Response to the Productivity Commission's *Disability and Care Support,* Draft Inquiry Report

Dr Michele Foster, Ms Ros Harrington, Dr Paul Henman
School of Social Work and Human Services
University of Queensland

1. The following submission to the Commission's Draft Report on *Disability and Care Support* is based on our professional and research interests and areas of expertise relating to care and support for people with disability, health and social policy, and public sector governance. Our response also draws upon our current research project 'Financing and Management of Lifetime Care for Adults with Acquired Disability and High Care Needs' co-funded by the Australian Research Council, the Queensland Public Trustee and the Queensland Motor Accident Insurance Commission. This study includes an investigation of experiences of lifetime care and support in the context of disability arising from sudden onset traumatic events and progressive disorders. Our comments are our own and can in no way be construed as representing our research partners.

2. The Commission is congratulated on preparing a detailed and comprehensive report on a topic of great public policy reform need. Our feedback on the Report seeks to advance the policy reform by identifying areas of further consideration, clarification and development.

Equity and Living Standards

3. The Report identifies the "current support system [as] underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports" (Overview and Recommendations, p 2). We support this view and recognize that the proposed policy reform outlined in the Draft Report is clearly directed at reducing some of the current system's shortcomings.

4. We are also of the view that the proposal, in its current form, will potentially create other problems not acknowledged in the Draft Report. There is, for example, potential for key inequities to arise in differences in living standards and levels of care and support: (a) within the NDIS population; (b) within the NIIS; and (c) between NDIS population (ie tier 3) and those with less impairment (ie tier 2). These inequities are expected to generate ongoing levels of stress and tension both politically and in the service delivery system. In other words, the draft reforms are important, reforms but not an entire solution.

5. ***Inequities within the NDIS population***. At present the proposal is that 'assessments would concentrate on the reasonable and necessary supports that people require'. This principle requires further careful development and operationalisation. Currently, the principle would appear to imply equality of treatment (or horizontal equity), namely that people with identical levels of impairment will get identical levels of care and support services from the NDIS. However, under these arrangements equality of outcome may be compromised, primarily because of the decision to not means-test the NDIS care and support packages. This is a potential barrier to achieving an equitable response across the Australian Population for people with severe or

profound disabilities. As the proposal stands, individuals and families with greater income and assets will be able to augment their NDIS package to achieve a higher living standard. This is also a characteristic of the current systems of State-based disability support, but this inequity is likely to widen under the new proposal as a result of current practice to make some allowances for family capacity. The case studies in Box 1 illustrate some of these issues.

Box 1

Case Study 1

Mark is a 44 year old man diagnosed with Multiple Sclerosis. His condition deteriorated in the past 2 years at which time he was living at home with his daughter and walking up and down stairs. Since then he has needed an extra level of support and undertakes activities of daily living with assistance. Mark previously worked as a senior executive but is no longer in employment. He currently lives in a purpose-built apartment-style accommodation designed specifically for young adults with disability. At the facility, Mark's personal and domestic care is fully funded by the State Government and he has access to some limited physiotherapy and occupational therapy at no personal cost. Prior to moving to his current accommodation Mark was living in a residential aged care facility, but with advocacy and lobbying by his family he gained government funding to transfer to his current place of residence. Mark pays privately for additional therapy, including massage, podiatry and hydrotherapy outside the facility, which is subsided by his private health insurance. Mark has access to a car owned by the facility for personal activities, otherwise he uses public transport subsidised by government. He receives a regular income from private income protection insurance and his own savings.

Case study 2

Patricia is a 52 year woman who suffered a cerebro-vascular accident (CVA) which resulted in severe physical disability over 8 years ago. Prior to this Patricia worked part time and was the primary carer for her three school aged children. Patricia spent a year living in a residential aged care facility after her CVA, and the following two years living with her mother. During this time Patricia had very high physical support needs, with her mother providing the majority of her personal care in the absence of adequate Government funding for community supports. Patricia was subsequently admitted to a State government funded residential rehabilitation facility for young people with acquired brain injuries where she resided for two years. While there, Patricia received intensive daily therapies and regained the ability to speak, eat independently, stand transfer and participate in light domestic duties. After considerable lobbying by facility based staff Patricia was granted a place in a purpose-built apartment style accommodation designed specifically for young adults with disability and funded by a different State Government department. She currently pays 40% of her disability support pension in rent, in comparison to the 85% she was required to pay in the rehabilitation facility. Patricia has continued to make gains in her mobility with the assistance of limited centre based physiotherapy which she receives at no cost. She would like to receive more regular physiotherapy to help her progress to walking independently and ultimately to return home to live with her mother. Patricia has limited financial resources to pay for additional therapy after the majority of her life savings were redirected towards meeting the needs of her family. Her mother supplements her income to help pay for specialist appointments and everyday needs, and continues to visit her regularly on week-ends despite living three hours away by public transport.

6. An important task for the Commission is to consider the living standard level to be achieved by 'reasonable and necessary' support since this will be defined differently by different people and reflect individual preferences. For example, will the principle of 'reasonable and necessary' enable individuals the choice for support in their own homes, should they wish it? What level of choice for geographical location will it provide individuals? Will it enable informal carers, be they partners, parents or children, to return to the full-time workforce if they want that? What support will it enable them to continue, or even become, a parent should they desire? What levels of social participation will the support allow (e.g. annual holidays for the individual)? One way to clarify what is 'reasonable and necessary' is to determine a specified universal minimal standard of care and support that is expected to be achieved. These issues present a significant challenge in terms of balancing a universal minimal standard of care and meeting the goal of individualisation and choice, as indicated by the extract below taken from our research with a 54 year old woman diagnosed with Motor Neurone Disease.

   > *The really difficult side was trying to get other care. I looked at initially to just self-fund some, but I couldn't find anybody in seven agencies [who wanted to come to my area]. The care that I get…is good, not great…I think ideally for me it is to have a live-in carer but to find them, and we've tried over the last six months and we've interviewed, or my family's interviewed up to eight people, but finding someone that actually wants to live-in and care for you. It seems great, but it's not an easy task…And to try and fund, to try and have a live-in carer, I physically couldn't afford it. To have a live-in carer will cost somewhere around fourteen to fifteen hundred dollars a week. So it's something I can't quite fund at the moment. So we are trying to share.*

7. Other proposed design features such as the 20% discount on payments for family members providing care, incorporating pensions and allowances designed to support and foster the ongoing availability of informal carers into individual budgets (presumably to redirect these funds towards purchasing of paid care), and the ability to "cash out" the sum equivalent to rent for up to 40 years within a specialised accommodation facility, has the potential to disadvantage people with disabilities and their families who have limited financial resources.

8. Providing a 20% discounted rate of payment for a continued caring role does not acknowledge the loss of income these families might have incurred as a consequence of their choice to provide care in the home. A more equitable arrangement would be to discount the rate for family-provided care by a lesser sum, or alternatively apply the 20% discount rate, but allow the family to invest the 20% shortfall into a disability trust which would ensure that some capital is accumulated over time for the individual receiving care.

   While introducing the capacity to cash out *specialist disability* housing may facilitate enhanced choice for people with disabilities, enabling them to choose where and with whom they might live, inequities are likely to result from variances in individuals' capacities to benefit from this proposed feature.

   - Those with greater financial resources will be able to supplement rental payments to live in more favourable locations.

- The capacity to cash out a lump sum equivalent to the anticipated long term cost of rental (potentially over 40 years) will advantage those with the financial resources to self purchase accommodation. While this option could serve to build capacity by fostering private investment in alternative housing models (such as in the Hope Villages Australia Urban Village Model outlined in the Disability Investment Group Report 2010), in the absence of a quota system enabling individuals without sufficient capital to access these models, a two tier system of support is likely to emerge, whereby those with greater financial resources are able to ‘buy in’ to specialist housing, while those with limited financial reserves remain dependant on familial supports.
- Without careful regulation of how housing models immerge under a consumer choice model, there is potential that new housing models driven by ‘economies of scale’ result in the establishment of large disability specific accommodation complexes or villages, which could further serve to marginalise and segregate young people with disabilities and is inconsistent with a person-centered care approach. The potential for provider capture of vulnerable populations under this design feature also requires close consideration.
- Under existing funding arrangements, those living in long term residential facilities funded by State health departments (such as those operating in Queensland) could continue to pay a high proportion of their weekly income in rent (as illustrated in Case Study 2) given that the proposed NDIS would not fund health care services.

9. Inequities may also result from the principle of ‘reasonable and necessary’ care as a result of different capacities of individuals and families to advocate for themselves to address perceived ‘reasonable and necessary’ care and support needs. Our research has demonstrated that access to some care and support services only occurs after much advocacy by the individual or family. Moreover, we have several documented cases of people being unaware of what rights and choices they may be entitled to, because they have been not properly informed. We therefore view the proposal to address this issue through provision of information about entitlements and the assessment process, and advocacy services as a positive step. However, we suggest a further improvement would be to provide a clearly defined and publicly accessible schedule of benefits. This would also assist those individuals and families who wish to self-advocate and in cases, contest the decisions of the National Disability Insurance Agency.

10. ***Inequities within the NIIS population.*** The proposed creation of “no fault” state and territory based catastrophic injury schemes would do much to ensure a more equitable and streamlined approach to meeting the life time care and support needs of individuals after injury within each jurisdiction. However, current inequities are likely to continue across State and Territory boundaries in the presence of key variations in motor accident insurance scheme design (elaborated in S

11. ***Inequities between the NDIS and non-NDIS population***. The provision of higher and fairer levels of services to the disabled population through the NDIS will necessarily create an inequity with those just outside the NDIS system. Managing these perceived and real inequities is an important topic for consideration. More significantly, the current proposal suggests the NDIS be partially funded by redirecting current State disability services funding to the NDIS. This suggestion does not appear to acknowledge that State disability services also support people who will not be

eligible for NDIS services. How these people will be supported in the new regime and how that support will be financed will need to be considered in greater depth in the Final Report.

12. The perceived and demonstrated fairness of the system are important considerations for the Commission and have the potential to reinforce or undermine the wider legitimacy of the system.

Funding and Governance

13. The Commission's proposal recommends a 'consumer-choice' model, whereby people with disability have much greater say and control over their individual support packages, including the organisations and providers who would provide their supports. Under this model, it is proposed that individuals will have the power to choose their service providers, with the support of intermediaries (disability organisations) if they desire; and 'service providers would be expected to respond to the preferences of individual clients'. We endorse the move away from a provider-centred toward a more person-centred system. However, in our view the current proposal does not adequately deal with some of the challenges of implementing a choice model.

14. As the international literature indicates, 'choice' is not equitably distributed across the population (Ferguson, 2007). There will always be individuals who are more advantaged in terms of access to personal, social, family and economic resources which in turn means that they have greater capacity to exercise choice and to derive better outcomes compared to those who do not possess similar resources.

15. Choice will depend on what is available and affordable, and the stability of the service delivery sector. In our research in Queensland, areas of perceived lack of choice included limited options if wanting to move and especially if wanting to move closer to home; and limited choice of quality respite close to home. (See also the case study in Box 1). There was also an overwhelming lack of choice in relation to transport services for adults with high care and support needs. Moreover, our study has found that the three biggest areas of unmet need were health and rehabilitation services; flexibility in care provision; and transport. This finding is broadly consistent with previous research by the Australian Institute of Welfare (AIHW) and the Senate Standing Committee on Community Affairs (2007). While the current proposal implies the need for increased funding, it does not specifically address the issue of development of infrastructure, or the inherent differences in resources across jurisdictions. These issues represent a potential barrier to realising the goal of portability of support packages across State and Territory borders.

16. There are challenges surrounding the 'informed consumer'. The current proposal does not address the significant investment that will be required to ensure that (a) information is provided in a format that is accessible and appropriate to people with vastly different needs; and (b) that choice actually happens. In terms of the latter point, further clarification of the roles and lines of responsibility of the NDIA case manager, disability organisations and service providers would be beneficial.

17. More explicit detail is needed about the assessment of needs of families and informal carers and how choice will be operationalised for them. The current proposal states that the assessment

process would ‘consider what reasonably and willingly could be provided by unpaid family carers and the community’. Our research confirms that the contribution of family, friends and community is routinely critical to the person’s care and wellbeing, and ability to remain in community living. While difficult to quantify, in some cases it means being available 20-24 hours a day compared to ½ - 8½ hours of care offered by a service provider, and families being willing to manage emergencies and crises.

18. Clarification is required about what information will be provided to families and informal carers about what is available and their entitlements. There is potential for quite different support if the assessment process involves asking families what they will provide, rather than giving families the choice of what is reasonable and appropriate to their circumstances in the context of knowing the full range of entitlement. These issues are exemplified in the extract below taken from an interview with a spouse of a man diagnosed with multiple sclerosis.

> *They [the service provider] administer it. Like we were nominated and we accepted, but they do the whole thing there…Like they came out and interviewed [him], but we don’t see the account…Yeah, we’re just assuming that they’re doing the right thing and we’re getting the hours and everything. We don’t know, you know, but I’m sure they are*

19. The ‘consumer-choice’ model proposed also implies a preference for market mechanisms as a way in which to advance service quality and innovation. Markets do offer many benefits, but also have some important limitations, including instances of market failure. Competition based on price alone may cause small organisations, including in the non-government sector, to exit the market due to a limited resource base to compete with large organisations which spread administrative and managerial costs across multiple services. The dominance of large multi-site service providers poses challenges to personalised care delivery. Within a competitive market, the individual and family social and economic capital also becomes a critical means of access and quality of life.

20. Long term disability also has a high financial cost for the individual and their families. Poverty can be a consequence of the choice many families have made to provide ongoing care and support in the home for their family members with a disability – particularly in those families where one parent has a disability, or in families where a single parent is caring for a child with a disability (in the presence of high levels of marital breakdown in families poorly supported to sustain their caring roles in the past).

21. Our research also indicates that many individuals incur a range of privately funded expenses. Several have needed to pay personally for modified cars, home modifications, furniture, equipment and other items to manage their disability. Some have substantial ongoing expenses, such as maintenance of hoists and equipment. In some cases, family income decreases as family members reduce or cease their former work in order to provide what they regard as necessary support for their family member with a disability. In short, the ‘choice’ for family members to be able to return to employment should be considered as a critical component of ‘choice’ for recipients of NDIS care and support packages.

22. An important inclusion in the Commission’s report is the proposal for a Memorandum of Understanding between health and the NDIS in each State. This is an acknowledgement that people’s needs cross sector boundaries and that the interrelationship of the health and disability sectors is important under the new proposal. As the extract below taken from an interview with a spouse of a woman diagnosed with Motor Neurone Disease indicates, there will need to be consideration given to the processes for joint planning and how case management will be operationalised across transitions.

> *Well when you haven’t sort of had anybody in a hospital situation and in Joan’s condition or any type of major problem, it’s very daunting... You know, you’re telling me that she’s got no case person and you’re leaving me with something that I’m not qualified to deal with. Yeah, so where do you go from there? You know, well they are saying ‘well go back to your main care provider’ and they are saying to me,’ well we can give you what we can give you’. You just have to make the applications’ and I said, ‘well we have already done that’...Whereas I think if there was like with chronic situations if there was like a guideline of, you know, this is who you can go to, like a program thing, I think you’d be a little bit more settled in your own mind as to how to deal with it. It’s all just guesswork as far as I was concerned...If you’re sick you go to the hospital and hope to God that they can help you, but when they send you home and say ‘well we can’t do anything’, you know what avenues are you supposed to take, you know.*

23. In the presence of a Memorandum of Understanding will there be sufficient incentives within the proposed system to encourage appropriate and timely transitions between health and disability systems and to avoid cost shifting? Our research indicates that when informal care arrangements break down a public hospital admission is highly likely, even for compensable patients. This creates ongoing tensions between health and disability sectors until an appropriate alternative care arrangement can be found. As with the NIIS, fee-for-service funding for hospital admissions could help to avoid cost shifting onto health budgets.

Funding and governance issues: NIIS

24. The Commission has identified a number of NIIS design features which will need to be determined on a jurisdictional basis such as overall scheme funding and governance arrangements. The funding model for delivery of support services will ultimately be critical to the development of service system capacity. This involves consideration of whether to adopt a levy based (prospective payment) system or fee for service funding arrangements.

25. In Australia, the National Health and Hospitals Reform Commission (NHHRC, 2009) reported that in contrast to prospective payment systems, fee-for-service systems, such as those operating in the private sector, increase throughput and access to care. The Victorian Transport Accident Commission (TAC) scheme operates a fee-for-service payment system for hospital based acute medical and rehabilitation services. Hospitals are paid in advance for the services they are anticipated to deliver and then reimbursed for any additional bed days occupied by TAC clients. In addition the TAC funds hospital in the home rehabilitation programs, and also attendance at outpatient rehabilitation (TAC, Accessed March 2010). The majority of these services are provided within the private sector.

26. Fee-for-service funding arrangements have also been introduced for specialist acquired brain injury (ABI) teams providing services to non-compensable individuals with severe traumatic brain injury in Victoria in recent years. Concomitantly, there has been a subsequent increase in funding for ABI, expansion of ABI disability support services and improved capacity of the service system to respond to the varying needs of people with ABI (Stringer, 2007). Similarly, in NSW, a fee-for-service payment system operates for all compensable patients receiving services from NSW Health specialist brain injury rehabilitation units, transitional living units, and community rehabilitation teams, with only the acute phase of hospital admission covered by a hospital services levy (Greater Metropolital Clinical Taskforce, 2006).

27. In contrast, in Queensland, emergency and hospital based acute care and rehabilitation services for people acquiring severe traumatic brain injury are funded through existing health care budgets and levies. This includes the sole public sector case management service in the state, the Acquired Brain Injury Outreach Service (ABIOS). Levies are collected at the time of CTP premium payment, and are allocated to fund a reasonable proportion of costs incurred for compensable patients injured in road traffic accidents (Queensland Statewide Rehabilitation Medicine Services Plan 2008 - 12).

    While a levy based system avoids some of the administrative costs of funding service delivery, it presents a number of challenges:-

    - It does not foster service development in response to need when there is no clear tracking mechanism for CTP claimants across their lifetime and throughout their interaction with publicly funded health care services.
    - When incorporated into broader health care budgets these funds may not be directed to meet the discreet health and specialist rehabilitation needs of CTP claimants which may be low on the list of State health department priorities.
    - It can provide a financial disincentive to early discharge for those with high and complex care needs who are slow to recover, thereby increasing pressure on acute care beds, impeding access to rehabilitation services, and shifting the costs of care onto healthcare budgets. One CTP claimant's family in our research reported a two and a half year delay in discharge from an acute hospital bed.
    - When indexed to CPI a levy does not reflect the rising costs of health care delivery (The Allen Consulting Group 2006)
    - The real dollar value of a levy is susceptible to other pressures on CTP premiums when: (a) set at a fixed percentage of overall CTP premium revenue, or; (b) the principle parameter for levy determination is discretionary (e.g. that it fund a reasonable proportion of the cost of publicly provided healthcare).
    - This funding mechanism also has implications for the development of private sector services within the state. One mother of a son with severe traumatic brain injury reported that when she inquired why there were no private hospitals specialising in TBI rehabilitation in Queensland, the response was "Who would pay for it!".

References

Australian Institute of Health and Welfare (2009a), Disability support services 2007-08: national data on services provided under the Commonwealth State/Territory Disability Agreement. Disability series. Cat. no. DIS 56. Canberra, AIHW.

Australian Institute of Health and Welfare (2009b), Disability in Australia: multiple disabilities and need for assistance. Disability series. Cat. no. DIS 55. Canberra, AIHW.

Ferguson I. (2007). Increasing User Choice or Privatizing Risk? The Antinomies of Personalization British Journal of Social Work, 37, 387–403

Greater Metropolital Clinical Taskforce. Transitional Living Program Evaluation: Stage One Report: Brain Injury Rehabilitation Directorate, 2006.
Queensland Statewide Rehabilitation Medicine Services Plan 2008 - 12. Retrieved March 2010. from http://www.health.qld.gov.au/publications/qh_plans/default.asp.

National Health and Medical Research Council (2009). The Australian Health Care System: The Potential for Efficiency Gains (A Review of the Literature). The National Health and Hospitals Reform Commission.

Senate Standing Committee on Community Affairs (2007), Funding and operation of the Commonwealth State/Territory Disability Agreement. Senate Printing Unit, Parliament House, Canberra, ACT.

Stringer, K. (2007). Acquired Brain Injury Case Management: Review Discussion Paper February 2007: Disability Services Division, DHS North and West Metropolitan Region.

TAC (Accessed March 2010). from http://www.tac.vic.gov.au/jsp/content/NavigationController.do?areaID=22&tierID=1&navID=B9EC32EA7F0000010104A4B61AE334F6&navLink=null&pageID=722

The Allen Consulting Group. The health economist view: Final Report. Report to Queensland Health, 17 March 2006.

Qualifications of respondents

Dr Michele Foster is Senior Lecturer in Health and Social Policy at the University of Queensland. Her primary research interest is in the area of policy and health services research, with an emphasis on policy implementation, professional decision-making and consumer experience. Dr Foster has a track record in the area of brain injury rehabilitation research and service development for adults with acquired disability following catastrophic injury, trauma and serious illness. She is currently the lead CI on a 3-year ARC Linkage project to examine lifetime care and support for adults with acquired disability and high care needs.

Ms Ros Harrington is a full time PhD candidate. Her thesis examines the association between motor accident insurance scheme design, service system capacity and quality of life after severe traumatic brain injury (TBI). She has extensive experience working as an occupational therapist in Queensland and her areas of specialisation include neurorehabilitation, mental health and consumer and systemic advocacy. In her previous role within a brain injury service, Rosamund established and chaired a cross-government advisory group whose main aim was to improve discharge pathways for adults with slow-to-recover acquired brain injuries.

Dr Paul Henman is Senior Lecturer in Social Policy at the University of Queensland. He holds degrees in computer science and sociology. His research focuses on technology and governance in the development and administration of social policy. Dr Henman previously worked in the Australian Department of Family and Community Services, and he regularly conducts research consultancies for State and Federal government agencies. His research on the costs of raising children and living standards has directly contributed to reforms in Australian child support policy. His most recent publication is *Governing Electronically: E-government and the reconfiguration of public administration, policy and power* (Palgrave 2010).