Australian Government: Productivity Commission

# Draft report into Disability Care and Support

# Submission by Physical Disability Council of NSW

April 2011

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# **Introduction**

PDCN appreciates the commitment and merit of the draft report into Disability Care and Support produced by the Productivity Commission. Research into self- directed funding and person- centered approaches nationally and internationally will be useful in the implementation of the National Disability Insurance Scheme (NDIS). .PDCN appreciates

the opportunity to provide further comment on the draft report, and has provided comment focusing on the following chapters:

- Chapter 3 Who is the NDIS for?
- Chapter 4 What individualised supports will the NDIS fund?
- Chapter 6 Who has the decision- making power?
- Chapter 7 Governance of the NDIS

# **About the Physical Disability Council of NSW (PDCN)**

The Physical Disability Council of NSW (PDCN) is the peak body representing people with physical disability across New South Wales. Physical disability is part of the lives of 240,000 residents, from young children and their representatives to aged people. They live across the state, from the Greater Sydney Metropolitan area to rural NSW and they are from a wide range of socio-economic circumstances.

# **Discussion**

# Chapter 3 – Who is the NDIS for?

## **Draft recommendation 3.1**

The National Disability Insurance Scheme (NDIS) should have three main functions:

- To cost-effectively minimise the impacts of disability, maximise the social and economic participation of people with a disability, and create community awareness of the issues that affect people with disabilities. These measures should be targeted at all Australians
- To provide information and referral services, which should be targeted at people with, or affected by, a disability
- To provide individually tailored, taxpayer-funded support, which should be targeted at the subset of people with disabilities who are assessed as needing such support.

The draft report into disability care and support identifies how the National Disability Insurance Scheme (NDIS) will be implemented. The report identifies the following three functions of the NDIS:

- Tier 1 Community awareness programs aimed at creating awareness of the issues that affect people with disability
- Tier 2 Promotion of information and referral of services that are not funded as part of the NDIS

 Tier 3 - Provision of funded individualised supports for people with disabilities who meet the eligibility criteria.

PDCN supports draft recommendation 3.1, detailing the implementation of the three tiered approach. As part of implementation of tier 1, PDCN would like to stress the importance of implementing strategies that enhance social participation of people with a disability and their carers, that do not communicate imagery and written text that reinforce negative stereotypes and paternal attitudes.

#### **Draft recommendation 3.2**

Individuals receiving individually tailored, funded supports should be Australian residents, have a permanent disability, (or if not a permanent disability, be expected to require very costly disability supports) and would meet one of the following conditions:

- Have significant difficulties with mobility, self-care and/or communication
- Have an intellectual disability
- Be in an early intervention group, comprising:
  - Those for whom there was a reasonable potential for cost-effective early therapeutic interventions (as in autism and acquired brain injury)
  - Those with newly diagnosed degenerative diseases for whom early preparation would enhance their lives (as in multiple sclerosis)
- Have large identifiable benefits from support that would otherwise not be realised, and that are not covered by the groups above. Guidelines should be developed to inform the scope of this criterion.

PDCN supports the eligibility criteria identified in tier 3 as it provides a more representative sample of the different disability types, looks more broadly than just functional need and recognises the different causes of disability.

PDCN believes that the Productivity Commission needs to clarify the difference between the terms 'severe to profound disability' used in the scope of the review <sup>1</sup> and 'significant disability' used elsewhere in the draft report. This ambiguity could result in misunderstanding and further inconsistencies between different states and territory governments, resulting in unnecessary appeals and risking the long-term viability of the NDIS.

<sup>&</sup>lt;sup>1</sup> Australian Government Productivity Commission (2011) Draft Report into Disability Care and Support-Terms of Reference (v)

<sup>&</sup>lt;sup>2</sup> ABC Canberra 'Research cuts will create 'brain drain' http://www.abc.net.au/science/articles/2011/04/07/3185190.htm?site=canberra

Recent media publicity has concerned PDCN regarding the impact of a reduction in research funding on the operations of this tier. This media publicity has highlighted a significant reduction in National Health and Medical Research Council funding of \$400,000 over the following three years.<sup>2</sup>

# **Draft recommendation 3.3**

The NDIS should provide advice to people about those instances where support would be more appropriately provided through non-NDIS services. Support should be provided outside the NDIS for people whose:

- Disability arose from a workplace accident or catastrophic injury covered by insurance premiums
- Support needs would be more appropriately met by the health and/or palliative care systems, comprising:
- Those who would benefit from largely medically oriented interventions (including less restrictive musculoskeletal and affective disorders, and many chronic conditions)
  - Many people with terminal illnesses
- Support needs would be more appropriately met by the aged care system
- Needs were only in relation to mainstream employment, public housing or educational assistance.

PDCN agrees that people are unlikely to use services unnecessarily, but is concerned that this draft recommendation does not include people with physical disabilities currently receiving HACC (Home and Community Care) services who are not eligible for NDIS funding, following Council of Australian Government (COAG) reforms to aged and disability services, putting approximately 20,300 people in NSW in future jeopardy.

To illustrate this concern, Australia wide 2,079, 022 hours of personal care support were provided between 2008- 09 for people aged between 0-64 years <sup>3</sup>, with approximately one third living in NSW and hence 693, 000 personal care hours <sup>4</sup>. Additional data from the NSW Department of Ageing, Disability and Home Care 2008- 09 Annual Report <sup>5</sup> identifies that 500 people with disabilities received High Need Pool funding, accessing 480, 000 hours personal care support per annum. In calculating the number of personal care hours not used by people eligible for NDIS funding, PDCN has deducted the total

<sup>&</sup>lt;sup>3</sup> Australian Government Department of Health and Ageing- Home and Community Care Minimum Data Set 2008/09 Annual Bulletin, Table A19: HACC services received, assistance type by age, 2008-09

<sup>&</sup>lt;sup>4</sup> Advice provided by NCOSS

<sup>&</sup>lt;sup>5</sup> NSW Government Family and Community Services Ageing, Disability and Home Care 2008/09 Annual Report

numbers of personal care hours used by people in NSW, minus the number used by people on High Need Pool leaving 203,100 of personal care hours provided to people not eligible for NDIS funding. Assuming that people using HACC services but not eligible for NDIS funding, receive approx 10 hours of personal care assistance per week, then 20, 300 of people with a disability maybe under serviced following COAG reforms to aged and disability services. This would add to existing unmet need, reinforce stressful relationships between people with disabilities and their carers, and act contrary to the intent of early intervention strategies identified in the draft report.

Other HACC services commonly used by younger people with disabilities include home modifications and centre- based day care.

## **Draft recommendation 3.5**

Whatever the actual funding divisions between the NDIS and aged care that are put in place, people should have the option of migrating to the support system that best meets their needs, carrying with them their funding entitlement.

Upon reaching the pension age (and at any time thereafter), the person with the disability should be given the option of continuing to use NDIS-provided and managed supports or moving to the aged care system. If a person chose to:

- Move to the aged care system, then they should be governed by all of the support arrangements of that system, including its processes (such as assessment and case management approaches)
- Stay with NDIS care arrangements, their support arrangements should continue as before, including any arrangements with disability support organisations, their group accommodation, their case manager or their use of self-directed funding.

Either way, after the pension age, the person with a disability should be subject to the co-contribution arrangements set out by the Commission in its parallel inquiry into aged care.

If a person over the pension age required long-term aged residential care then they should move into the aged care system to receive that support.

In implementing this recommendation, a younger age threshold than the pension age should apply to Indigenous people given their lower life expectancy, as is recognised under existing aged care arrangements.

Labour force data identifies stark differences in unemployment and labour force participation rates between people with a disability and people without, showing that people with physical disability are more than twice as likely to work part time.

Subsequently many people with a disability rely on income support payments as their sole, main or supplementary source of income. Consequently home ownership or the accrual of superannuation and/or financial assets is not possible or otherwise minimal.

Without his ability to accrue lifelong savings it cannot be assumed that younger with disabilities have the same capacity to pay for aged community and/ or residential services. As a consequence government authorities need to adopt flexible mechanisms that recognise financial disadvantage. It is understood that the people with a disability of pension age opting to use the aged care system for community supports and residential aged care will be subject to income and assets tests before receiving services, with equitable access to residential care for those unable to pay accommodation costs. Additionally it needs to be recoginised the increased incidence of disability among people of indigenous backgrounds and their subsequent need for equitable access into aged care services at a younger age than the pension age.

# Chapter 4 – What individualised supports will the NDIS fund?

## Draft recommendation 4.1

The NDIS should cover the current full range of disability supports. The supports would need to be 'reasonable and necessary'. The NDIS should also support the development by the market of innovative support measures (using the approaches set out in draft recommendation 8.3).

PDCN supports the principle identified by the NDIS that the term 'reasonable and necessary' be defined in a similar way to that used by NSW Life Time Care and Support Authority, and subsequently defined as:

- 1. The benefit to the participant
- 2. The appropriateness of the support or service being requested
- 3. The appropriateness of the provider
- 4. Cost effectiveness of the chosen service, but this criterion may not be as relevant for a person opting to manage self- directed funding.

PDCN agrees that payment for drugs, cigarettes, alcohol, prostitution and gambling should not be accepted as legitimate NDIS funding.

PDCN believes that self directed funding will encourage and drive an expansion in the availability of different services types, better meeting the needs of people with a physical disability. Whilst supportive of a market- based economy in the larger metropolitan centres, PDCN is concerned about its implementation in regional and remote Australia. The draft report recognises the success of self- directed services currently available in

regional parts of Western Australia, and PDCN urges the Productivity Commission to seek further advice from the Perth Home Care Services on the implementation of these services.

#### **Draft recommendation 4.2**

There should be no income or asset tests for obtaining funded NDIS services.

PDCN believes that NDIS funds should be provided irrespective of the individual's financial circumstances as people with disability often have limited or minimal savings, household assets or superannuation due to their limited earning capacity, and as a result are unable to invest in equity later in life.

Constant barriers that reinforce financial disadvantage may well inhibit further social participation, one of the key functions of the NDIS, reinforcing the need for governments not to impose fees for essential services.

## **Draft recommendation 4.3**

There should sometimes be a requirement to pay a modest fixed upfront contribution to the NDIS, with free access to services after that point. The NDIS should waive the amount where families have already contributed significantly towards the costs of support through unpaid care.

PDCN believes that it is unreasonable to seek a modest fixed upfront payment from people who experience financial hardship on an ongoing basis, whether payment is being made by the person with the disability or their carer. Income sought via a one-off modest upfront payment would probably not be sufficient to offset the administrative procedures associated with charging a fee.

## Draft recommendation 4.5 and requested information

Services that meet the needs of much wider populations, including people with disabilities not covered by the NDIS, should lie outside the scheme:

- Health, public housing, public transport and mainstream education and employment services, should remain outside the NDIS, with the NDIS providing referrals to them
  - but specialised employment services, disability-specific school to work programs, taxi subsidies, and specialised accommodation services should be funded and overseen by the NDIS.

Box 4.1 of the draft report identifies the following fourteen broad categories to be funded under the NDIS:

- 1. Aids and appliances
- 2. Home modifications
- 3. Vehicle modifications
- 4. Personal care
- 5. Community care
- 6. Respite
- 7. Specialist accommodation support
- 8. Domestic assistance
- 9. Transport assistance
- 10. Specialist employment support
- 11. Therapies
- 12. Case management
- 13. Crisis/ emergency support
- 14. Guide dogs and assistance dogs

PDCN agrees with the distinction made between mainstream and specialist supports, but is of the opinion that this division may need to be reviewed at a later date following further social reform. Furthermore PDCN would like to provide the following comment regarding a number these service types:

 Vehicle modifications – Due to the limited availability of public transport and excessive cost of taxi travel, PDCN would recommend that driving assessment and instruction be provided as part of the NDIS enhancing potential independence and community participation. Without the ability to drive a persons' full potential is not recognised, and he or she will always be dependent on others.

# Personal impact

As a person with a severe physical disability the ability to drive has had a stupendous impact on my life, and been a building block and essential part to me attaining many future life goals such as moving away from my family home and attaining employment. Without the ability to access professional driving instruction, I would have not of known whether purchasing a car was worth it or not, and secondary to this, what modifications were required.

- Respite services The following breakdown of data from the Disability Services
   Commission in Western Australia shows how important respite services are within
   individualised programs:
  - Respite support (42%)
  - Personal care (12%)

- Aids and equipment (12%) and
- Leisure support (12%) <sup>6</sup>

Whilst PDCN appreciates the importance of maintaining primary care relationships, PDCN believes that the focus on respite services have traditionally been around meeting the needs of the primary carer rather than considering the needs of the person with a disability, and hence believes that this section needs to be rewritten with the primary focus on the person with the disability.

<u>Taxi subsidies</u> – Access to transport is an essential part of community living and preventing social isolation for all members of the community, particularly people with a disability. Taxi travel is an essential need for many people with a physical disability to access employment, education, community supports, friends and family, and hence needs to be considered as a NDIS funded service.

In the past in NSW the monopoly on the provision of wheelchair accessible taxis (WATS) has been evident, but with the ability to make private bookings and the adoption of Lime Taxis this monopoly has become less, giving increased options to passengers of WATS.

- Case management, local coordination and development The draft report refers to
  case managers as providing the following support services: individual and family
  case management, brokerage, services aimed at developing capacity development
  and advocacy. It concerns PDCN that locally- based case managers will be gatekeepers of information and will not necessarily discontinue their involvement after the
  assessment phase, preventing individual NDIS recipients from taking self control.
- To ensure transparency and accountability at the local area office, the roles of the case manager and regulatory responsibilities need to have clear boundaries.
- Individual and systemic advocacy PDCN believes that whether referring to individual or systemic advocacy, that these services need to be considered differently, and then again differently from case- management services. Advocacy is speaking acting, writing with minimal conflict of interest on behalf of the sincerely perceived interests of a disadvantaged person or group to promote, protect and defend their welfare and justice. Consequently advocacy services are of prime importance, and need to not be answerable to either funding sources or direct

<sup>&</sup>lt;sup>6</sup> Australian Government Productivity Commission (2011) Draft Report into Disability Support and Care submission 250

service providers.

Because advocacy services may be used at indeterminately, and often in times of crisis, PDCN believes that it is not appropriate that funds for advocacy services be sought from self- directed packages As a consequence PDCN believes that advocacy services should be funded by a government body, preferably one with an awareness of human rights, and not a service provider with a commercial interest, as is on the open market. .

- <u>Electricity costs</u> Any framework for providing rebates and concessions needs to take account of the real and current costs faced by people with physical disability face. This means that the eligibility criteria for concessions and rebates should be broad enough to encompass all additional and unavoidable costs rather than (in some cases) only being available for specific life support machines or physical aids. It is vitally important that the value of financial assistance does not erode over time due to energy price rises. As such, rebate and concession frameworks should include a process for indexation so that any energy price rise triggers a review of rebate and concession levels.
- Income support In response to the request for further feedback about the following payments: Carer Payment, Carer Supplement, Carer Allowance, Mobility Allowance, and the Child Disability Assistance Payment, PDCN is of the opinion that these need to be considered as income supports, and subsequently considered as a mainstream service, not provided as part of tier 3 of the NDIS.
- <u>Prostheses</u> PDCN agrees that in the interests of equity, that eligibility should include where the prosthesis is used for the replacement of either the upper or lower limb/s, for people aged between 0- 64 years, where a limb needs to be replaced due to trauma and/ or disease. Other surgical procedures should be considered as mainstream routine health responsibilities.

# **Draft recommendation 4.6**

The Disability Support Pension (DSP) should not be funded or overseen by the NDIS. The Australian Government should reform the DSP to ensure that it does not undermine the NDIS goals of better economic, employment and independence outcomes for people with disabilities. Reforms should aim to:

- Encourage the view that the norm should not be life long use of the DSP, among:
  - people with non-permanent conditions
  - people with permanent conditions who could have much higher hopes for employment participation

 Provide incentives for people to work (even if only for a few hours per week) and for targeted rehabilitation for those with reasonable prospects of employment.

These reforms should not be limited to new entrants into the DSP

PDCN agrees that implementation of the NDIS needs to be seen as a separate reform process to that of the Disability Support Pension (DSP), and that any future reforms to the DSP does not undermine the NDIS goals of better economic, employment and independence outcomes for people with disabilities.

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# Chapter 6 Who has the decision-making power?

# Draft recommendation 6.1

Governments should give people with disabilities eligible for benefits under the NDIS, or their nominated proxies, various options for exercising choice, including the power to:

- Choose directly the service provider/s that best meet their needs
- Choose disability support organisations that would act as intermediaries on their behalf when obtaining services from service providers, and/or
- 'Cash out' all or some of their individual budgets if they wish, with the NDIA (National Disability Insurance Authority) making direct payments to their bank accounts, and allowing people to purchase directly the detailed package of supports that best meets their preferences ('self-directed funding'), subject to the constraints set out in draft recommendations 6.2, 6.7 and 6.8.
  - The specific arrangements for self-directed funding should be underpinned by the principle that, subject to the assessed individual budget and appropriate accountability requirements, the arrangements should maximise the capacity for a person to choose the services that meet their needs best and that promote their participation in the community and in employment.

In principle PDCN supports draft recommendation 6.1, but believes that for a person not familiar with this initiative, that this recommendation needs to state that accepting a self-directed package or self-directed funding is optional. The draft report acknowledges that both nationally and internationally uptake of self-directed funding has been initially slow, and states that at public hearings feedback identified a concern from some people with

<sup>7</sup> Australian Government- Productivity Commission Draft report into Disability Care and Support (2011) Page 6.8

disabilities that they would have to use self-directed funding. Following this concern the draft report reinforces that this would not be the case in the proposed NDIS'. <sup>7</sup>

#### **Draft recommendation 6.2**

Self-directed funding should include the following key stages.

- It would be informed by any prior planning and aspirations expressed by the person during the assessment phase (draft recommendation 5.2).
- The individual budget for self-directed funding would be based on the formal individual assessment of the person's needs and would include the cashed out value of all goods and services covered by the NDIS, except those where specialist knowledge is required for informed choices.
- The person with a disability and/or their support network or chosen disability support organisation — would create a personal plan and a concrete funding proposal to the NDIA that outlines the person's goals and the type of support that is necessary and reasonable to achieve these within the allocated budget.
- The resulting funding proposal would require approval by the National Disability Insurance Agency (NDIA).

# There should be a capacity for a person to:

- Obtain quick approvals for changes to a funding proposal
- Add their own private funds to a funding proposal
- Allocate the individual budget to any mix of preferred specialist and mainstream goods and services, subject to the requirements that:
  - the person spend the budget in areas related to his or her disability needs and consistent with the funding proposal
    - the scope to cash out funds set aside for large non-recurrent spending items should be limited to the (rare) circumstances where the NDIA has approved this as an appropriate decision.

Whilst PDCN reinforces the importance of a funding proposal that ensures flexibility, and that recipients should not need to trade-off funding for high cost non- recurrent items such as a building and motor vehicle modifications against essential services such as personal care, PDCN believes that due to the nature of many one- off non-recurrent payments that recipients should have the foresight to request a reassessment where approval can be sought directly from NDIA .without needing to trade-off essential services and supports.

# **Draft recommendation 6.3**

The NDIA should pay annual allocations of self-directed funding in monthly installments paid in advance, with the capacity for the person to 'bank' up to 10 per cent of the annual allocation to the subsequent year.

PDCN supports the conditions contained in this recommendation ensuring that funding is provided in advance in monthly installments, and that recipients have the ability to 'bank' up to 10% of their annual allocation to purchase one- off non- recurrent items, such as aids and appliances. This is considered as an appropriate amount of savings when compared to other community members.

## Draft recommendation 6.4

There should be a capacity for people to recruit and employ their own support workers, subject to the proviso that these should not be close family members, other than when:

- Care is intermittent and provided by a non-resident family member
- Exceptional circumstances are present and after approval by the NDIA
- The person is in the family employment trial spelt out in draft recommendation 6.5.

PDCN endorses the flexibility of people acquiring self- directed funding to have the option of employing their staff such as used in the Attendant Care Direct Funding Pilot Program. Whilst it is understood that in regional and rural localities where travel times maybe excessive such as experienced in the Pilot Program, PDCN does not agree that the employment of close family members should be encouraged as this goes against the intent of accessing outside assistance, and may acerbate family stresses. And as a consequence PDCN has some general concerns about draft recommendation 6.5, but more particularly with the risk of creating unrealistic dependencies between the recipient and family members, and not having plans that cater for the future.

# Draft recommendation 6.5

There should be a trial of the employment of family members under self-directed funding to assess its risks, advantages, disadvantages and optimal design, with its wider adoption if the evaluation proves positive. The trial should use an appropriately rigorous scientific approach, drawing on the evaluations used in the United States 'Cash and Counseling' programs. For the trial:

- The NDIA should determine that there are few risks from hiring relatives for each family in the trial
- The individual budget should be discounted by 20 per cent
- Support should be initially limited in duration to six months, with continuation of any arrangement for a given family based on the benefits and costs to that family
- Risks should be carefully managed to ensure appropriate use of funds and to safeguard people with disabilities and carers (draft recommendation 6.8).

PDCN does not agree that the employment of close family members should be encouraged as this goes against the intent of accessing outside assistance, and may

acerbate family stresses. And as a consequence PDCN has some general concerns about draft recommendation 6.5, but more particularly with the risk of creating unrealistic dependencies between the recipient and family members, without adequate long-term plans.

#### Draft recommendation 6.6

## The NDIA should:

- Inform people with disabilities and their proxies of the various options for self directed funding
- Provide support for people using self-directed funding, including easy-to understand guidance about the practical use of self-directed funding, including standard simple-to-follow forms for funding proposals, hiring employees and for acquittal of funds
- Promote the use of self-directed funding, with examples of innovative arrangements
- Provide training to local case managers and front-line staff about self-directed funding
- Encourage the formation of disability support organisations to support people in the practical use of self-directed funding.

PDCN endorses the availability of current, accurate, accessible resources and guides for all stakeholders involved in the implementation of the NDIS.

# **Draft recommendation 6.7**

Before offering self-directed funding to a person, the NDIA should:

- Meet with the person with a disability and their carers, and take account of their experience and skill sets
- Use that and any information provided during the assessment phase to determine whether the person and/or their support network are likely to be able to:
  - make reasonably informed choices of services
  - manage the administrative and financial aspects of funding if they wish to oversee these aspects by themselves

PDCN approves of the procedure identified in this draft recommendation but suggests that that the wording of the first dot point be modified as not all people with disabilities have with a formal carer, or necessarily want to be assessed with one. This proviso may not be as relevant for children or young adults, but can not be assumed for adults who have grown up before the implementation of self- directed funding, or people with a recently acquired disability.

# Draft recommendation 6.8

In offering self-directed funding, the NDIA should ensure that:

- It reduces the risks of neglect or mistreatment of people with a disability by support workers or other service providers hired by users in the informal sector, by:
  - ensuring easy and cheap access to police checks
  - giving users the capacity to complain to the NDIA about inappropriate behaviour of providers, and to have these investigated
  - monitoring by local case managers
- It reduces the risks to support workers employed under self-directed funding by requiring that they are covered by workers' compensation arrangements and have an avenue for lodging complaints
- It adopts a risk-management approach for receipting and other accountability requirements, which:
  - requires less accountability for people with low risks or who have demonstrated a capacity to manage their funds well
  - takes into account the compliance costs of excessive accountability measures
    - allows a small component of the individual budget to be free of any receipting requirements.

PDCN believes that this recommendation needs to be clarified to minimise any future misunderstanding. Presently it could be read that accessing self- directed funding can only be sought if there is a reduction in a number of risk factors. To avoid this ambiguity PDCN suggests the following:

That as part of offering self- directed funding that the NDIA needs to implement the following strategies to minimise risk:-

- To reduce the risk of neglect or mistreatment of people with a disability by support workers or other service providers hired by users in the informal sector, by:
  - ensuring easy and cheap access to police checks
  - giving users the capacity to complain to the NDIA about inappropriate behaviour of providers, and to have these investigated
  - monitoring by local case managers
- To reduce the risks to support workers employed under self-directed funding by requiring that they are covered by workers' compensation arrangements and have an avenue for lodging complaints
- Adoption of a risk-management approach for receipting and other accountability requirements, which:
  - requires less accountability for people with low risks or who have demonstrated a

capacity to manage their funds well

- takes into account the compliance costs of excessive accountability measures
- allows a small component of the individual budget to be free of any receipting requirements.

#### Draft recommendation 6.9

The NDIA should undertake ongoing monitoring of self-directed funding arrangements, with a quarterly report to the board of the NDIA on issues arising from self-directed funding. There should be a full evaluation three years after their commencement to assess any desired changes in their design.

PDCN believes that the NDIA needs to be reviewed by an outside independent organisation to ensure transparency and accountability, rather than an assessing its own internal operations.

#### Draft recommendation 6.10

The Australian Government should amend the Income Tax Assessment Act 1936 and the Social Security Act 1991 so that the following are not treated as income for assessment of taxes or eligibility for income support or other welfare benefits:

- Self-directed funding paid by the NDIA and, in the interim, by state and territory governments
- Early compassionate release of eligible superannuation amounts for disability expenditures which meet the criteria set down by the Superannuation Industry (Supervision) Act 1993.

These suggested measures to reduce the risk of fraud this would be recommended by PDCN.

# **Chapter 7- Governance of the NDIS.**

# **Draft recommendation 7.1**

The Australian Government should establish a new independent Commonwealth statutory authority, the National Disability Insurance Agency (NDIA), to administer the National Disability Insurance Scheme.

The NDIA should be subject to the requirements of the Commonwealth

Authorities and Companies Act 1997 (CAC Act), not the Financial Management and Accountability Act 1997.

PDCN supports the adoption of a statutory authority to administer the NDIS called the National Disability Insurance Agency.

#### **Draft recommendation 7.2**

An independent board should oversee the NDIA. The board should comprise people chosen for their commercial and strategic skills and expertise in insurance, finance and management.

 As specified in the CAC Act, the board should not be constituted to be representative of particular interest groups, including governments, disability client or service provider groups.

The Australian Government and the state and territory governments should together establish an appointment panel comprising people with skills and experience in these areas, including people with a clear interest in disability policy issues.

• The panel should nominate candidates for each board vacancy against tightly specified selection criteria set down in the Act governing the NDIA. Appointments should be based on the majority decision of governments.

The Australian Government, with the agreement of the majority of state and territory governments, should have the power to remove the chair or dissolve the board as a whole.

PDCN supports the appointment of an independent board with a broad knowledge of financial management to facilitate the long- term viability of the program.

# **Draft recommendation 7.3**

The board would have the sole power to appoint the CEO and to sack him or her if necessary, without authorisation from governments. The Australian Government, together with state and territory governments, should establish an advisory council. The council should provide the board of the NDIA with ongoing advice on its activities and effectiveness in meeting its objectives, from the perspectives of people with disabilities, carers, suppliers of equipment and services and state and territory service providers and administrators.

The council should comprise representatives of each of these groups.

PDCN supports this recommendation which separates the strategic nature of the board

with expertise in insurance and financial management, from the advisory board comprising of representatives of interest groups, including disability peaks, service providers and government representatives. Appointment of board members with financial management skills with additional experience and skills in disability would be advantageous.

PDCN supports the adoption of an employment policy encouraging employment of people with a disability within the NDIA.

#### **Draft recommendation 7.4**

The arrangements between the NDIA and governments should be at arm's length, and subject to strict transparency arrangements.

The federal Treasurer should have responsibility for the NDIA.

## **Draft recommendation 7.5**

The Australian Government, with the agreement of state and territory governments, should provide the NDIA with its own legislation that specifies its objectives and functions, and its governance arrangements.

- Financial sustainability should be a specific obligation of the board, the management and the minister, and this obligation should be enshrined in legislation. It should specifically guide any external review body (draft recommendation 7.8).
- An entitlement to reasonable support should be enshrined in legislation, together with details about people's eligibility for services and the range of services to be offered.

Future changes to the legislative framework should be undertaken only by explicit changes to the Act itself, made transparently, and subject to the usual processes of community and Parliamentary scrutiny, and in consultation with all state and territory governments.

• Such proposed legislative changes should be accompanied by an independent assessment of the impact of the changes on the sustainability of the scheme.

PDCN supports this recommendation that sees the value of protecting the NDIS from political influences.

# **Draft recommendation 7.6**

An independent actuarial report on the NDIA's management of the NDIS should be prepared quarterly and annually, and provided to the board, the regulator, the federal Treasurer, and to all state and territory governments. It should assess risks, particularly in regards to the capacity of the expected funding stream to

meet expected liabilities within its funding framework, the source of the risks and the adequacy of strategies to address those risks.

PDCN supports a regular review process such as identified in this recommendation.

#### **Draft recommendation 7.7**

A specialist unit should be established within the federal Treasury to monitor the performance of the NDIA against a range of cost and performance indicators, and report its findings annually to its minister, state and territory governments and the public.

PDCN supports this recommendation to monitor performance of the NDIA with key performance indicators identified for the three broad functions of the NDIS.

## **Draft recommendation 7.8**

The NDIA should be independently reviewed, initially after its first three years of operation, and every five years thereafter, with the outcomes publicly and promptly released.

PDCN supports a regular review process which is open and transparent with its findings made assessable in a timely manner.

#### **Draft recommendation 7.9**

The NDIA should be subject to benchmarking with other comparable corporate entities to assess its relative efficiency in its various functions, with the federal Treasury initiating benchmarking studies.

PDCN supports this recommendation on the condition that a comparable entity is sought to compare effectiveness and efficiency.

# **Draft recommendation 7.11**

The wording of the NDIA Act should limit the capacity of merits review processes to widen eligibility or entitlement. It should require that any claims by NDIA clients would need to:

• Meet a 'reasonable person' test

- Balance the benefits to the person with a disability against the costs to the scheme, including any adverse implications for the long run sustainability of the scheme from the review outcome
- Take into account the obligation of people with disabilities or their families to avoid decisions that unreasonably impose costs on the scheme.

PDCN supports the recommendation that the NDIA clearly identifies eligibility criteria, what services and supports it will provide and under what circumstances these will be provided.

#### **Draft recommendation 7.12**

The NDIA should include an internal complaints office that would:

- Be separate from the other parts of the NDIA dealing with clients and service providers
- Hear complaints about breaches of the service charters (draft recommendation 7.10)
- Reassess contested NDIA decisions on a merit basis.

The office would be headed by an independent statutory officer who would review appeals made by people with disabilities and support providers against the decisions of the NDIA.

- The NDIA legislation should create this role and specify that the officer would be independent, would act fairly and impartially, basing their decisions on the available evidence, and could not be directed in their decision-making.
- A person or support provider should only be able to appeal the decisions of the office on matters of law, rather than on merit, to the courts.

The NDIA should publish the number, types and outcomes of complaints and appeals (subject to privacy protections).

PDCN supports the establishment of a complaints mechanism, supports the mechanism being independent, and supports the *publishing of the number, types* and outcomes of complaints and appeals (subject to privacy protections). However, PDCN does not believe that the mechanism should be located within an internal complaints office in the NDIA.

PDCN believes that it is essential for the complaints process/mechanism to be completely separate from NDIA (although enshrined in NDIS legislation). Perceptions of independence have always been very important where complaint decisions are made that affect the health and wellbeing of individuals. In Victoria, a research study in 2004 about consumer perspectives and health practitioner's

boards found "concerns of some complainants about whether the boards were perceived to be sufficiently independent, impartial, and fair in their processes.<sup>8</sup>

People with disability deserve an independent and transparent vehicle for their complaints about the NDIA. It is clear that a public perception of independence is only be achieved when the processes associated with decisions of the NDIA, and the process associated with the investigation of complaints is the responsibility of, and located with, an organisation separate from the NDIA.

# **Draft recommendation 7.13**

If the proposal in draft recommendation 7.12 for appeal processes supported by an independent statutory officer are not adopted, then the Australian Government should create a specialist arm of the Administrative Appeals Tribunal to hear appeals on merit about the NDIA's decisions subject to the constraints of draft recommendation 7.11. The Australian Government should set aside significant additional resources to fund this specialist arm and should include a larger reserve for the NDIS, calculated to take account of the higher risks of this approach.

See comments in 7.12. PDCN supports this recommendation with the risks of review processes curtailed through clear legislative guidance

oging in the consumer perspective. Final Report: (

<sup>&</sup>lt;sup>8</sup> Bringing in the consumer perspective. Final Report: Consumer experiences of Complaint processes in Victorian Health Practitioners Boards October 2004, p8