream and community supports to support them in meeting their goals and aspirations.

Group 3 involves assisting people receiving low levels of disability support in the same way as Group 2 clients and extends to helping them determine the most appropriate way to manage their supports (eg self-management, financial intermediary or service intermediary), and assisting them to find, access and change service providers...⁶

The new legislation must therefore enable the Ability Links Coordinators to work with all people with disability, thereby not limiting legislative coverage just to people receiving or eligible for specialist disability services or high level supports.

Inclusion of people with disability currently using community care services

There are around 50,000⁷ people with disability in New South Wales using community care services under the NSW Community Care Supports Program, not funded from NSW disability services. The NSW Disability Network Forum considers that it is necessary for people using these services to have access to enhanced support through person centred approaches. While the eligibility criteria in the legislation may include low level users of community care services, there are concerns that these people may not be included.

It is very unclear how people with disability relying on low level community care style services will continue to be supported. Consequently, people with disability with low level needs must receive necessary supports and this must be assured within the Act.

Independent Advocacy and Independent Information

The NSW person centred system and people with disability supported by it will be assured of improved outcomes and operations with the ready availability of independent advocacy and independent information when needed and requested. The Forum contends that the enhanced and sustained provision of independent advocacy and independent information alongside the person centred system will improve its functioning in the following ways:

- **Value for money:** at times when people are feeling overwhelmed, uncertain or confused and require external advice or reassurance from people with individual and systemic expertise, independent advocacy and independent information can provide this role at a very cost effective investment.
- **Safeguards:** Internal safeguards measures are never enough to provide adequate protections. For people with disability, their families, guardians and others the provision of a parallel independent advocacy and independent information alongside bureaucratic and provider systems to assist with person centred planning, individualised funding and

⁶ Report of the Ability Links Taskforce Nov 2012:

http://www.adhc.nsw.gov.au/data/assets/file/0006/262905/ALNSW_Taskforce_Report_for_website.pdf

⁷ Australian Government Department of Health and Ageing (2011) *Home and Community Care Program Minimum Data Set 2009-10 Annual Bulletin*, Australian Government Department of Health and Ageing, Canberra, Table A3.

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other issues affecting them will ensure that there are a range of protections for people who historically have been extremely vulnerable in many ways.

- **Early warning:** The support of timely, non-aligned, independent information and/or Independent advocacy could allow issues to be identified and handled with expertise at the earliest possible stage to avoid costly escalation. Further, this could enable the service or system to work better by identifying failures or opportunities for improvement, or by simply solving a problem for a person when there is nowhere else to go.
- **Levels of administration and cross-agency issues:** There is long standing expertise in many Independent Advocacy and Independent Information organisations in responding to the needs of people with difficult and/or complex issues, across a broad range of government agencies at the individual and systemic levels. This experience is important to the person with disability and their supporters in navigating the complex levels of federal, state and local government responsibility.
- **Broad options and non-systems issues:** the support of independent advocacy and information is required in dealing with everyday issues to do with housing, budgeting, managing the household, personal decisions and accessing professional supports. While often not seen as imperative in the scheme of support services, these can be critical inhibitors to inclusion and participation or a good life. Independent advocacy and information can have the flexibility to address these everyday issues in the short and longer terms at the individual and systemic levels.
- **Assisting the person-centred system to work better:** Building independent advocacy and independent information supports at an early stage, will ensure that there is flexible assistance for people with disability (particularly where there is no systemic capacity to respond). Flexible assistance for people with disability ensures that issues for the person with disability do not needlessly escalate, that gaps or program/system response issues can be identified quickly, that misunderstandings are competently and objectively managed and that whole-of-life issues are handled with care.

Person with disability directs their decisions

A person-centred approach begins with the person with disability directing their individual plan and directing their self-assessment. The NSW Disability Network Forum contends that the legislation should start from this point, and then provide the opportunity to build in the support, for some people with disability who seek it, to direct, and participate /be involved in the decisions that will affect their supports towards inclusion and participation.

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Protection against liability

The NDIS draft Bill provides protection for a person with disability against liability (section 97) where someone has used the funding for non-approved purposes. The NSW Disability Network Forum believes this to be an important protection for the person with disability that should be included in the NSW legislation.

Restrictive Practices

The NSW Disability Network Forum contends that restrictive practices should be fully described in the Act, regulations and in policy. The use of restrictive practices must be independently monitored and reported and progressively reduced over time. The use of restrictive practices should be overseen by an independent Senior Practitioner who has responsibility for managing the reduction of restrictive practices. The use of restrictive practices and complaints arising from them must not be handled internally by disability service providers.

Least bureaucratic legislation

The Forum contends that the new legislation should provide the least bureaucratic and thereby the most enabling environment within which the person with disability can purchase or secure appropriate supports and services. The standard and level of quality care should be negotiated between the person and the supplier, with the assistance, if required, of a family member, an advocate, a support planner or other chosen supporter. Consumer protections must be provided as for any purchasers or consumers of services. For people using intensive, very high level support services such as accommodation support services, some intensive personal care and other similar supports, there may need to be in-built quality assurance mechanisms. National standards for disability services could set the benchmark for continuous improvement of supports to people with disability and could differentiate for potential purchasers the types and levels of required individual support.

Safeguards

The NSW Disability Network Forum acknowledges that safeguards have to be built into the legislation for the protection of people with disability in extreme or adverse circumstances. There are real dangers, however, that these safeguards could become regular practice and could therefore restrict the very choice and control that the Principles and Applications of the Principles seek to promote. The way in which the legislation is interpreted and implemented will be laid out in regulations and policy. Accordingly, the Forum strongly recommends that the legislation is as clear as possible in its Principles and implementation clauses so that subsequent interpretation on safeguards does not limit or restrict opportunities, or serve to become regular pre-determined general practice for groups of people. Consequently, the Forum also recommends that the Act and regulations and policy be framed within an enabling approach rather than in a restrictive or prohibitive manner to avoid always inhibiting options for the person with disability rather than promoting options for independence and social, economic and political participation.

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Dignity of risk

The NSW Disability Network Forum promotes dignity of risk for people with disability. As a corollary to providing safeguards for people with disability against harm, misadventure and criminal activity, the right to dignity of risk ensures that the person can make reasonable choices with reasonable risks to live a good life, like other people. It is a form of risk management, in preference to risk elimination which only serves to unreasonably prohibit the personal choice and freedoms of the individual.

Choice and control

The Forum is concerned that other legislation or policies could unintentionally and unduly limit the choice and control of the person with disability, for example workplace health and safety legislation or duty of care policies. This is a situation where workers might act to eliminate a perceived risk rather than manage it, confusing duty of care with dignity of risk or simply not paying attention. In this scenario, a better consideration and the appropriate action could have been in favour of the right to dignity of risk for the person with disability. Accordingly, the Forum agrees with Disability Act 2006 (Victoria) section 5 (n) that “supports should be provided in such a way that reasonably balances safety with the right of persons with a disability to choose to participate in activities involving a degree of risk.”⁸

Accountability

The NSW Disability Network Forum considered that the Act did not provide sufficient accountability to Government, either on the range of services provided, the quality of services or the extent to which the services provided to people with disability addressed the Objects or the Principles of the Act. Any new legislation should be clear in its accountability mechanisms to both Government and, under a person-centred approach, to the people with disability whom the legislation supports.

Range of options to enable choice

The Issues paper and the Discussion paper both describe that the new person-centred environment as providing choice and control for the person with disability in the supports need to enable their independence and participation in the community. The Forum contends, however, that realistic choice depends on the availability of a range of options from which to select the most suitable or appropriate form of support. Under the new person centred system, this must extend beyond traditional specialist disability providers to include local, mainstream, private and commercial, informal and other supports as required and chosen by the person. The NSW Disability Network Forum recognises that the range of choice will evolve over time and that specialist disability providers will be part of that mix but the new legislation must enable the broadest possible range of choices available to the person with disability.

⁸ Reforming NSW Disability Support Discussion Paper, page 56:

http://www.adhc.nsw.gov.au/data/assets/file/0020/263252/Reforming_NSW_Disability_Support_Discussion_Paper.pdf

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People with disability on the margins

The Forum expressed concerns regarding the lack of specific identification in the legislation of marginalised people with disability, particularly but not exclusively, people with disability with no significant relationships, homeless people with disability, people with disability in contact with the justice system and parents with disability. The Forum recommends that the draft legislation be closely reviewed before completion to ensure that these and other marginalised groups are fully included in the provisions.

Official Community Visitors Scheme

The NSW Disability Network Forum strongly supported the continuing role of the Official Community Visitors Scheme. Official Community Visitors provide a critical monitoring role with an essential level of independence, separate to departmental and provider interests. The Forum considered that the Community Visitors Scheme could complement other areas of reform, by providing an important safeguard and official reporting mechanism. There was discussion at the Forum about the role of Community Visitors in relation to supports provided in a person's home. The Forum recommends attention be given to changes and expanding the Community Visitors role in relation to the new forms of support that people with disability could purchase and engage, while ensuring considerations of consent and privacy of the person.

Complaints and Appeals AND

Community Services (Complaints, Reviews and Monitoring) Act 1993 NSW or CS CRAM Act

The Forum strongly recommended that CS CRAM Act be continued and strengthened. The CS CRAM Act should be amended to reflect the UN Convention on the Rights of Persons with Disabilities and the Principles in new legislation. The Forum recommends that the Appeals process must be time limited to ensure that appeals reach a decision within a reasonable and predictable timeframe, providing some assurance for the appellant.

The Forum contends that the new legislation should not become overly bureaucratic. This will work against the stated aims of person-centred outcomes.

Capacity building for people and families

The NSW Disability Network Forum strongly recommends that the legislation provides for on-going capacity building for people with disability and families. Capacity building for people and families will improve their ability to make efficient and effective use of the person-centred system and to retain and maximize the personal abilities and resources of people with disability and families, and to be creative and innovative in their independence and participation. The person-centred system will benefit from people with disability taking a more direct leadership role over time, thereby reducing the inefficiencies of the current system.

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Accessible Formats

It should be mandatory under the new legislation that all general information and notices are provided in a range of accessible formats. Regarding information provided specifically to a person with disability, that information must be provided in a manner that is most likely to be understood by that person, then equally to their family member, nominee, advocate or other chosen supporter.

Disability Action Plans & National Disability Strategy

NSW has actively supported the implementation of the National Disability Strategy by being the first jurisdiction to release its National Disability Strategy Implementation Plan 2012-2014. This plan sets out how NSW agencies will respond to the policy objectives of the National Disability Strategy and what tasks and achievements can be expected during this timeframe. Accordingly, the new legislation should fully enshrine reporting and implementation obligations under the National Disability Strategy and for Disability Action Plans and their relation to outcomes for people with disability.

Disability Action Plans by NSW Government Agencies should constitute continuous improvement strategies towards progress in responses to people with disability in NSW. The Plans should be reported against milestones and periodic new Plans should not simply report activity but how the agencies have made advances in engaging with, supporting or responding to people with disability in an ongoing basis. The Plans must be the active responsibility of a senior officer's duties and should be monitored and publicly reported.

People with disability choose who can accompany them

The new legislation should enable people with disability to choose who should accompany them to which appointment on which occasion. In actuality, people with disability choose different people to accompany them on different occasions, like anyone else. A person with disability must be able to be accompanied by any person of their choosing. This is in addition to any official nominee status described in legislation. This will be especially important for some people, for people in specific circumstances and for people in particular cultural groups.

Privacy

Due to the nature of the information contained in a person's individual plan, particular consideration must be given to privacy and issues of consent, how that information is stored and shared and whether these are best enshrined in disability legislation.

Review of decisions

The NSW Disability Network Forum recommends that all decisions should be reviewable in order not to inadvertently overlook or omit an important reviewable decision now or in the future. Further, the Forum recommends that a person with disability, a family member or nominee, or an advocate or any person should be able to request a review of a decision. This will provide a valuable safeguard for the vulnerability of the person with disability in various settings.

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Review of Act

The NSW Disability Network Forum contends that any review of the Act must be public and include public consultation prior to finalisation of the review report.

Conclusion

The NSW Disability Network Forum appreciates the opportunity to provide input to the Review of the NSW Disability Services Act. The Forum looks forward to providing more in-depth analysis and feedback later in the year to the actual draft legislation on a more planned timeframe.

If you require any further information or clarification, please contact the NCOSS secretariat, Christine Regan at chris@ncoss.org.au ph. 02 92112599 ext. 117

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