



**Prepared for the NSW Department of Family and Community
Services**

Ageing, Disability and Home Care

Development of New Disability Legislation

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Prepared by the Physical Disability Council of NSW

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Who is the Physical Disability Council of NSW?

The Physical Disability Council of NSW (PDCN) is the peak body representing people with physical disabilities across New South Wales. This includes people with a range of physical disability issues, from young children and their representatives to aged people, who are from a wide range of socio-economic circumstances and live in metropolitan, rural and regional areas of NSW.

The objectives of PDCN are:

- To educate, inform and assist people with physical disabilities in NSW about the range of services, structure and programs available that enable their full participation, equality of opportunity and equality of citizenship
- To develop the capacity of people with physical disability in NSW to identify their own goals, and the confidence to develop a pathway to achieving their goals (i.e. self advocate).
- To educate and inform stakeholders (i.e. about the needs of people with a physical disability) so they are able to achieve and maintain full participation, equality of opportunity and equality of citizenship.

The Physical Disability Council appreciates the opportunity to consider, and make comment in relation to the review of legislation in NSW for people with disability.

Discussion

1. *What do you think are the main objectives that the new disability legislation should aim to achieve?*
2. *Do you think the Objects in the current Act are sufficient or reflect current ways of thinking about people with disability in our community? If not, how do you think they should be changed?*
3. *Do the objectives in any other pieces of legislation that you may be aware of provide guidance for what should be in the NSW legislation? If so, which ones?*
4. *Do you think there should be a purpose section as well as an objects section? If so, what do you think this should say?*
5. *What do you think are the key roles and functions for Ageing, Disability and Home Care, Department of Family and Community Services NSW, as the lead public sector agency in the NSW disability sector? Do the Objects of the current Act reflect these functions? If not, how should they be changed?*

- I. To ensure consistency in reforms to the revised Disability Services Act (Act), PDCN believes that it would be more appropriate if the name of the Act was consistent with terminology used in Convention on the Rights of Persons with Disabilities¹. Subsequently PDCN would recommend that the Act was renamed to either the Disability Supports Act or the Disability: Choice and Control Act.
- II. Legislative reform needs to ensure that the objectives and principles of the revised Act are consistent with the objectives and principles included in the UN Convention of the Rights of Persons with Disabilities (CRPD). Subsequently the fundamental goals of the revised Act need to state the purpose of providing individual choice and control, and with the ability to ensure the full and equal enjoyment of all human rights and fundamental freedoms.
- III. Principles need to recognise that people with disability are not necessarily recipients of welfare through specialist disability services, but having a multitude of other options including the ability to access supports from mainstream, local, private or commercial facilities, as well as from specialist disability supports. Reforms need to recognise that as part of being in control of service delivery that people with disability will become consumers with civil rights and responsibilities. As a consequence people with disability from time to time may need to access information about topics, not necessarily related to disability, such as;
 - Concessions and entitlements
 - Consumer protection
 - Complaint mechanisms
 - Financial matters including credit, debt and mortgage concerns
 - Discrimination
 - Guardianship legislation
 - Occupational Health and Safety
 - Residential and tenancy rights
- iv. With the implementation of Stronger Together 2, the Ageing, Disability and Home Care (ADHC) needs to adopt strategies that will promote;
 - Leadership among Ability Link Coordinators
 - Innovation that facilitate early intervention strategies
 - Opportunities for skill development among persons with disability
 - Community development to ensure local engagement and empowerment

¹ <http://www.un.org/disabilities/convention/conventionfull.shtml>

6. *What principles should be reflected in disability legislation? Why?*
7. *How could the Act's principles be improved to ensure that people with disability are placed at the centre of planning, decisions and delivery of support and services?*
8. *Are the Act's principles and applications effective in ensuring the human rights of people with disability are protected?*

- v. The Discussion Paper – Reforming NSW Disability Support identifies the following fundamental eight key principles also contained in the CRPD:
- A. Respect for inherent dignity, individual autonomy, including the freedom to make one's own choices, and independence of persons.
 - B. Non-discrimination.
 - C. Full and effective participation and inclusion in society.
 - D. Equality of opportunity.
 - E. Accessibility.
 - F. Equality between men and women.
 - G. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.²

The proposed current Act includes a Schedule containing guiding Principles and examples of how these guiding principles will be applied. PDCN is concerned that these principles do not conform with the CRPD, and would recommend the following improvements to ensure greater consistency;

Principle		Flexibility and Responsiveness
Application of principle	of	To meet the individual needs and goals of the persons with disabilities receiving services
PDCN Preferred option		Facilitate tailored and flexible responses to the individual goals and needs of the person with a disability (Victoria) ³

² NSW Department of Family and Community Services (2013) Discussion Paper - Reforming NSW Disability Support

³ NSW Government (2013) Reforming NSW Disability Support Discussion Paper

Principle	Least restriction
Guiding principle	Persons with disabilities receiving services have the same right as other members of Australian society to receive those services in a manner which results in the least restriction of their rights and opportunities
PDCN Preferred option	Be provided in a way which reasonably balances safety with the right of persons with a disability to choose to participate in activities involving a degree of risk (Victoria) ⁴

Principle	Realising individual capabilities
Application of principle	Persons with disabilities have the right to realise their individual capacities for physical, social, emotional and intellectual development
PDCN Preferred option	Advance the inclusion and participation in the community of the person with a disability with the aim of achieving their individual aspirations (Western Australia) ⁵

- vi. The CRPD refers to the principle of accessibility which is defined as ‘the means that governments must act to make sure that people with disability have the same access to buildings, housing, services, information, leisure, and other areas of community and social life, but this is not identified in Schedule 2 of the Act. Subsequently it is recommended by PDCN, that Schedule 2 of the Act include the provision of physical access to buildings and housing.

9. *How should ‘disability’ be defined for the purposes of the NSW disability legislation? Why?*

10. *Are there any other terms that you think should be carefully defined within the legislation? If so, please advise which ones and why?*

- vii. PDCN recognises that the target population identified in the Stronger Together funding plan only includes people with disability in receipt of disability services, but PDCN would recommend that the target group includes all people with disability as identified by ADHC for the implementation of the new Ability Links Regional Offices:

“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.
- Group 2 involves working alongside people with disabilities who are not receiving disability services assisting them to expand their networks by

⁴ NSW Government (2013) Reforming NSW Disability Support Discussion Paper

⁵ NSW Government (2013) Reforming NSW Disability Support Discussion Paper

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 (egg self-management, financial intermediary or service intermediary), and assisting them to find, access and change service providers...⁶

Based on what has been proposed for Ability Links Coordinators, the revised Act needs to identify the target group as all people with disability, and not just people not receiving specialist disability services or those eligible for high level supports.

- VIII. The list of definitions in section 4 of the current Act are more relevant to functions of service delivery, and subsequently not relevant to a person centred approach. PDCN believes that it would be more accessible, and subsequently more appropriate if terms requiring further explanation were incorporated into documentation, such as frequently asked questions, information sheets and guidelines. To ensure accessibility this documentation needs to be available electronically, in hard copy and in community languages. Due to the changing landscape of service delivery for people with disability, PDCN would also advise that documentation was reviewed annually to ensure that these remained current.

11. What should the legislation cover in a person centred system?

12. Should the legislation refer to or regulate individual planning?

13. Should the legislation include principles to guide the development of individual plans? If so, what should these be?

14. Should the legislation contain the power to make standards or guidelines for individual plans that:

- *Protect the rights of people with disability? and*
- *Regulate access to funding?*

15. Should the legislation include a requirement about the broad purpose for which funds will be provided under individualised funding? If, so what should this be?

16. Should the legislation contain a power to specify the type of services and support that can be funded?

17. Should the legislation describe the types of funds management arrangements that can be used and under what circumstances (for example, fund holding or support coordination)?

18. Should the legislation require that certain types of funding will only be provided where an individual plan is in place?

⁶ Report of the Ability Links Taskforce Nov 2012

19. Should the legislation provide government with the power to limit the arrangements by which some people can manage their own funds if the risks outweigh the benefits?

- ix. To facilitate inclusion it is recommended that the revised Act not be too bureaucratic as this may prevent people with disability from exercising the rights and freedoms practiced by other people without a disability. For the revised Act to be successfully implemented it is assumed that users of the legislation have a good understanding and aptitude of the CRPD and are able to apply the object and principles of the CRPD to the Act.
- x. It is recommended that the revised Act contain clauses identifying;
- Eligibility criteria, as identified paragraph vii
 - Guidelines that outline the principles and process used in person centred planning, where the planning process starts with the person with disability identifying his or her support needs
 - Legislation describing the different funding arrangements. It needs to be highlighted that as part of the person centred planning process it will always remain up to the person with disability to articulate the preferred funding arrangement. If the person with disability is unable to identify the preferred choice, then a family member, nominee, advocate or other chosen supporter may assist with this process
 - Funding guidelines that include a list of goals and outcomes. This needs to be accompanied with a note explaining that needs identified are not necessarily an exhaustive list of all goals or outcomes, and subsequently a persons' identified goal may not necessarily be consistent with these guidelines
 - It is recommended that the revised Act include a clause protecting the person with disability against the liability of a support or nominee acting on behalf of him or her
 - Reforms identifying accountability and governance procedures, including the requirement for all ADHC funded services to conduct employment screening on employees, volunteers, directors and committee members
 - The inclusion of a clause identify the importance of the policy on probity in employment for ADHC funded services
 - Additionally reforms that require ADCH commitment to an ongoing provision of resources and funding to ensure skill development and empowerment of people with disability
- xi. It is recommended that the revised Act exclude clauses referring to the following:
- Service types – PDCN considers that a list service types may be too prescriptive, and not necessarily include a service type relevant to the participants goals and aspirations
 - Expenditure of funds on illegal or inappropriate pursuits – It is also considered by PDCN that because members of the general public have the ability to

participate in pursuits that other may consider to be inappropriate, or not, regardless of whether paid for privately or out of public funds, that this freedom should also be available to a person with disability.

20. Should restrictive practices be regulated by law? If so, why?

21. Should provisions regulating restrictive practices go in:

- The new disability legislation, or
- Some other law like the *Guardianship Act 1987* (NSW)? Why?

22. How should legislation define 'restrictive practices'?

23. What process should govern the approval of restrictive practices and what issues should be considered in this process?

24. Under what circumstances should restrictive practices be allowed in 'emergency situations'? How should these situations be defined? Should there be any limits on the use of restrictive practices in such situations?

25. Should the new disability legislation establish an office responsible for overseeing the use of restrictive practices? If so, what functions and powers should the office have? Why?

- xii. Information gathered via community consultations and public hearings, PDCN believes that due to abuse and neglectful practices in the past, that restrictive practices should be fully described in the Act, and in regulation and policies relevant to the Act. The use of restrictive practices must be independently monitored and reported and progressively reduced over time.
- xiii. 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.

26. Should the new legislation embed the broad standards regarding service quality of specialist disability services?

27. Should the new Act refer to agreed State and/or national standards for specialist disability services?

28. What role, if any, should disability legislation play to minimise the risk of harm to people with disability who choose mainstream providers or providers who are not monitored or regulated?

xiv. The most recent edition of the NSW Standards reflects a change from a focus on normalisation and value status to a human rights framework. The 2011 edition of the Standards has been streamlined from ten to six standards in line with the revised National Standards. These streamlined standards are:

1. Rights
2. Participation and inclusion
3. Individual outcomes
4. Feedback and complaints
5. Service access
6. Service management.

With these changes to the Standards there have been a number of other changes including:

- Individual Needs and Decision Making and Choice have been merged to a single standard called Individual Outcomes
- Valued Status has now been included in the standard on Participation and inclusion
- Privacy, Dignity and Confidentiality is now a core element in the new Standard on Rights
- Family Relationships have been incorporated across all standards instead of a stand-alone standard.⁷

PDCN does not believe that ADHC is responsible for the quality of service provided by mainstream services that are not monitored or regulated by ADHC. Commercial and mainstream services need to adopt measures to remain competitive. Measures may include the particular expertise and experience of providers, staff capabilities, costs and availability of supports, conditions related to support delivery, quality assurance mechanisms, complaints mechanisms

29. Should the new Act establish additional safeguards for people with disability who are more vulnerable?
30. If specific safeguards are to be established what principles should inform them?
31. Should disability legislation require people providing specialist disability services to undergo background screening such as criminal records checks?
32. If people are screened, should this be limited to people providing particular specialist services? If so, which services? Why?

⁷ NSW Government Department of Family and Community Services, Ageing, Disability and Home Care (2011) Standards in Action

33. Should people with disability who live in supported accommodation have additional external oversight safeguards to protect their rights?
34. What are the most important elements of any scheme to give them additional safeguards?

- xv. Whilst PDCN understands the purpose of service and workforce safeguards for people with disability who are more vulnerable, such as people living in congregate care and children in receipt of support services, PDCN recommends that the Act, and relevant documentation be framed within an enabling approach rather than in a restrictive or prohibitive nature to prevent safeguards from being used inappropriately where they inhibit opportunities that may otherwise enhance independence and social, economic and political participation.

The Young People In Nursing Homes National Alliance recommends that authorities in Australia be guided by the Centre for Policy on Ageing in the United Kingdom, where services and facilities providing social care are built on the following seven principles:

- **Prevention:** empowered people and strong communities will work together to maintain independence. Where the state is needed, it supports communities and helps people to retain and regain independence.
 - **Personalisation:** individuals not institutions take control of their care. Personal budgets, preferably as direct payments, are provided to all eligible people. Information about care and support is available for all local people, regardless of whether or not they fund their own care.
 - **Partnership:** care and support delivered in a partnership between individuals, communities, the voluntary and private sectors, the NHS and councils - including wider support services, such as housing.
 - **Plurality:** the variety of people's needs is matched by diverse service provision, with a broad market of high quality service providers.
 - **Protection:** there are sensible safeguards against the risk of abuse or neglect. Risk is no longer an excuse to limit people's freedom.
 - **Productivity:** greater local accountability will drive improvements and innovation to deliver higher productivity and high quality care and support services. A focus on publishing information about agreed quality outcomes will support transparency and accountability.
 - **People:** we can draw on a workforce who can provide care and support with skill, compassion and imagination, and who are given the freedom and support to do so. We need the whole workforce, including care workers, nurses, and occupational therapists.
- xvi. Research from the Centre for Ageing Policy identifies the following reflective insight regarding safeguards; -

'Choice and control can only be meaningful if people can make informed choices, in an environment where they can make decisions freely and safely. Giving people control over their care and support does not mean they are abandoned. Safeguards

against poor practice, harm and abuse need to be an integral part of managing care and support'.⁸

- xvii. The Probity in Employment Policy for Funded Services⁹ identifies service management requirements for ADCH when recruiting new staff, for staff promotions, volunteers, student placements, directors and committee members for all services in receipt of ADCH funding. To ensure a common understanding of roles and responsibilities it is crucial that this Policy be referenced in the revised Act.

35. Should the Official Community Visitors scheme be transferred to the new legislation? If so, how could the role of the Official Community Visitors be made more effective?

36. Should the Official Community Visitors scheme apply just to 'visitable services' as currently defined? If not, how should the scope of the scheme be expanded? Why?

- xviii. PDCN acknowledges the important role of the Community Visitors Scheme in providing a critical monitoring role with an essential level of independence, separate to departmental and provider interests. Furthermore PDCN would recommend that this important safeguard be retained, with an expanded role based in the community with the ability to access and utilise these services as part of a person-centred plan.

37. What should people with disability be able to make complaints about?

38. Does the CS CRAM Act adequately address concerns about services by people with disability or their families, carers or advocates? If not, what changes are needed?

39. How should the complaints mechanism in the CS CRAM Act apply to the broader range of service providers likely to operate under individualised funding arrangements?

40. Are the principles that guide responding to complaints in the CS CRAM Act appropriate?

41. Should disability legislation rather than the CS CRAM Act regulate management of complaints about disability services?

- xix. PDCN recommends that CS CRAM Act be retained, but strengthened so that it is amended to reflect the CRPD, and the principles of the revised Act. It is fundamental that the integrity of the CS CRAM Act be maintained to provide a mechanism that facilitates an independent and accessible process for the resolution of complaints.

⁸ Centre for Policy on Ageing (2010) 0 A Vision for Adult Social Care: Capable Communities and Active Citizens

⁹ NSW Government, Department of Family and Community Service, Ageing, Disability and Home Care (2012) Probity in Employment Policy for Funded Services

42. Are the current review provisions under the Act appropriate and effective? If not, how should they be changed?
43. What review or appeal processes should be available under the future system of individualised funding and what kinds of decisions should be able to be reviewed?

xx. The existing Disability Services Act provides little scope for service users to lodge complaints, but with provisions for service providers to have decisions reviewed, mainly about funding issues. In the past ADHC has not had a good reputation with regards to complaint management for service users. Commonly complaints have been made regarding eligibility of programs, inadequate service provision, quality of services, and disagreements between roles and responsibilities of ADHC and those of contracted disability service providers. Subsequently PDCN recommends that the revised Act require a robust and transparent complaints mechanism with a consistent appeals process, based on the model rules outlined by the NSW Ombudsman Office.

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44. How can disability legislation best ensure that all government agencies make services accessible to people with disability?
45. Are Disability Action Plans an effective means of ensuring that government services are accessible? Why?
46. Should the legislation specify:
 - How disability action plans should be developed? and
 - What they should cover? If so, what should be included?
47. Who should monitor compliance with Disability Action Plans? Should plans be enforced? If so, how?
48. Which NSW Government departments, divisions, agencies or other entities should be required to develop disability action plans? Why?
49. What role should government play in:
 - Promoting respect for people with disability? and
 - Ensuring their participation and inclusion?
50. What role, if any, should disability legislation play in awareness raising in NSW?

¹⁰ NSW Government, NSW Ombudsman – Handling Complaints (CSDO- 02) <http://www.ombo.nsw.gov.au/news-and-publications/publications/fact-sheets/community-and-disability-services/handling-complaints-csd02> - accessed 19 February 2013

xxi. To assist with the promotion of person centred planning to other service providers and government departments, ADCH needs to lead by example by implementing the following;

- Ensuring that the needs of people with disability are integrated into key corporate, planning and funding plans and policies
- Provision of regulations, policies, manuals and guides that demonstrate the Principles and Objectives of the Act. The following documents from the Victorian Department of Human Services website have been selected to demonstrate this:
 - Disability Services Individual Support Package (2012) - Handbook – Available in English and in 16 community languages
 - Individual Support Package Guidelines (2013) - Information Sheets
 - Direct Payments for Service Providers (2012) – Frequently Asked Questions
 - Peer Support for Managing your Individual Support Package (2012) - Information Sheets ¹¹

xxii. As part of the evolution of the availability of human rights for people with disability, Disability Action Plans (DAPs) have served an important role in facilitating awareness and understanding of the needs of people with disabilities, particularly for agencies not familiar with providing direct services to people with disability.

PDCN recognises the value of DAPs in the delivery of achieving the following for people with disability:

- Access to venues that meet the Disability (Access to Premises- Building) Standards
- Provision of information in different formats
- Availability of a complaints mechanism
- Increased staff awareness
- Facilitate recruitment, training and the promotion of people with disability

To ensure accountability DAPs, these plans should include the following information:

- Actions required to meet the desired objective
- Allocated resources and funding required to implement each action
- Time period required to implement each action
- Links to higher order policies and strategies
- Person/ department responsible for overseeing implementation of each action
- Person/ department responsible for reviewing completion of yearly targets and reviewing completion of the Plans

¹¹ Victorian Government, Department of Human Services – Documents and Resources <http://www.dhs.vic.gov.au/about-the-department/documents-and-resources> - accessed 21 February 2013

ADHC should retain a responsibility in guiding other government departments/ agency regarding the needs of people with disability and may also act as the clearinghouse of all Disability Action Plans, but not for the implementation of plans. PDCN believes that government departments need to own the Plan prepared by that department, be responsible for its implementation and reporting against each action in the department's Annual Report. Whilst all government departments potentially provide customer service and can employ a greater number of people with disability, PDCN believes that all government departments should prepare DAPs.

- xxiii. To enhance disability awareness PDCN suggests that ADCH oversee the implementation of DAPS for services contracted by the department, but for contracts not typically for disability supports.

51. How can we best engage people with disability in decision making about policy and legislation in NSW? How can legislation support this?
52. Is the Disability Council of NSW able to undertake its functions effectively under its current legislation? If not, why not?
53. Should the provisions relating to the Disability Council be transferred from the *Community Welfare Act 1987* (NSW) to the new legislation? If so, what functions should it have? What advantages and disadvantages might be associated with this change?

- xxv. PDCN believes that it is critical that ongoing funding and resources be made available through the Consumer Development Fund to facilitate the empowerment of people with disability. It concerns PDCN that without skill/capacity development people with disability will struggle with the additional responsibilities of person-centred planning and become more dependent on family members and carers. Ideally for both the carer and the person with disability, sufficient supports should be available that people with disability are not depend on carers for admin or physical support.

54. Should disability legislation recognise the particular needs of some groups of people with disability? If so, which groups should be recognised and how?
55. What role, if any, can disability legislation play in ensuring that the home and family of people with disability are respected and recognised?
56. Should the principle of respecting children and their family relationships as they grow up be reflected in legislation, and if so how?

57. How could new legislation allow us to support carers in line with the *Carers (Recognition) Act 2010* (NSW)?

xxiv. Whilst the primary focus of the draft Act is on the needs of people with disability, it does not identify the impacts that a secondary disability may have. PDCN believes that the revised Act needs to recognise the impact of having a secondary disability with the inclusion of the following two additional principles;

- 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.¹²
- Have regard for people with disability who may have additional needs due to their nationality, race, gender and geographic location.

xxv. Whilst PDCN understands the importance of the care and support provided to all members of the community provided by family members, PDCN believes that the purpose of the revised Act, it needs to maintain a primarily focus on the needs and rights of people with disability.

58. What role, if any, could disability legislation play in ensuring sufficient opportunity for people with disability to participate in cultural life in NSW?

xxvi. It is crucial that the revised Act conforms with Articles included in the CRPD, and subsequently needs to acknowledge the importance of Article 30- Participation in Cultural life, recreation, leisure and sport.¹³

¹² Victoria, *Disability Act (2006) Section 5 (3)*

¹³ UN Convention on the Rights of Persons with Disabilities (2006)