

Roberta Bausch
The Australian Government Productivity Commission
GPO Box 1428
Canberra City, ACT 3377

Dear Ms. Bausch,

Please accept this post draft report submission written on behalf of The Mai Wel Group, for the Productivity Commission's Inquiry into disability care and support. A not-for-profit organisation that has been operating as a large disability support service provider in the Hunter Region for over fifty years, The Mai Wel Group is positioned as an invaluable information source. Portraying the application of secondary research and recommendation, this submission addresses three fundamental Terms of Reference, including:

- One: Examine a range of options and approaches, including international examples, for The provision of long-term care and support for people with severe or profound disability
- Four: *Consider costs and financing of any proposed scheme, including models for financing.*
- Five: *Implementation issues of any proposed scheme.*

More specifically, The Mai Wel Group's examination of such Terms of Reference is based on the questions found in the initial Issues Paper.

I invite you to review this submission and encourage you to contact us any questions or feedback.

Thank you,
Emma Hardy
(On behalf of The Mai Wel Group).

Productivity Commission Inquiry: Disability Care & Support

The National Disability Insurance Scheme

Submission written by Emma Hardy, on behalf of:

The Mai Wel Group

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1.0 Introduction:

A not-for-profit organisation devoted to improving the quality of life for those with disability, we at The Mai Wel Group cater to the individual needs of over 900 clients by providing continued opportunity and service access. Offering accommodation, employment support and community participation programs to our clients, we also aim to create peace of mind and build a trusting relationship with the families and friends of those with disability, by administering reliable information. With 34% of informal carers reportedly feeling stressed and 18% suffering frustration (Bureau of Statistics, 2009), The Mai Wel Group, recognises that a lack of support can have adverse effects not only on the wellbeing of the client, who is seemingly placed in an under-resourced and underfunded environment, but also on the emotions and relationships maintained by relatives.

Working concurrently with Australia's support system has inevitably enabled us to experience both the positives and negatives of our profession. We have enjoyed the pleasures of witnessing our clients reach their full potential in a safe and enthusiastic environment, yet have unfortunately also been exposed to the darker realities of a flawed system, where individuals have continuously fallen through the gaps.

Our submission fundamentally aims to address the first, fourth and fifth Terms of Reference observed within the Productivity Commission's Inquiry, with particular emphasis on lead times, funding ideas and approaches towards the proposed National Disability Insurance Scheme (NDIS). Throughout our fifty years, The Mai Wel Group has come to recognise differentiations in service quality among providers and it is of our understanding that the implementation of the NDIS will inevitably promote a more conformed support system within Australia. We believe that such differences have arisen due to the existence of numerous definitions of disability and its four distinguishing categories known as mild, moderate, severe and profound. As one of the Hunter's largest disability service providers, we no longer want to hear of incidents of individuals being omitted from the system due to error or lack of service availability. As a result, this submission primarily proposes:

- △ The implementation of a single and somewhat clearer arbitrary definition for disability and its classifications of mild, moderate, severe and profound. This definition needs be applied to all national and state policy and legislation.
- △ The continued assessments of those with disabilities based on the transitional stages of life.

2.0 Background:

Differing support systems operating between Australia's States and Territories has inevitably complicated the eligibility determinants of those with disability and has also resulted in instances of inadequate or insufficient service availability. Whilst bilateral agreements were initially established between all Australian States and Territories in 2000 to alleviate such problems, methods for managing demand still "vary substantially between jurisdictions in terms of the degree of registers, waiting lists and application processes" (Australian Institute of Health and Welfare, 2007).

At The Mai Wel Group, we believe that no State, Territory, nor client, should be left behind by the system. The Mai Wel Group agrees with the Productivity Commission's issues paper (2010), which cited the need for reform due to a highly fragmented support system. It is of our understanding that the implementation of the proposed NDIS will remedy these issues by providing a concise and national approach to disability support mechanisms.

3.0 Approaches Concerning Eligibility

3.1 The definition of Disability

Key Question 1

"Who should be the key focus of a new scheme and how may they be practically and reliably identified?"

(Productivity Commission, 2010, pp.5)

Exacerbating the flaws of the current Australian disability support system is the fact that the term 'disability' does not maintain a uniformed definition in legislation and other official documents (Productivity Commission, 2010, pp.7). Whilst we acknowledge the variables associated with disability, it is of our understanding that in order to successfully deem someone eligible for support, they must align with set criteria outlined by a pre-determined definition. We also feel that single arbitrary definitions should be adhered to the four categories associated with disability. We recommend the application of a concise, yet encompassing definition that will inevitably alleviate confusion and prohibit people from falling through the gaps of the system. Mai-Wel would like to suggest that the definition of severe and profound disability extends beyond the conventional boundaries of communication, personal care and mobility and embraces behaviour and mental health.

3.2 Determining Eligibility

Section 6, Question 4

"Is 'Severe or Profound' disability an appropriate criterion for the need for support?"

(Productivity Commission, 2010, pp.17)

The proposed context within which eligibility will be assessed under the Scheme is somewhat concerning for the staff at The Mai Wel Group. If eligibility is determined exclusively by the assessment of severe or profound characteristics, it is of our understanding that many people with disability will miss out on the support services that they require. Current assessment for severe and profound disability only observes the restriction in one's ability to carry out core daily tasks such as dressing and eating (Giles et.al, 2003, pp.130). It does not consider medical and other influential characteristics. Our experience suggests that factors including location, socio-economic status, the availability of informal carers and most importantly, the overall wellbeing of the client, are all indicative support measures, which should be considered in assessment procedures under the NDIS. Alleviating occurrences of omission, we identify that a holistic approach would be more beneficial when determining individual eligibility. Mai-Wel is aware that there is a small allocation of funds under the proposed NDIS for information and referral for those not assessed

as having a severe & profound disability. We are concerned that this larger group may require greater intervention than information and referral and require on-going support across their life cycle and are concerned that there may be insufficient funds allocated to accommodate these needs.

3.3 Incorporating Natural Aging

Section 6, Question 9

“How should the scheme address disability associated with natural aging, and why?”

(Productivity Commission, 2010, pp.19)

Whilst we understand that the Australian Aged Care System is in place to manage the needs of those over 65 with disability, The Mai Wel Group is uncertain about the effects of an age-specific cut off within the proposed NDIS. Foremost, indicators are not always clear when determining if disability was caused purely due to the client's age, as underlying factors may exist. This issue is further heightened by the fact that predictions suggest the number of older people with profound disability will increase by 70% within the next 30 years (Giles et al, 2003, pp.130). This statistic raises the fundamental question of whether the Aged Care System will be able to individually facilitate the needs of an aging population. We feel that these aspects highlight that some people with disability, aged 65 years and over may require specific disability support services in order to meet their needs and therefore, should not be left out of the NDIS.

When determining appropriate eligibility standards for the NDIS, we feel that it is imperative to consider that people's situations changes over time. Circumstances can improve, worsen or merely stay the same. With this in mind, The Mai Wel Group proposes that assessments for support occur regularly. In order to limit the number of people with a disability being omitted from the system, we suggest that assessments are automatically conducted during the transitional stages of life. For example, evaluation will occur during newborn, toddler, school age, post school,

entry to work and retirement. Achieving early intervention, this method recognises that there are people who develop disability later on in life. They too need to be supported by the system. Mai-Wel also has concerns regarding the Budget as a means of funding the scheme and how it would be possible to require the required amount of money each year to fund the scheme irrespective of who is in Government.

4.0 Funding of The NDIS

Section 10, Question 5

“What would be the best way of financing a national disability scheme, and why?”

(Productivity Commission, 2010, pp.37)

The \$12.5 billion per annum allocation of funds for the NDIS (Productivity Commission, 2011, pp.4) is a considerable and much needed boost towards Australia’s disability support mechanisms. Whilst we agree with the Productivity Commission’s observation that the boost would alleviate underfunding, we feel that it will also create higher expectations of the system. After all, the funding increase recognises that people want quality support services and value for money. The Mai Wel Group agree that the Scheme may lead to the uncertainty of some service providers, however, we conceive that it will essentially advance the quality standards of current facilities nationwide. Undoubtedly reducing the amount of stress and concern from family and friends, we feel that an increase in funding will have many positive impacts.

Utilising recent criticisms of the Queensland Flood Levy to demonstrate our understanding, we feel that the implementation of a tax levy to fund the Scheme, without any form of significant advertising campaign, would be somewhat detrimental. With 73% of people who were polled by the Sydney Morning Herald, opposing the Flood Levy (Levy, 2011), it is our understanding that Australians would be just as unlikely to embrace the proposed changes when they are continually being hit in the hip pocket. Due to this, an advertising campaign exposing the fact

that disability can happen to anyone needs to be disseminated prior to the NDIS being operational.

Contrastingly, another way to raise revenue for the Scheme would be to adopt a “do with, not do for” approach. The Australian Bureau of Statistics (2009) identifies that there are about 4 million people in Australia with a disability. If every one of those people were to contribute just one dollar to fund the NDIS, they would raise an instant \$4 million towards the guarantee of a better support system. We view this contribution people with a disability as an inclusive and proactive approach for the implementation of the Scheme.

5.0 Leading Time Required for a Successful NDIS

Key Question 15

“How long would be needed to start a new scheme, and what would happen in the interim?”

(Productivity Commission, 2010, pp.6)

Three years to devise an entire Scheme and have it ready for implementation into a small client-based region, is considered as a rather modest amount of time to bring about national conformity. However, after observing the implementation timetable for the NDIS in the Productivity Commission’s Draft Report (2011, pp.12), we agree that it is achievable. Furthermore, as the Hunter has historically been utilised as the location for pilot schemes, we at The Mai Wel Group would welcome the Region’s selection once more. The Hunter is an effective environment for the initial full-scale rollout.

To ensure a coherent approach to the NDIS’ implementation we suggest further interaction between the community and the Federal Government during the three years interim. Further public consultation and stakeholder meetings need to be conducted. At The Mai Wel Group, we believe that the more knowledge gained on the topic, the more efficient our support system will be and the greater ownership

both people with a disability and the general public will have will ensure the success of the NDIS.

6.0 Conclusion

Our submission intends to reveal the fundamental issues that need to be addressed in the proposed NDIS. As a large, Hunter-based disability support provider, we feel that the application of a singular arbitrary definition for disability, combined with a proactive approach to funding and planning, will inevitably result in a more efficient system. The Mai Wel Group recognises the stresses that friends and relatives

experience when trying to find appropriate services for their loved one. Aiming to minimise such stresses, The Mai Wel Group hopes that this submission will provide guidance for the Scheme and lead to the cessation of incidences where individuals fall through the gaps.

7.0 Recommendations

- △ The NDIS requires application of a single arbitrary definition of disability and its four categories. This concise definition will feature in all legislation and public policy documents concerning disability. Not only used to limit confusion within the system, the definitions will be a key feature in determining eligibility.
- △ In order for people with a disability to receive the support that they require and to avoid inundation of the Aged Care System, eligible over 65 year olds with a disability need to be catered for under the NDIS.
- △ The NDIS' initial rollout should occur within the Hunter Region. The Hunter is historically a pilot region for Governmental schemes. Services in the Hunter Region have a reputation for collaboration and close connections with their local communities which are essential ingredients in the success of any proposed NDIS pilot.

- △ A strong advertising campaign is required in order for the Australian public to embrace the campaign. This campaign needs to portray the fact that disability can affect anyone and that the NDIS represents value for the money being invested in the scheme not only for people with a disability but the general public .To be truly inclusive and proactive, people with a disability need to be involved in all aspects of the campaign.

8.0 Sources

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- Levy, M, 2011, *Levy to Pay for \$5.6b Flood Bill*, *The Sydney Morning Herald*, viewed 20th April, 2011, <<http://www.smh.com.au/business/levy-to-pay-for-56b-flood-bill-20110127-1a64x.html>>

9.0 Documentation

Calls for Contributions:

How can you contribute to this inquiry?

Reviews of services for people with disability have shown many people are frustrated by current arrangements or get insufficient support, and feel alone, angry or depressed as a result.

The key question for the Commission is not how bad the current system is — nearly everyone thinks it needs to be overhauled. What we want to know is how to build a good system. You may have ideas about the features of a new long-term disability care and support scheme, based on your own experiences as a person with a disability, or as a service provider, carer, family member, friend, employer or workmate of a person with a disability. The rest of this issues paper sets out many questions that will need to be answered when designing a new scheme.

You can give us your ideas in many ways. You can:

- make a formal submission. In that case, you should look at attachment B about how to make a submission and attach the submission cover sheet so that we know it is a formal submission (attachment C). Submissions do not have to be long
- present at a public hearing
- provide answers to any or all of the questions in this paper, based on your personal experiences. This is different from a submission. It is not a formal process, so it is much easier to do. You do not have to read our detailed instructions on how to make a submission or include our formal cover sheet or tell us details about yourself. Just include the words **PERSONAL RESPONSE** at the start of your comments. You might write just a few lines on a good idea. Because these responses tend to be shorter, we will combine people's ideas into a single document. We will publish the document on our website, but will not publish your name to protect your privacy. We have used personal responses in other inquiries, such as the inquiry into paid parental leave. For example, look at www.pc.gov.au/projects/inquiry/parentalsupport/personal-responses. If you are making a more detailed and lengthy response, you might want to think about making a formal submission.

Your views will help us prepare a draft report, which we will put out in February next year. After hearing more views from people, we will give a final report on a new disability scheme to the Australian Government in July 2011.

The Terms of Reference:**Productivity Commission Inquiry into Disability Care and Support**

I, Nick Sherry, pursuant to Parts 2 and 3 of the Productivity Commission Act 1998, hereby refer a national disability long-term care and support scheme in Australia to the Productivity Commission for inquiry and report by 31 July 2011. The Commission will begin the inquiry in April 2010.

Background

The Australian Government is committed to developing a National Disability Strategy to enhance the quality of life and increase economic and social participation for people with disability and their carers.

The Commonwealth, along with the States and Territories, has a major investment in disability specific support. However, there remains a significant level of unmet demand for disability services which impacts upon the lives of people with disability, their families and carers. Demographic change and the anticipated decline in the availability of informal care are expected to place further pressure on the existing system over the coming decades.

While Australia's social security and universal health care systems provide an entitlement to services based on need, there is currently no equivalent entitlement to disability care and support services.

The Government is committed to finding the best solutions to improve care and support services for people with disability. An exploration of alternative approaches to funding and delivering disability services with a focus on early intervention and long-term care will be an important contribution to the National Disability Strategy.

Scope of the review

The Productivity Commission is requested to undertake an inquiry into a National Disability Long-term Care and Support Scheme. The inquiry should assess the costs, cost effectiveness, benefits, and feasibility of an approach which:

- provides long-term essential care and support for eligible people with severe or profound disability, on an entitlement basis and taking account the desired outcomes for each person over a lifetime

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- is intended to cover people with disability not acquired as part of the natural process of ageing
- calculates and manages the costs of long-term care and support for people with severe and profound disability
- replaces the existing system funding for the eligible population
- ensures a range of support options is available, including individualised approaches
- includes a coordinated package of care services which could include accommodation support, aids and equipment, respite, transport and a range of community participation and day programs available for a person's lifetime
- assists the person with disability to make decisions about their support
- provides support for people to participate in employment where possible.

In undertaking the inquiry, the Commission is to:

1. Examine a range of options and approaches, including international examples, for the provision of long-term care and support for people with severe or profound disability. The Commission is to include an examination of a social insurance model on a no-fault basis, reflecting the shared risk of disability across the population. The Commission should also examine other options that provide incentives to focus investment on early intervention, as an adjunct to, or substitute for, an insurance model.
2. The Commission is to consider the following specific design issues of any proposed scheme:
 - eligibility criteria for the scheme, including appropriate age limits, assessment and review processes
 - coverage and entitlements (benefits)
 - the choice of care providers including from the public, private and not-for-profit sectors
 - contribution of, and impact on, informal care
 - the implications for the health and aged care systems
 - the interaction with, or inclusion of, employment services and income support
 - where appropriate, the interaction with:
 - national and state-based traumatic injury schemes, with particular consideration of the implications for existing compensation arrangements
 - medical indemnity insurance schemes.

3. Consider governance and administrative arrangements for any proposed scheme including:

- the governance model for overseeing a scheme and prudential arrangements
- administrative arrangements, including consideration of national, state and/or regional administrative models
- implications for Commonwealth and State and Territory responsibilities
- the legislative basis for a scheme including consideration of head of power
- appeal and review processes for scheme claimants and participants.

4. Consider costs and financing of any proposed scheme, including:

- the costs in the transition phase and when fully operational, considering the likely demand for, and utilisation under different demographic and economic assumptions
- the likely offsets and/or cost pressures on government expenditure in other systems as a result of a scheme including income support, health, aged care, disability support system, judicial and crisis accommodation systems
- models for financing including: general revenue; hypothecated levy on personal taxation, a future fund approach with investment guidelines to generate income
- contributions of Commonwealth and State and Territory governments
- options for private contributions including copayments, fees or contributions to enhance services.

5. Consider implementation issues of any proposed scheme, including:

- changes that would be required to existing service systems
- workforce capacity
- lead times, implementation phasing and transition arrangements to introduce a scheme with consideration to service and workforce issues, fiscal outlook, and state and territory transitions.

