VICTORIAN COALITION OF ABI SERVICE PROVIDERS INC.

RESPONSE TO THE PRODUCTIVITY COMMISSION DRAFT REPORT: DISABILITY CARE AND SUPPORT

APRIL 2011

To:

The Productivity Commission

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INTRODUCTION

Acquired Brain Injury (ABI) is a disability which touches the lives of a growing number of Australians, and can dramatically shape and alter personal outcomes, relationships, community accessibility, financial standing and physical, mental and social health, both for the person with ABI and for their families/carers.

The sufficient, equitable and appropriate care and support for people with a disability, including ABI, are key issues and an essential component of any developed social fabric.

In this light, Victorian Coalition of ABI Service Providers Inc. (VCASP) welcomes the opportunity to respond to the Productivity Commission's Draft Report on Disability Care and Support, and to provide further input in relation to the future development of a NDIS and NIIS by the Australian Federal Government.

This response paper follows on from the initial submission from VCASP to the Productivity Commission Inquiry into Disability Care and Support (Submission number 320), forwarded in 2010.

ABOUT VCASP

VCASP was established in 1998 in response to the need for coordinated policy and service development for people affected by acquired brain injury (ABI). VCASP is a not-for-profit peak body acting on behalf of public and private sector service providers who assist people with acquired brain injuries, their families and others involved in their support. VCASP advocates for the availability of appropriate services and resources, as well as information and research that can assist those experiencing the effects of ABI. VCASP has advised the Victorian Department of Human Services (DHS) and been involved in the ABI strategic plan and its implementation. As a key body, VCASP is actively involved in implementing innovative service delivery development, such as the response to people with ABI due to alcohol and other drug use.

VCASP COMMENTS ON THE DRAFT REPORT

VCASP congratulates the Productivity Commission on its comprehensive assessment of the individual and systemic issues currently experienced by people with disability and their families and, progress towards a solution for people with severe to profound disabilities. VCASP therefore welcomes the proposed universal scheme and supports the key recommendations of the Productivity Commission Draft Report Disability Care and Support.

The following submission reiterates issues of key importance identified by VCASP in its original submission to the Productivity Commission and provides additional information regarding the VCASP position as it relates to issues including ABI and mental health, assessment, an indigenous strategy and the capacity to implement a pilot scheme in Victoria.

Overview of VCASP Productivity Commission Submission

In its initial submission in August 2010 (Submission no 320), VCASP highlighted a number of areas of key importance in the delivery of a sustainable and equitable disability support system.

These key issues included:

- Direct funding and systemic strengthening roles for the NDIS: direct funding to individuals, and systemic and organisational strengthening both within the disability sector, and within the non-disability and community sectors.
- The current equity gap between the compensable and non-compensable must be addressed. VCASP supports one no fault disability scheme for Australia as the basis for the provision of disability care and support
- Timely and early disability support involving specialist providers
- Capacity to move 'in and out' as support needs and circumstances change
- Coordination of supports across sectors
- Assessment for eligibility needs to be functional not diagnostic, and relevant to each disability
- Assessment should attend to whole of life issues
- Dynamics which inflate descriptions of people's disabilities need to be avoided

- Most assessments are straightforward; processes are needed for exceptions
- Assessing ABI can be complex and appropriate clinical and whole of life assessment tools are needed
- People eligible for NDIS direct funding should be primarily those with severe and profound impairments, including people with psychiatric disability
- People with a mild ABI would be eligible if their impairment necessitated complex care. Complex care needs arise from medical care and medication, homelessness, addiction, or criminal justice involvement (Commission Submission Paper 320, 2010)

The development and implementation of an NDIS and NIIS scheme is a vital reform towards the required systemic change in the provision of support for people with disabilities. Funding and infrastructure which builds upon established State and Federal initiatives and works collaboratively within the knowledge and skill base of sector organisations can, over time, result in appropriate systemic reorientation of disability support mechanisms.

REITERATION OF COMMON ABI ISSUES

The following reiterates some of the themes of the original VCASP submission and asks that the Productivity Commission address these within final report.

These specific issues include:

- ABI is a complex disability which can cross a number of support sectors, inc. mental health, criminal justice, etc. Furthermore its complexity and individuality of response requires assessment and care staff with a specific and detailed skill set. The NDIS must include the capacity to respond with the appropriate knowledge and skills to the needs of individuals with an ABI.

- As a disability with varying needs over time, ABI requires not only a whole-of-life response, but a response which is adaptable to changing needs.

- Whilst VCASP agree that the primary focus of NDIS funding should be people with severe and profound impairments, focus must also be provided to persons at high-risk or potentially engaging in high-risk behaviours, which necessitate complex care, such as people with ABI

experiencing homelessness, people with ABI and complex alcohol and other drug (AoD) issues, and people with ABI within the Criminal Justice system.

NATIONAL INJURY INSURANCE SCHEME

VCASP is encouraged by the capacity of the Productivity Commission Draft Report to reflect the issues highlighted within the VCASP paper, and in particular, to the development of a separate no-fault National Injury Insurance Scheme (NIIS) to provide specialist response to catastrophic injuries such as traumatic brain injuries.

In its initial response to the Productivity Commission, VCASP stated:

'There are specific advantages anticipated for people with an ABI from the NDIS. The NDIS offers lifelong, as needed, support for eligible individuals, that is accessible regardless of cause of ABI or the nature of a person's living arrangements; and improved quality of life for everyone with ABI regardless of degree of impairment. Of particular importance ... is the direction to reduce the unfairness in entitlements for individuals with like-injuries currently inherent in the divide between the compensable and non compensable systems.'
(Commission Submission Paper 320, 2010)

Models of support for ABI which occur within the compensable sector should be available and accessible to all persons with an ABI, regardless of at-fault status or where the injury occurred. VCASP believes that the development of a NIIS structure, which could build upon the positive attributes of current systems such as the TAC whilst also responding to any current inadequacies within that system, can be of groundbreaking benefit to the ABI sector.

PATHWAYS BETWEEN NDIS/NIIS AND THE MENTAL HEALTH SECTOR

In response to the Productivity Commission' s Information Request – Chapter 3, on the issue of boundaries with mental health, VCASP would like to highlight the key importance of effective and timely interface between the disability and mental health sectors. It should be noted here that effective and timely interface is also required with the acute and rehabilitation health, and aged care sectors.

Provision of appropriate support in such areas of expertise as mental health, rehabilitation and aged care will often require a response which is situated outside of the disability system. However

it is of key importance that sectors are supported by investment in, and coordination of, interface services between sectors. Examples of effective interfaces are:

- the Brain Disorders Program at Royal Talbot Rehabilitation, for people with mental health and acquired brain injury.
- the funding of experienced attendant support workers during stays in acute hospitals to ensure essential programs are maintained during those stays, and the use of case managers employed through the ABI Slow to Recover program, to ensure community rehabilitation programs are deliverable in residential aged care settings.

Mental health and ABI

Studies indicate that people with an ABI are significantly more likely to suffer from mental health problems, compared to the general population. It is estimated that prevalence rates for axis I disorders that began after traumatic brain injury may be as high as 48%, (Koponen, 2002), and incidences of mental health issues may be as high as 44% for all forms of diagnosed ABI (Acquired Brain Injury Outreach Service, 2011). Importantly, these mental health problems most often occur as a consequence of having experienced an ABI. (Department of Human Services, 2004).

The severity and impact of mental health issues on the lives of individuals with ABI and their families should not be underestimated. Suicide rates among people with brain injuries are reported as being at 2.7- 4 times higher than within general community (Teasdale & Engberg 2001; Simpson & Tate, 2002)

The changes in mental function caused by an ABI are complex. Mental health problems common among people with an ABI include adjustment disorders, depression, anxiety, and drug and alcohol abuse. In addition, the brain injury itself can cause symptoms similar to syndromes such as psychosis and dementia, and can lead to significant problems with impulse control, social skills and self-awareness. (Department of Human Services, 2004)

Given the multiplicity of risk factors for people with brain injury, the provision of appropriately targeted and tailored mental health strategies is vital. However access to specialist psychiatric assessment and treatment is very difficult especially for people with traumatic brain injury.

As discussed, mental health issues often occur amongst people with an ABI as a consequence of their injury. It is appropriate therefore that any provision of care by the NIIS insurance scheme

should include access to appropriate mental health services. Such access and care should reflect the intensity of the nature of mental health issue, and its longevity of effect, which may continue for decades post-injury (Koponen 2002).

VCASP has identified the positive programs available to Victorians with ABI and a mental illness undertaken in the area of ABI/mental health, and in particular the work of CBDATS.

As stated within the VCASP 2010 Submission to the Productivity Commission,

'Coordination of services around each individual, and family if present, is particularly important for people with an ABI given the frequency with which multiple agencies are involved, including cross sector arrangements. Cross sector arrangements supporting an individual have proved persistently difficult to organised and maintain. ..... Effective support for people with an ABI and additional complex care requirements needs initiatives across sectors. There are parallels between the system design for mental health and for ABI, especially with regard to the interface between clinical and inpatient approaches to critical care (the 'health' system) and the community re-integration and rehabilitation needs of people with either or both presentations. Community Brain Disorders Assessment and Treatment Service (CBDATS) is a jointly funded initiative between Victorian disability and mental health sectors. CBDATS is a statewide mobile consultative and treatment service providing support for adult consumers between the ages of 16 – 65, who experienced an acquired brain injury (ABI) or neurodegenerative disease and psychiatric disorder, including problems with behaviour management. CBDATS tackles dual disability and secondary consultation to both mental health and ABI disability sector.'
(Commission Submission Paper 320, 2010)

Access to such programs, with appropriate increase in funding, training and support, can work to address the serious and often devastating impact that mental health can play within the lives of people with ABI and their families.

VCASP advocates direct access to such services through the NIIS scheme, in cases of severe and profound acquired mental health issues, and appropriate pathways of referral into the mental health sector for all other persons with ABI accessing the broader NDIS scheme.

ASSESSMENT AND ASSESSMENT TOOLS

In response to the Productivity Commission' s Information Request – Chapter 5, seeking feedback on the use of assessment tools, and their appropriateness for assessing the care and support needs of individuals, VCASP wish to highlight the following issues.

VCASP agrees with the Productivity Commission's viewpoint that 'an assessment tool must provide a reasonably close estimate of a person's support needs and the resource allocation to achieve it. It should avoid being too generous or too tough. The process must be fair, rigorous, and safeguard against exaggerated claims of support needs' (Productivity Commission 2011)

As stated within the initial VCASP Submission paper,

'Notwithstanding the need to develop a national assessment process, our experience shows that the vast majority of assessment decisions of this kind are straightforward and non controversial based on available information, context and functional assessments. It is the complex and 'by exception' situations which require a more resource intensive process. An assessment panel with the option to draw on specialists is suggested. When further assessment needs to be undertaken it should be by professionals knowledgeable about ABI and independent from service providers. The MACNI (multiple and complex needs initiative) model from Victoria for people with complex needs is a relevant example.

Assessment requires an understanding of the person, their environment and the activities that they are wishing to engage in every day. ..... currently there is an over reliance on neuropsychological or medical assessments in isolation from information about how people manage in their specific context. There is a need with the NDIS to develop or endorse appropriate clinical and whole of life assessment tools.'
(Commission Submission Paper 320, 2010)

VCASP highlights the need for any assessment tools utilised to cover the complex and broad spectrum of areas of impact which an ABI may have on a person's life.

Assessments will need to respond to physical effects, psychological effects, social functioning and connection, and cognitive effects, all of which play an important role in the capacities of an individual, and their required levels of support.

Examples of specific social functioning assessment tools include the Tasmanian 'ERAT' tool for Youth Criminal Justice.

As an ongoing and 'changeable' condition, which can impact upon diverse areas such as mental health, AoD, social functioning, assessment of ABI will require a broad range of assessment tools, and for these assessments to be conducted at regular intervals.

Furthermore it is requisite, due to the specific medical and social issues experienced by people with an ABI that the persons conducting assessments are adequately skilled in the area of ABI. Such outcomes can be obtained through the use of current ABI assessment organisations and personnel, with adequate additional funding to meet the need of timely and appropriate assessment.

Assessment of individuals may be at risk of delay or reduced effectiveness in rural/regional areas, and in areas culturally removed from the broader society. Assessments will need to be promptly provided at a local level to persons residing in all areas of the community.

In all circumstances assessment of an individual shall occur within legislated time frames, and with adequate recall to appeal, as established in the Disability Act 2006.

CAPACITY TO ESTABLISH A 'PILOT' SCHEME IN VICTORIA

VCASP are encouraged by the potential for a Disability Care and Support Scheme to be piloted in 2014, and by the strong and publicly-voiced support of the incoming Victorian State Government for the establishment of a pilot program (Wooldridge, 2010).

VCASP believe that the Victorian ABI service sector and government sector is well positioned to undertake this pilot role, in connection with the State Government and NDIA, where services are adequately funded, trained and resourced for these initiatives.

VCASP's 2010 submission paper states:

In Victoria, the Traffic Accident Commission is an example of a social insurance scheme with well regarded and effective roles beyond direct funding to individuals after road trauma. These roles include research, data collation and analysis, and public education and prevention. Similar initiatives would be welcome in the NDIS and are lacking in current arrangements.
(Commission Submission Paper 320, 2010)

Within this context, it remains critical that in the development of this program, mechanisms are developed to retain existing services for existing client groups, whether those services are provided at a Federal-funded, COAG, or State-funded level.

CROSS-SECTORAL COMMUNICATION

Within the structure of the scheme, there needs to be a continual and over-arching recognition of the frequent co-morbidity of ABI conditions.

As stated within the 2010 VCASP submission, the Scheme will require:

'...better coordination with other sectors important in and already engaged in the lives of people with disabilities (notably, housing, education, mental health, alcohol and other drugs, employment, homelessness services and aged care) through responsibility for partnership developments.'
(Commission Submission Paper 320, 2010)

The NIIS will need to have the capacity to respond either by direct action of through referral to areas such as mental health, AoD etc which may be factors (either consequential or contributing) in an individual's ABI condition, and to have effective cross-sectoral communication with health, aged care, and accommodation services.

Tier 2 information and referral responses will need to keep track of individuals with co-morbidity needs, who may be lost in cross-sectoral movements.

In the area of Criminal Justice, individuals with an ABI must have access to appropriate plans and management as established in Part 8 of the Disability Act 2006 (Victorian Government 2006), to a level at least commensurate to that of persons with an intellectual disability.

ADEQUACY AND REVIEW OF FUNDING FOR ABI

Overall VCASP believes that funding estimates for ABI must recognise the variable nature of support over a person's lifetime. Provision of care under the NIIS including funding levels will require re-evaluation at regular periods, to ensure that care is adequate. As a condition which is in most cases life-long and ongoing, any re-evaluation of level of support needs, either in NDIS

or NIIS funded schemes, will require the capacity for support levels and available funds to an individual to increase, as well as any anticipated decrease through early intervention.

VCASP stated within its 2010 Productivity Commission submission:

'*Disability supports which are timely and not crisis-driven mean people with ABI can receive assistance when they are most able to benefit. It is envisaged that the NDIS system would recognise multiple points of entry to the service system and multiple patterns of recovery and support. That is, a systemic recognition that recovery and disability support for ABI cannot be understood solely as a linear progression from acute to rehabilitation to disability and community support. The NDIS needs to allow people to 'move in and out' of the system with no loss of entitlement and overall continuity of lifelong support, and to be assisted within other sectors, particularly mental health, alcohol and drug, employment and education.'*
(Commission Submission Paper 320, 2010)

Funding must also seek to maintain and build upon existing services in the interim period leading to the full establishment of a NDIS/NIIS. For example, the current COAG funded YPIRAC scheme, known in Victoria as m*y future my choice*, has addressed the needs of many individuals well. In Victoria however no services have been provided to people over the age of 50 years whose circumstances remain arguably some of the most neglected for people with disabilities across Australia.

TRAINING AND SKILL LEVELS

In response to the Commission's statement on page 39, re levels of training required, in which the Commission states:

'*The Commission is sceptical of imposing any additional requirements for credentials and training of the disability services workforce. In particular there should be no minimum training requirement to work as a personal support worker.'*

VCASP wish to strongly state our position that persons with an ABI require specialist care, at all levels of support, and that the provision of skilled support, in turn, leads to reduced social impacts, and increased capacity to recovery.

Whilst VCASP recognises that invaluable support and care offered by both the workforce and at-home carers, VCASP believes that a minimum level of training is required for the care of

people with an acquired brain injury, and that a component of that level of training must include specific education in the area of ABI.

This training should form part of an overall systemic strengthening of the disability sector that also includes accreditation and monitoring of performance of service providers and DSO's.

VCASP's 2010 Submission stated:

'*Systemic strengthening of the disability support system to ensure greater accountability for outcomes for people with disabilities through, for example, increasing the capacity and range of service providers, workforce planning, data collection about quality of provision outcomes, and accreditation and monitoring of service providers.'* (Commission Submission Paper 320, 2010)

Programs such as 'Slow to Recover' which provide specialist high-level support provide an example of the capacity of programs employing trained and skilled staff to deliver positive outcomes for individuals, with long-term social and financial benefits.

VCASP note the Commission's statement that:

'*The NDIS should also undertake research to examine how training affects outcomes for people and ensures safety for workers.* (Commission Submission Paper 320, 2010)

and welcome any opportunity to conduct further research on the capacity for training in ABI to affect outcomes for people.

INDIGENOUS COMMUNITIES AND ACQUIRED BRAIN INJURY

VCASP supports the Productivity Commission contention that additional strategies will be required to ensure access to disability services for Aboriginal and Torres Strait Islander people.

Many opportunities to build capacity, in both indigenous and generic and specialist disability organisations have been identified by the VCASP membership. These include:

- Professional development opportunities where expertise is shared, to increase the capabilities of indigenous staff to assess eligibility for disability support in compliance with Victorian State government disability legislation and associated policy;

- Professional development opportunities to assist with the development and implementation of best practice ABI interventions;
- Access to for example neuropsychological assessment and aids and equipment
- Specialist and generic disability organisations to implement effective cultural practice and to engage indigenous organisations in meaningful partnerships.

This recognises, given the incidence and prevalence of disability amongst indigenous populations, that indigenous organisations are already undertaking disability and culturally appropriate work without resources or access to information or expertise that are generally available to specialist and generic disability services as a matter of course. It should also be noted that ABI Specialist Services are not adequately funded to spend the time required to develop the relationships and partnerships necessary to develop and implement strategies which will build capacity.

OTHER ISSUES

- NDIS and NIIS assessments: VCASP recommends that assessors be appropriately trained in the specific needs and identifying issues and behaviours within ABI, and that a comprehensive toolkit in ABI be developed as part of such compliance and capacity.

- NDIA and other developed Boards within the Scheme: VCASP recommends that any Boards and/or decision-making panels of the NDIA, NDIS and NIIS include within them persons with knowledge of ABI and TBI conditions.

- VCASP notes the Commission's recommendation that an independent review be undertaken in 2020 into the Scheme, to consider the merits of widening coverage, in particular the potential to widen coverage of the care and support needs of the non-catastrophic. VCASP welcomes this 2020 review, and would support any development of appropriate data in the lead-up to 2020 which can assist in this review and examination.

CONCLUSION

VCASP supports the key recommendations of the Productivity Commission's report, including the development of a separate NIIS Scheme, and recommends its introduction along with structural reform which enables an effective interface between the disability sector and the mental health, health and aged care sectors. VCASP supports the introduction of a pilot scheme in Victoria in 2014, which builds upon established capacities within the State.

VCASP commends the Productivity Commission on the development of a progressive, comprehensive and groundbreaking report, and for its recommendations regarding a systems approach to meet the needs of people with a disability. VCASP acknowledges the opportunity provided by the Commission through formal submissions and forum consultations for individuals and organisations to comment, and thanks the Commission for the opportunity to forward our response to the Draft Report. We look forward to the Productivity Commission's Final Report, and offer our support to the future introduction of the NDIS/NIIS Scheme across Australia.

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