VICTORIAN YOUNG PEOPLE IN NURSING HOMES CONSORTIUM RESPONSE TO THE PRODUCTIVITY COMMISSION DRAFT REPORT

APRIL 2011

INTRODUCTION

The Victorian Young People In Nursing Homes Consortium (VYPINH) welcomes the development by the Productivity Commission of its Draft Report on Disability Care and Support, and strongly supports the principal themes and structures proposed in the Draft Report. The VYPINH Consortium recognises the capacity for this Scheme to improve accessibility, standards of care and support, and social inclusion for people with disabilities across Australia, and in particular the opportunity it will create to address the needs of those young people with disabilities whose options still are confined to entry into residential aged care (RAC).

The following paper outlines our response to the Commission's paper, particular to the issues central to the lives of people within, or potentially subject to future entry to residential aged care.

ABOUT THE VICTORIAN YOUNG PEOPLE IN NURSING HOMES CONSORTIUM

The VYPINH Consortium, which began in September 2001, comprises representatives from groups such as Melbourne City Mission, MS Society, Victorian Coalition of ABI Service Providers, Office of the Public Advocate, and representation and participation by young people in nursing homes, their families and advocates.

The Consortium provides an opportunity for sector workers and young people in nursing homes to meet and determine issues and potential options in order to improve the lives of people residing in, or in consideration for entry to nursing homes/aged care.

The Consortium has advocated at a State and Federal level (including holding the first National Summit about the issue of YPINH, in 2002), for recognition of the issues for YPINH,

and supported policies and initiatives such as *my future my choice*, developed by the Victorian State Government. We are currently anxiously awaiting the outcome of the COAG meeting which will determine the future for the Young People In Residential Aged Care (YPIRAC) initiative which will have run the course of its five year agreement in July this year.

COMMENTS ONTHE DRAFT REPORT

The VYPINH Consortium wishes to draw attention to the following areas, of key interest to the support and inclusion of the YPINH group.

Specialist capacity / Effective assessment

Persons with severe to catastrophic levels of injury and disability, who are in RAC or at risk of entry to RAC who will access the NDIS or NIIS Scheme, typically will require an individualised and specialist response, which attends to whole-of-life issues. This specialist response includes the need for skilled assessments and staff trained for specialist interventions including community based rehabilitation, as well as the need for specialised and frequently high cost aids and equipment.

As stated within the 2010 VYPINH submission:

- *Specific to the area of YPINH, it is vital that a non-RAC workforce maintains the skills in high-support care which currently exists within the aged care sector, in addition to knowledge and skills in the social and physical needs specific to young people with disabilities such as ABI, MS, etc.*

The VYPINH submission goes on to recommend that there be:

- *Provision of individualised rehabilitation programs, equipment, and facilities*

and that:

- *Assessment requires an understanding of the person and their environment. There is a need with the NDIS to develop appropriate clinical and whole of life assessment tools.*

(Commission Submission Paper 320, 2011)

It is particularly important to develop a system of individualised supports that responds to the specific needs of different types of disability. For example, people with an Acquired Brain

Injury require their supports and services delivered within a framework of rehabilitation, both medical and social. This differs significantly from a framework appropriate to the developmental approach which has been successful in the support of people with an intellectual disability and autism. Similarly those with neurological deterioration disorders require a responsive disability system that can interact flexibly and swiftly with the medical system when exacerbations occur.

The VYPINH Consortium congratulates the Commission for its recognition of the primary importance of an individualised approach in its proposals. It is equally important to recognise the need to ensure that specialist knowledge is supported structurally in the design of this new system. 'Generic' assessment processes can easily overlook the particular needs of people with differing disability types unless backed up with specialist knowledge. 'Common intake' processes have frequently placed relatively inexperienced workers on the front line, whereas highly skilled and experienced work can avoid misdiagnoses and the need for recovery using more expensive service responses.

The report recommends that 'assessors should be drawn from an approved pool of allied health professionals' (p5.21), and 'assessors would be mentored in their first six months of assessments, and all assessors would be regularly assessed to ensure comparability of outcomes and to avoid' sympathetic bracket creep'' (p5.21, and recommendations 5.3 and 5.4)). It is clear that this approach addresses the points made above to some degree. (Productivity Commission, 2011)

However, it is equally important to recognise the danger inherent in creating a large scale, risk-averse bureaucratised industry which becomes closed to innovation. Knowledge and understanding about disability (particularly cognitive aspects) is continuously expanding and successful interventions addressing recovery from catastrophic injury are rapidly evolving. New and innovative therapies and techniques must be encouraged in assessment and planning processes, and trials be allowed.

There is already a significant pool of practice knowledge about successful approaches to support people with a disability in the community, and not all of that rests in the allied health professions. Equally the knowledge in the allied health professions can vary greatly, and those in the acute system (for example) frequently make assessments that are inappropriate for community based rehabilitation and support. We recommend that there is greater breadth built

into the required qualifications for assessors, and continuous review and external input into the practice of assessment.

Requirement for ongoing monitoring and review

The Consortium believes that the NDIS and NIIS should be created as a fluid and adaptable system, with the capacity to reflect the changing needs of people with disabilities and their families/carers, and the sector. To this end, we believe that this requires ongoing review, and that it is done against a range of measures (along with the monitoring of economic and corporate performance outlined in recommendations in Chapter 7 of the draft report). These include:

- That the NDIS and NIIS are benchmarked to ensure equity of provision and outcomes;

- That outcomes achieved under the current disability systems operating across Australia are maintained through transition to a single system, and not reduced to the lowest common level;

- That successful individualised programs in Victoria, such as the ABI Slow To Recover program and the Continuing Care Pilot for people with neurological disorders are continued and expanded;

- That quality systems, backed up through legislative frameworks and charters of human rights in individual states and territories (see below*) are maintained and improved to equal highest levels across Australia in the new scheme;

- That advocacy, both at an individual as well as at strategic level is maintained and funded as an essential adjunct to the new scheme, with independence from the NDIA and the providers of disability services.

- That interfaces between the NDIS and NIIS, and the other areas of government such as Health, Justice, Education, Aged Care and Social Security are built into the new system and resourcing is identified to guarantee partnership approaches are achievable.

* Documents and legislation currently enacted within Victoria and which should operate as a foundation to such benchmarks include:

- The Disability Act, 2006 (principles and practice implications)

- Quality Framework for Disability Services in Victoria (2007); Standards for Disability Services; Industry Standards for Disability Services
- The Disability State Plan 2002-2012
- A Fairer Victoria
- The Victorian Charter of Human Rights
- The United Nations Convention on the Rights of People with Disabilities (2007)
- Guardianship and Administration Board Act, 2006
- Social Inclusion: Social Inclusion Board 2009 (definition and practice principles)

Research

The VYPINH recognises the need to continue ongoing support to a disability research agenda, and supports recommendation 10.2. It is essential to also recognise that there are many independent sources of research that are relevant to this agenda, (Winkler, Sloan, & Callaway, 2007a, 2007b) and it is important to ensure these independent sources are recognised under the new scheme.

As in the medical profession, there are differing 'schools' of knowledge that provide a robust framework for advancing our understanding and skills in disability support. It is important to ensure that an 'independent research capacity under the NDIS' is not captured by any particular knowledge stream, to the detriment of others.

Build upon existing infrastructure

The Consortium notes the present need, and opportunity, to build upon existing service infrastructures

As stated within Summer Foundation submission:

To inform the construction of a good service system... ... which builds on: What we know is working in Victoria for young people with severe to profound disability including the Department of Human Services (DHS), Disability Services my future my choice initiative and the ABI: Slow to Recover Program Southern Health, existing infrastructure and the good work

undertaken across the Victorian ABI compensable and non-compensable, neurological and generic disability service systems.

(Commission Submission Paper 556, 2011)

As stated within the 2010 VYPINH submission:

Whilst programs such as my future my choice are addressing the issues of YPINH in part, there remains a significant and systemic lack of access to appropriate, non-RAC accommodation and services, particularly for people aged 50-65.
Increased access to services, adequate financial support, improved disability workforce skills and improved cross-sectoral communication, are fundamental elements which will result in improvements to the issue of YPIRAC, and which should be fully incorporated within a NDIS.
(Commission Submission Paper 320, 2011)

The Consortium is encouraged by the capacity for the Scheme to enhance the support and inclusion of people in nursing homes, and to move to address long-standing issues of access to resources and funding for clients and service providers.

The Consortium believe that there are positive initiatives and programs currently in place, which can be enhanced by a scheme which builds upon and expands upon those existing structures within the sector. There are many examples of weakness in the current system, but many of them are due to the poor capacity of the system to match demand. Rationed service options in the current system can be easily dismissed as ineffective, whereas they need to be measured against their capacity to address individual needs. For example, the *my future my choice* program in Victoria has demonstrated that it has successfully met individual needs in very complex situations, but overall evaluations have shown it to have been unable to address all the needs identified in the target group (YPINH under 50 years of age).

Advocacy

A notable gap in the Commission's report is the importance of advocacy in ensuring that services and supports for people with a disability are delivered and quality is maintained. This is particularly important when considering that the recommended framework for this new national system is rights-based.

The current disability system in Victoria provides for safety net provisions such as Office of the Senior Practitioner, overseeing seclusion and restraint, a Disability Commissioner with jurisdiction over all funded disability support agencies as well as the Office of the Public Advocate and a range of funded advocacy agencies such as Disability Justice Advocacy. In combination these serve to ensure the disability service system continues to be appropriately managed and targeted.

The recommendations for a role for the NDIA and DSO's to 'help people to make informed choices (p8.23), and for case managers and DSO's to assist clients in 'switching providers' (p 8.27) are manageable where there is good will and cooperation. There is also skilled advocacy work occurring across the disability services.

However the complexities inherent in delivering supports to people with complex needs, and where disability is one of a number of concurrent issues being faced (eg poverty, homelessness, family breakdown etc) suggests that this underestimates the need for a more active and targeted advocacy role to ensure the system is fair and responsive. Dedicated advocacy will provide valuable oversight to the proposed scheme, because advocates will be directly involved where failures in the system occur.

Increasingly there are significant advances being made by people with disabilities in creating self-advocacy organisations (eg Brain Injury Matters in Victoria). These groups add value to the monitoring and oversight of the NDIS and NIIS (Information requested by commissioners, Chapter 8). The funding of these valuable organisations has been in a parlous state under the current system, where much needed direct services have been prioritised.

Under the Victorian Disability Act, the quality framework determines that all services need to include consumer participation at all levels of the organisation. Agencies currently draw heavily on the self-advocacy approach to address this goal, and this needs to be addressed in the creation of the NDIA as well. That will in turn provide valuable monitoring capacity to ensure the system remains relevant and properly targeted.

Interface across sectors

We note the request for information by the Commission on the interface between the NDIS/NIIS and mental health and associated sectors (Productivity Commission, 2011, Chapter

3). The YPINH group currently interacts significantly with the mental health, acute and rehabilitation health systems, and the aged care sector. These are clear areas where expertise required to support this group is located outside the disability system. However, the difficulties faced in transferring and coordination between systems have required investment in interface services, such as the Brain Disorders Program at Royal Talbot Rehabilitation, for people with mental health and acquired brain injury.

As well, the funding of experienced attendant support workers during stays in acute hospitals ensures essential programs are maintained during those stays, and the use of case managers employed through the ABI Slow to Recover program ensures community rehabilitation programs are deliverable in residential aged care settings. The VYPINH recommends that there are 'partnerships' created across sectors that enhance the best outcomes where the needs of individuals crosses areas of expertise.

Whilst the individualised approach to service delivery can identify most effective options within the disability system, not all supports will be most appropriately delivered under that framework – eg community rehabilitation nursing is a specialist field that can contribute to recovery after injury and works effectively alongside disability provision. It would not be appropriate to try to absorb these fields into the disability system, when it can be better supported through the health system.

Therefore, the VYPINH recommends that responsibility continues outside the NDIS, but that resources for interface services are identified and committed, to ensure partnership development is maintained between the relevant systems. These will then have responsibility for the key areas of transition between systems, referrals for support and pathway development.

Capacity to Pilot the NDIS/NIIS Scheme

The Consortium notes the Commission's interest in developing a pilot of the Scheme in 2014, and wishes to express our support for the establishment of this pilot within Victoria. The Consortium believe that Victoria's disability, community and allied health sectors are well-placed to deliver on such a pilot, and acknowledges the support announced by the Victorian State Government to the development of a pilot program in 2014 (Wooldridge, 2010).

An adequately and appropriately resourced pilot NDIS and NIIS program within Victoria can deliver on the goals outlined in the Victorian State Plan 2002-2012. Delivery on all these goals has so far failed because of rationed and inadequate resourcing. It will also address the still outstanding achievements of the YPIRAC scheme, known in Victoria under the program *my future my choice*, which addressed the needs of some YPINH well, but failed to achieve these outcomes for many in that target grou*p*. That initiative also completely missed out on delivering these same outcomes to those YPINH over 50 years of age, whose circumstances remain arguably some of the most neglected for people with disabilities across Australia.

Other Gaps identified:

The VYPINH recognises the scope of the inquiry was to develop a response to the needs of those with severe to profound disability. The Consortium's work is primarily concerned with this group as they are the individuals currently most likely to end up living in Residential Aged Care. It is also clear to us that with more appropriate opportunity, many of this group can make significant gains through well-targeted rehabilitation and support. The NDIS and NIIS schemes need to recognise that the concept of 'severe and profound' is not a stable condition in many cases and needs to allow for the those whose level of disability may vary considerably over their lifetimes. Being able to respond flexibly over a lifetime will ensure that these individuals are not excluded because they do not qualify as having a 'permanent disability' (recommendation 3.2).

It is also noted that there is silence in the commission's draft report about supports for those with mild to moderate disability more generally. While the scope of this proposed scheme has been to address the needs of those with higher levels of disability, it is clear that there is also merit in coordinating services across all groups of people with a disability, not least because there will be individuals whose needs will increase to severe and profound if neglected. Therefore it would be important to address the issue of where these other supports will come from. For example, State, Territory and Local Governments currently contribute significantly to these group's support needs, as do non-government and charitable organisations. Formalised interface with the NDIS and NIIS would ensure those groups are not abandoned in the creation of a new national scheme for those with higher level support needs.

CONCLUSION

The VYPINH Consortium commends the Productivity Commission for its forward-thinking and groundbreaking report, and its recommendations for a comprehensive approach to the needs of those with a disability across Australia. We welcome the opportunity to comment on the Draft Report and we look forward to the Commission's Final Report, and the chance to support its adoption nationally.

REFERENCES

Commission Submission Paper 320 (2011) *Submission from Victorian Young People in Nursing Homes Consortium to Productivity Commission Inquiry into Disability Care and Support.* Victorian Young People in Nursing Homes Consortium, August 2010

Commission Submission Paper 556 (2011) *Summer Foundation Productivity Commission Disability Care and Support Submission.* Summer Foundation Ltd, August 2010

Productivity Commission 2011, *Disability Care and Support*, Draft Inquiry Report, Canberra

"Winkler, D., Sloan, S., & Callaway, L. (2007a). *Younger people in residential aged care: Support needs, preferences and future directions.* Melbourne: Summer Foundation Ltd

Winkler, D., Sloan, S., & Callaway, L. (2007b). *From a home to their home: Alternatives to young people living in nursing homes*. Melbourne: Summer Foundation Ltd.

Wooldridge, M. (2010) *Coalition Government leads discussions on implementation of NDIS (Media Release)* accessed online April 2010 at: http://premier.vic.gov.au/2010/12/coalition-government-leads-discussions-on-implementation-of-ndis/