Submission from VCASP and VBIRA to
Productivity Commission Inquiry into Disability Care and Support

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1. Introduction

This submission is a joint response to the Productivity Commission's review of Disability Care and Support from the Victorian Coalition of Acquired Brain Injury Service Providers (VCASP) and the Victorian Brain Injury Recovery Association (VBIRA). VCASP and VBIRA represent issues for people with acquired brain injury (ABI) and their families, excluding those people with progressive neurological impairments. This submission considers issues for the broad spectrum of people with ABI and recognises that the particular issues for people with catastrophic injury will also be represented in more detail in submissions from other groups. We do recognise that people with catastrophic severe and multiple physical and cognitive injuries require high costs to be supported well.

This submission aims to describe:

- The disability support needs of people with ABI
- To comment on the desirability of the directions proposed for the NDIS in the Productivity Commission's Issues paper, both in general terms and specifically from the perspective of people with an ABI
- To provide specific advice about the foundations of the NDIS, namely eligibility and assessment; who has decision making power and for what; the parameters of disability support; and how the new scheme should be funded and organised.
- To identify aspects of the current system which do work well and are consistent with the NDIS proposal
- To signal areas of uncertainty and confusion about the new directions.

The submission does repeat some points in the various sections for ease of the reader wanting our ideas about specific issues. We recognise that some of our ideas are in the formative stages and will benefit from further analysis and perusal of other responses. We look forward to the opportunity to comment on and develop these ideas as the Productivity Commission consultation process continues. We congratulate the Productivity Commission for their insight into the shortfalls of the current disability support system.

1.1 About VCASP and VBIRA

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. VCASP is a key body involved in implementing innovative service delivery development, such as the response to people with ABI due to alcohol and other drug use.

The Victorian Brain Injury Recovery Association (VBIRA) is a not-for-profit association formed in 2000 by health professionals active in the medical management and rehabilitation for people with an ABI. VBIRA provides a forum for health workers to meet, collaborate and exchange information about ABI in order to improve the quality of life for people who have severe ABI. VBIRA is active in ongoing education of clinicians including quarterly education forums on specific ABI rehabilitation topics and an annual workshop which attracts 200 clinicians. VBIRA's education program aims to expand the capabilities and rehabilitation knowledge of clinicians working with people with ABI.

In Victoria, VCASP and VBIRA have been significantly involved in the development of services and professional education about the support needs of people with an ABI, and their families and carers. VCASP and VBIRA have provided input into developments in Victorian compensation systems such as the Transport Accident Commission and Victorian Work-Cover Authority, and recently into the Young People in Residential Aged Care (YPIRAC) initiative of the Council of Australian Governments (COAG) 2006.

1.2 About acquired brain injury (ABI)

ABI can result from a number of causes, including head trauma, hypoxia, infection, tumour, substance abuse, assault, degenerative neurological disease and stroke and cerebral haemorrhage. ABI can cause physical, cognitive, psychosocial, and sensory impairments, which may lead to restrictions in various areas of life. In broad terms people with an ABI fall into two groups: those with minimal physical and major cognitive impairments; and those with severe and multiple physical and cognitive impairments, who are also predominately non-speaking, but may be aware of their surroundings. (Case studies used throughout the document will exemplify issues for both groups). The nature of the disability support required can vary with each individual and fluctuate over time. Timely and early interventions have a large benefit, in particular for people with acute brain injuries, that is, for all acquired brain injury that occurs suddenly.

It is important that people can seek disability support at any stage of their lives post injury. Some people who have recovered from physical injuries will only suspect brain injury at a later time and seek entry to the disability support system. Currently these people can be denied access to disability support because of misunderstandings that because a head injury occurred many years ago, it is no longer relevant. Some people will not suspect ABI and remain unsupported experiencing, for example, unemployment or unstable employment and social isolation. The terminology of 'previous ABI' (DIG 2009a, 2009b) suggests a concerning misunderstanding of the long term nature of cognitive, emotional and behavioural impairments arising from brain injury which persist beyond recovery from physical injuries, as the following case study highlights.

Case study one: Mild head injury but severe functional impairment

Tom, in his thirties, was assaulted in the workplace. He had multiple lacerations and skull fractures, but little suggestion of brain injury. He experienced a brief loss of consciousness and there was no brain pathology from a CT scan. He received no rehabilitation and was deemed fit to return to work by various medical specialists. Rehabilitation specialists were not involved to assess functional impairment.

Tom returned to work as a contractor driving a delivery van. However, he now had a very limited ability to plan and execute the requirements for his job or for an organised life. He drove about but did not complete the deliveries. He was argumentative with work mates, employers and medical staff. He was judged to be 'difficult'. His house gradually became pitifully disorganised. He could not complete necessary administration for his business, tax and finances. Tom didn't recognise his need for assistance.

Tom is severely functionally impaired. More recent functional assessments have revealed a man who despite a mild brain injury and retaining his intelligence, has a severe impairment in his cognitive executive capacity affecting planning, insight and self monitoring and problem solving. He is not able to go about daily life without considerable prompts and assistance.

Unlike the developmental disabilities, acquired brain injuries can occur when individuals have had significant life experience without a disability. However, children, adolescents and young adults with ABI from various causes face particular problems because of limited life, education and work experience prior to their injury. Skills related to learning or work may be even harder to develop if the brain injury occurs early in life.

In general, ABI is not ageing–related and occurs at all ages. ABI, particularly traumatic brain injury, commonly affects people in early adulthood, and survivors may not have substantially reduced life expectancy. Therefore, people with ongoing support needs as a result of traumatic brain injury commonly live for 20 to 40 years after injury.

Alcohol related brain injury is more common in middle aged to older men. As there is no single episode that created the brain injury, many of these people may be undiagnosed and not recognised as having a disability, as distinct from having an addiction.

Drug and substance related brain injury is being evidenced in a new group of younger people in particular. These people are likely to be excluded from services if they were still using substances and be undiagnosed in terms of brain injury. This group may have complex lifestyle issues (for example, criminality, health and mental health status). There is very limited recognition of this group in terms of their disability and minimal system capacity to monitor their emergence or to respond to their support needs.

Stroke is more common as people get older, although 25% of strokes occur in people aged less than 65 years. The older age group who have had a stroke is perhaps the best understood form of ABI in the wider community. Older people who have had a stroke tend to be better linked to the hospital rehabilitation system and more likely to experience continuous contact with the service system if they live in an area where this is available. In terms of return to work following a stroke, people aged between fifty and sixty face additional bias in terms of the ‘older worker syndrome’, or simply see work as no longer relevant to them. Younger parents experiencing stroke often find very limited supports to assist them. Younger people with aneurysms are often treated in (aged care) rehabilitation and then transferred to disability support. However, this is not a straightforward process.

The following case study (case study two) highlights issues some of the complex issues facing people with an ABI and the service system aiming to support them. A responsive system is needed with multiple entry points, where people can go in and out of as needed, and be assisted as appropriate by specialist response capacity as well as access to generic systems.

Case study two: Many support needs

As a young child, Betty experienced an acquired brain injury and an associated condition requiring acute hospital admissions from time to time. Betty is now in her early thirties and has a part-time job. She left tertiary studies some years ago. She has always had friends although she has lost contact with many people over the years. She is a keen swimmer and writer.

Over the years, Betty is finding she is becoming less mobile, particularly when she is *'down the street*.' A wheelchair has helped her independence in the community and she is able to get around her flat and do most things for herself. Betty finds it difficult to move quickly or to push furniture, lift objects and do complicated or heavy hand/ arm actions.

Betty largely coordinates her own support arrangements. At times she has been homeless, at other times she has shared rental houses with friends. She found friends couldn't and didn't want to provide the type of support she needs. *'Friends found it hard to live with me*.' She did live in a flat with outreach support but the tenure wasn't long term and the agency workers had *'differing ideas of support to me – they helped me move in and then I didn't see them*.' Support for Betty means emotional and physical presence. Other support agencies said Betty couldn't get their services as she was already linked to one agency through the flat. She did want the flat, but the support was wrong.

Betty then lived for a while in a one bedroom furnished transitional flat in another part of town, with one hour of home help per fortnight from Council. She had organised the Council assistance. Office of Housing then offered her a house in another part of inner Melbourne. Where she wanted to live, where she is now and the new area are all different. She had no friends, contacts or family in the current and new areas. She has dealt with three metropolitan government regions, with the result Betty was not able to get to know well any of the staff or office systems.

Betty now rents a one bedroom Office of Housing flat and has long term tenure. There is no permanent ramp. Betty has a portable ramp which she has to pick up, assemble, get herself back inside, drive the wheelchair out, get back inside (without the ramp), disassemble the ramp and put it inside, walk out and drive off.

Sometimes Betty is unwell. During these times she does not like to be alone at home. She uses a personal alarm. She sometimes calls the ambulance. *'Some one turns up usually RDNS or an ambo and says, do you want to stay home or go to hospital, great choice!'* If Betty is taken to hospital, hospital staff always want her to live where there would be staff around her all the time. This usually means a Supported Residential Setting. Betty doesn't want to – and won't - do this. She didn't want the specialist day service either.

Betty has a flexible funding package ($5000 annually). She likes to swim but needs someone to be with her. This takes 2 of 3 hours of support worker time per week. Then if she is sick it means she doesn't have the support hours. The options available are either more restrictive than she needs (as she does not need 24 hour staff support), or systemically expensive when she is forced to rely on emergency services for episodic support. Friends alone cannot provide the level of personal support required.

Betty has found it difficult over the years to coordinate stable housing, appropriate design and modifications and on call personal support. The formal system has geographically fractured her friendship network and has not undertaken a role of helping her to maintain and develop informal supports. No one has been available to coordinate her requirements for services.

SUMMARY POINTS

- An ABI is a long term disability which significantly affects people's abilities to become involved in community life in ways that allow quality of life.
- The term 'ABI' applies to a diverse group of people. The disability support responses envisaged with the new NDIS need to be sensitive to the many impacts, causes and life stage implications of all forms of ABI.

- Timely and early interventions have a large benefit, in particular for people with acute brain injuries.
- It is often not understood that severe functional impairment can occur with a diagnosis of mild brain injury.
- It is important that people with an ABI can enter the disability support system at any time post injury.
- Many people with ABI are not diagnosed early enough, reducing opportunities to facilitate recovery
- Coordinating diverse and changing service system responses is an important aspect of disability support

a. A large and growing group

People with ABI are a relatively large and growing group of people with disability. Fortune and Wen (1999) estimated the incidence and prevalence of ABI to be similar to intellectual disability. This study noted the difficulty of obtaining estimates of incidence and prevalence for ABI. Population estimates were found to be difficult for instances of non-traumatic brain injury and because ABI frequently remains undiagnosed when occurring concurrently with other conditions. The significant numbers of people with ABI believed to be in the criminal justice and unemployment networks are consistent with this under diagnosis. The indigenous population is also under-represented in current ABI services.

In recent years VCASP and VBIRA member agencies report more people with ABI and complex care needs being identified often years after their injury. This has had a direct effect on service system capacity to respond. People are being referred from generic community providers and are unknown to specialist ABI providers. Analysis of active client and wait lists indicates that this more recently emerged group of people with an ABI is often characterised by an active alcohol or other substance misuse issue, a mental illness, a personality disorder, family breakdown, intellectual disability, unemployment, homelessness or being at risk of homelessness. Generally this newly emerging group has had prior involvement with a number of service providers over a long period of time and continue to require a resource intensive response. In addition, unlike some disabilities, the incidence of people with ABI is growing due to improved medical input with more people surviving injury that previously would have died. These people often have high care and equipment needs due to severe and multiple physical and cognitive impairments. ABI is also associated with more frequent occurrences of foetal alcohol syndrome and alcohol fuelled violence (Bonyhady, 2010) and assaults particularly experienced by younger men.

These directions suggest that DIG (2009a, 2009b) underestimate the incidence and prevalence of ABI overall, as well as having omitted specific sub groups, namely, children and adolescents and people with alcohol related brain injury.

SUMMARY POINTS

- The incidence and prevalence of ABI is estimated to be comparable to intellectual disability. This implies people with ABI would be significant users of a disability support system.
- Incidence and prevalence figures used in DIG (2009a, 2009b) are under estimates of the population of people with ABI
- People with ABI are one of the larger cohorts of people with disabilities in the NDIS
- New people with complex needs are requiring ABI disability support many years post-injury
- It is likely the incidence and prevalence of ABI is increasing

2. Overview of the proposed National Disability Insurance Scheme (NDIS)

VCASP and VBIRA endorse the issues identified in the Productivity Commission's Issues paper (2010) which comprehensively analyses a disability support system which is not working. The following comments also respond to the directions outlined in the DIG (2009a, 2009b). This section has been divided into two sub sections: general comments about the NDIS and comments specific to ABI.

2.1 General comments

The broad directions proposed for NDIS as a new social insurance scheme are strongly supported by VCASP and VBIRA. If the NDIS is to reform the current disability system and respond to the identified shortfalls, many of the proposed features of NDIS must be relevant to all people with a disability. Our understanding of social insurance is that while it must be financially sustainable for the long term, it is not exclusively profit driven; and that there is therefore the capacity for social policy directives to influence policy.

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.

Based on DIG (2009a, 2009b) the NDIS aims to encompass people in current CSTDA and compensable schemes and more – both more people and more support. Direct funding for eligible individuals offers certainty to individuals and families so that they can plan their lives. This is desperately needed to improve the current system, which lurches from short term annual reviews, long waiting lists and new program arrangements where individuals and families have to start the whole process again and again. The recognition that disability support needs to be tied to relevant outcomes – that is, better lives given the nature of people's impairments for people with disabilities, and by implication their family members, is both logical and well over due. Outcomes could range from preventing secondary disabilities and ensuring someone is comfortable to more ambitious notions of community inclusion and participation.

The NDIS needs to respond to what is needed for the lives of people with a disability and their caring family members in the community. Community participation means the ability to have a meaningful community life in leisure, family and work. An important priority in the NDIS is the emphasis on increasing opportunities for employment for both individuals with disabilities and family members currently restricted to and by their caring roles. While employment will not be relevant for everyone, the current system has paid little attention to increasing employment options for people with ABI and not at all to the alternative employment aspirations of family members currently restricted to a caring role. There is enormous scope for increasing employment opportunities for people with an ABI. AIHW estimated that the numbers of people with intellectual disability in receipt of disability employment services exceeded the numbers of people with an ABI by more than a factor of ten.

The NDIS needs an emphasis on, and clear policy goals for, community re-integration based on a pattern of access to disability support which varies with people's needs and circumstances over their lifetimes, and which address support needs related to their preferred life roles. This must be supported by fairer and consistent administrative processes, reviewable decisions, evidence-based responses and better data about the performance of providers contributing to demonstrable outcomes for individuals.

However, the NDIS must recognise that individualised and direct funding alone won't change people's lives without development and improvements within and beyond the disability sector. The NDIS therefore can and should aim to improve the circumstances for all people with disabilities and their families, and specifically for this submission, people with disabilities arising from ABI. This suggests interdependent roles for the NDIS:

- Direct and individualised funding to eligible individuals and their families to enable community participation and increasing independence
- 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
- 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.

- Promotion of activities designed to improve support in the non-disability sectors (listed in the previous point) and wider community and so improve opportunities for people with a disability not eligible to be directly funded. This requires the authority to influence policy and practice in the non disability sectors
- General community development; information, advocacy, attitude change etc that will increase the capacity of the wider community to understand and better support people with disabilities.

Systemic and organisational level reforms will not flourish in a system driven solely by individualised funding. All effort and creativity will be directed to making as many people as possible satisfy the eligibility requirements for direct funding.

SUMMARY POINTS

- VCASP and VBIRA strongly support the proposed directions of the NDIS as a social insurance scheme
- The NDIS must improve circumstances for all people with disabilities, but this does not mean via direct funding for everyone
- Direct funding and systemic strengthening roles are envisaged for NDIS: direct funding to individuals, and systemic and organisational strengthening both within the disability sector, and with the non-disability and community sectors.

2.2 Comments about NDIS specific to ABI

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 to VCASP and VBIRA 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.

There is solid evidence that people with ABI do recover functional abilities and/ or experience fewer secondary disabilities with early, timely and sustained interventions and rehabilitation, in conjunction with tailored long term disability support, as the following case study shows.

Case study three: Recovery leading to minimal assistance required

John has an ABI due to hypoxic brain injury following blood loss from gunshot injury when he was 20 years old. When discharged to home he was walking but required close supervision due to poor balance; was unable to organise his movements (for instance unable to plan how to sit in chair, lie down in bed, get dressed) and did not initiate any action. Following appropriate therapy, training and support for carers, ability to adjust goal of therapy as he changed, ongoing funding and independent case management, he is now able to walk everywhere independently and safely except crossing roads due to visual problems; he needs minimal assistance with activities of daily life and can initiate his own needs. This means he can help in a church Sunday school group.

There are several aspects to the timing and nature of rehabilitation and disability support:

- People who are poorly managed in the beginning of care and support can require increased costs and experience poorer outcomes. This is particularly so with people with severe physical impairments who, if they do not have access to treatment and therapy shortly after their injuries are more likely to develop severe contractures of their limbs – which results in increased care needs, equipment needs and them experiencing pain.
- It is important not to reduce support too early as this may also prevent maximum recovery.
- People may recover function and have heightened support requirements due to their greater mobility and independence, for example, someone who wasn't mobile and now is able to move about.

The following case studies three and four further highlight the importance of ongoing disability support to recovery.

Case study four: Recovery following severe brain injury

Colin is a 48 year old man who sustained a severe brain injury in 2004 after he fell from a tree. He sustained a fractured skull and intercerebral/subarachnoid haemorrhage. Colin was admitted to the ABI:STR Program in June 2004 and was discharged home 4 months later to live with his wife.

Colin's injury left him with severe cognitive deficits including severe short term memory impairment, inability to initiate tasks, poor organisational and executive function skills and impaired balance, co-ordination and reduced stamina.

Colin initially received 3 hours per week of Occupational Therapy, Physiotherapy and Speech Pathology from the ABI:STR program. Colin also received support from a neuropsychologist to develop some strategies to assist Colin to deal with panic attacks. He also received 44 hours per week of attendant care to assist him to achieve his rehabilitation goals. Colin has always been motivated with his therapy and has worked hard to achieve his goals. He was very keen to remain living at home with his wife of 20 years and to reengage with his local community.

Now years on from his accident Colin is still living at home with his wife. He no longer requires therapy input. He still requires 44 hours per week of attendant care to prompt and support him to achieve his activities of daily living, but he is now initiating many tasks himself. Colin has taken back his role of maintaining the garden and is independently able to walk his dog himself.

Case study five: Support withdrawn too soon

Jill is a 42 year old woman who has a mild to moderate ABI after contracting viral meningitis as a younger adult. Prior to her ABI Jill worked for large corporation and lived a full and independent life. Following 6 weeks in hospital Jill was discharged to a rehabilitation facility where she undertook 6 months of intense inpatient rehabilitation. She was discharged back to her home with ongoing weekly outpatient rehabilitation and support from a disability skills development program.

Jill initially did very well and after a further 3 months at home was introduced to a return to work program. She could manage public transport and was gradually building up her return to work hours as support services were slowly withdrawn.

Jill has recently referred herself back to the disability support program. She reported that her return to work program failed after she fell one morning going to work. Following her fall she did not feel confident and therefore was unable to get herself to work. As her hours increased at work so did her fatigue levels and combined with the fall she no longer felt able to continue working. She was now living on the Disability Support Pension. Jill reported that she became increasingly depressed once she gave up work and struggled to leave the house most days. After about 12 months she moved from her home to be closer to her parents. She is feeling very socially isolated.

The skills development program is working with Jill to increase her confidence in using public transport and link her in to employment assistance as Jill would like to be able to work again part time. Jill feels that support services were withdrawn too soon.

People with disabilities and families want a recognisable contact point with the system so they don't have to search with numerous agencies to get their needs met. How people contact the system will depend on the nature of their ABI. Even if they cease support, they want to know who to reliably go to when/ if issues arise in the future (such as is available with the Traffic Accident Commission for anyone previously registered).

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. Support for the advocacy sector is a crucial element of these arrangements. (The components of disability support for people with an ABI are more fully described in Section 5.)

The clinical evidence shows that specialist ABI providers contribute to the best long term outcomes for individuals, frequently in partnership with other disability and various community providers. We welcome the aim of longitudinal research programs assessing outcomes through the NDIS which can build on the already available research about the effectiveness of targeted disability support responses including rehabilitation. More evidence is need about the support capacity of general disability support for people with an ABI.

The Productivity Commission Issues paper recognises that many people with ABI are located within agencies or care providers who are not primarily disability-focused. These may include, but are not limited to, aged care facilities, the criminal justice system, and the homelessness sector. Many of these people may be experiencing little or no contact with the disability sector, and many in fact do not identify as having a 'disability' at all or do not want to be with other people with disabilities. Some of these people with an ABI will be undiagnosed in particular in the education, unemployment and prison systems. A partnership approach can be effective in dealing with these individuals (for example, in education of young people with an ABI in schools, where teaching skills can be complemented with the therapeutic and rehabilitative roles of allied health and community services). This situation highlights the need for deliberate system development and cross-sectoral coordination roles for the NDIS, which as stated earlier, are beyond direct funding mechanisms for individual recipients.

SUMMARY POINTS

People with an ABI will benefit from an NDIS system that offers:

- Certainty about entitlement to lifelong 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

The following sections respond specifically to issues which are at the core of how the NDIS would be set up. These issues involve decisions about eligibility for direct funding, who decides, components of a disability support system and funding mechanisms. Comments are directed to the NDIS overall as well as any additional considerations for people with an ABI.

3. Eligibility for direct funding

'Eligibility' for NDIS is understood to mean eligibility for lifelong direct funded support, not entitlement to specific aspects for support. (This is the same way as there is entitlement for schooling between 5 and 15 years but not for the specifics of that educational experience.)

VCASP and VBIRA recognise that not everyone with disability has a severe or profound impairment and therefore not everyone would be eligible for direct NDIS funding for life. From experience, we note that unless the NDIS aims to improve circumstances for everyone with a disability through other mechanisms (see section 2.1), there will be larger than needed demands on the direct funding scheme.

3.1 Practical and reliable identification

a. General comments

VCASP and VBIRA endorse the WHO (2001) model of disability, which integrates key understandings of disability previously considered independently, particularly the medical model (about individual change) and the social model (about societal change). Intervention is conceived along three basic dimensions focusing on the functional, individual goals and the 'person in community'. Disability is understood to involve marked and often severe problems in capacity, ability and/ or opportunity to function and participate.

Eligibility for the NDIS should be based on the effect of the disability on someone's life, not the degree or type of disability or the grading of insult or injury. Hence the assessment process would identify which people have a severe impairment and what are the needs (not service types) arising from that impairment. VCASP and VBIRA endorse the process and issues describing what the assessment process must achieve (DIG 2009b, section 8). There may be various ways to address people needs. We recognise that responding to people's needs involves family, friends and community as well as identification of appropriate services and supports.

The NDIS assessment process needs to introduce clarity about who is 'in' and 'out' of direct funding. Existing eligibility processes predispose referrers to describing people as if they have greater disability because of the lack of other options for support (ie 'you're better off if you're in'). The new scheme must aim to minimise perverse incentives where people want to be eligible for direct funding which would see people with milder or less complex disabilities being described as more impaired. This point highlights the importance of the overall role for the NDIS with improving the quality of life for all people with disabilities, beyond direct funding just for those most impaired.

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.

b. Identifying people with an ABI

The effects of acquired brain injury are complex, and individuals are affected differently. The nature and severity of damage to the brain, along with other medical, psychosocial and personal factors, influence the nature and severity of resulting disability. Assessment can be complicated because individuals with ABI (the 'hidden' disability) can appear 'normal' while experiencing cognitive, behavioural or emotional disabilities.

Assessment requires an understanding of the person, their environment and the activities that they are wishing to engage in every day. VCASP and VBIRA believe that 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. VCASP and VBIRA want to contribute directly to the development and appraisal of such tools.

SUMMARY POINTS

- Assessment for eligibility needs to be functional not diagnostic, and relevant to each disability
- Assessment should attend to whole of life issues

- Dynamics in the system 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

3.2 Who should receive direct funding from NDIS

This section considers who should be eligible for funding, given the issues in assessment outlined in section 3.1.

a. General comments

The emphasis in the NDIS on people with severe and profound impairments and their family carers is supported by this submission. In broad terms, to be eligible for NDIS, people would have an underlying disease or disorder which is long term or permanent; severe functional impairments; and require assistance with daily activities due to impairments in areas such as mobility, communication, and self help. We understand the NDIS material to say caring family members of these people would also be eligible for support and we support this direction. Currently support for family carers is driven by poor disability supports. Improved supports for people with severe and profound impairments should lead to redesign of the nature of support available to caring families.

The separation of catastrophic injury from other severe and profound impairment is confusing (DIG 2009a, 2009b). It is not clear whether a parallel system is proposed for some people. Presumably whatever the structural decisions that are made, the relationships between these arrangements need to operate as if it is one system.

In terms of people with other disabilities, it is logical that people with psychiatric disabilities would be part of NDIS, and that primary mental health responses remain separate from the disability system. Further, people with both ABI and mental health issues, or other dual disabilities, should not be excluded from the system and effort is needed to ensure that their supports for all of their needs are not fragmented or partially ignored.

b. People with an ABI

The definitions of severe and profound impairment must be inclusive of people with ABI with a broad spectrum of cognitive impairments and complex care requirements. Complex care needs mean individuals who are at risk of isolation from the community and markedly reduced access, or ability to maintain, supports and services.

Assessment based on functional abilities would recognise, for example, that people with mild/ moderate brain injury and complex care requirements can have a profound / severe functional impairment. Historically a traumatic head injury was categorised at an early stage into mild, moderate, severe injury, but not impairment. It is now recognised that people with mild injury can be very impaired and that people with severe injury can significantly recover. For example, people with 'mild' ABI who present much later after injury, perhaps were never diagnosed earlier, and now have cognitive, behavioural and other difficulties, which make returning to work difficult and in more extreme instances, people are homeless with alcohol and drug addictions or involvement with the criminal justice system (refer again to case study one).

People outside the direct funding system would be people who have an ABI and care needs arising from limited areas of life and/or mild cognitive impairments or can be supported in other sectors. The NDIS needs influence in these sectors to ensure access to funding, specialist skills and knowledge for this group through the development and maintenance of information and resources (and this could include options for group supports), such as exists in the ‘local area coordination scheme established in Western Australia.

Uncertainty remains in relation to the best strategy for people who have a stroke, (which is deemed to be an ageing-related disability) and for people who are over 65 years and experience an ABI, which is not ageing related (such as traumatic brain injury). Qualifying for aged care supports from the age of 65 years should not take away from access to appropriate skills and expertise to assist with specific disability related needs. Ways of dealing with the care and support needs of these people who have a disability as a result of ABI could involve a joint effort between 'disability' support and 'aged care' support for those over 65. The question is whether this is funded through the direct funding role of NDIS, or through the wider sector development initiatives also proposed for the role. With either approach it would be important to ensure that appropriate disability support is available to people in aged care (and in other sectors). This point is also relevant for the numbers of people with ABI, younger than 65 years currently living in nursing homes.

Table one: Frequency of disability type of residents aged less than 60 years in a sample of Victorian nursing homes

Disability type*	***% (number)***
Cancer	.3 (1)
Muscular dystrophy	1 (2)
Quadriplegia	1 (2)
Motor Neurone Disease	1 (4)
Paraplegia	1 (4)
Cerebral Palsy	2 (5)
Deafness/ hearing impairment	2 (5)
Other	2 (6)
Psychiatric disability	2 (8)
Parkinson's disease	3 (9)
Dementia	5 (16)
Blindness/ vision impairment	5 (17)
Huntington's disease	7 (22)
Intellectual disability	15 (48)
Multiple sclerosis	17 (55)
Acquired brain injury	37 (122)
**Each resident may have more than one disability*	

(Winkler, Farnworth & Sloan 2006)

Table one lists the comparatively high numbers of people with an ABI, compared with other disabilities, who are less than 60 years of age in nursing homes in Victoria, (based on a survey of 800 nursing homes and 626 responses). The majority of people with ABI in Table one required nursing home level care (1-4), however, nursing homes are not able to provide disability support. The reader is referred to VBIRA (2007) which discusses the current service system configurations and problems and makes recommendations for improvements.

SUMMARY POINTS

- 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 leads to complex care. Complex care needs arise from medical care and medication, homelessness, addiction, or criminal justice involvement.
- More thought is needed people with ABI and other needs, for example, how to ensure people over 65 years with an ABI receive disability support in partnership with aged care.
- Too many people with ABI unnecessarily spend time in nursing homes

3.3 Reducing unfairness for people with an ABI

Reducing the systemic unfairness experienced by people with an ABI is a high priority for VCASP and VBIRA. People with ABI experience unfairness from the current system in several ways. Many people are not diagnosed as diagnostic services are limited and the benefit of a diagnosis is questionable when the 'label' has had little benefit in terms of access to services and supports.

VCASP and VBIRA work across the compensable (such as, Traffic Accident Commission where there is a 'no-fault' access to support) and non-compensable systems. This experience has raised awareness of the paradox where people with comparative injuries currently get significantly different levels of support because of how their injury was acquired. For example, timely service is experienced by people in the compensable system with access to rehabilitation in early stages post injury, compared with those experiencing long waiting times in the non compensable system.

It is important to introduce expectations of 'life in the community' again for people with an ABI right from the beginning, in the acute and rehabilitation stages of recovery, and continue the reinforcement of this expectation throughout their interaction with disability services. This is currently only reliable possible for people eligible for compensation. There is a 'stark inequality of access to therapy between funded and non compensable people' (VBIRA 2007).

Some people with traumatic brain injury are likely to have had experiences that make them eligible for compensation (such as brain injury at work or in traffic accidents) while others who may have had a traumatic brain injury through an assault or fall would not be eligible. In fact, many traumatic brain injuries are not compensable. Other sub-groups, for example, those with alcohol and drug related brain injury or who have had brain infections would have no compensation eligibility. There is also a group caught between decisions about compensation, such as those waiting for settlements to be decided, often over many years, or those who have inadequate or exhausted compensation payouts. This system is not fair.

The system is not fair for people with more than one disability or impairment. People with ABI frequently have other conditions, such as addictive behaviours and mental illness. There's also the issue of people with intellectual disability being vulnerable to ABI through assaults. To date people with ABI have been tossed between sectors especially mental health; and aged care (in relation to stroke and catastrophic injuries). Apart from the Young People In Nursing Homes initiatives, sound links between sectors are not happening and there are few cross sector examples of processes for cooperation and co-contributions to truly coordinate around the individual. The protocol that has been created to coordinate Aged Care Assessment Services with Disability Client Services assessments for people referred for Residential Aged Care in Victoria, is now indicating some ‘perverse’ outcomes, with the evidence suggesting that young people are now having their access to accommodation delayed further while the processes of referral back and forward is completed. Also, there are now some young people getting poorer accommodation outcomes, being referred to Supported Residential settings and Boarding Houses where they have minimal support. For some this is less appropriate than the previous experience of being referred to a Residential Aged Care facility and getting ‘lost’ from the disability services system. There is no cooperation between systems for example, people with ABI in nursing homes can’t get rehabilitation through aged care; and people with ABI in disability accommodation can’t get funding for continence consumables; and the same person could be in either situation.

Currently, in the non compensable system, who gets service access is often the person or advocate ‘with the loudest voice’ or those with the ‘connections’ to people in funding bodies. There are limited provisions to enable those who do not speak English, those who have difficulty understanding systems, those who do not have family to advocate for them, or those who are non speaking but have no cognitive impairment (‘lock in syndrome’) to be fairly and equally represented.

Families also experience unfairness through being penalised for caring and therefore their family member not using or being eligible for various support and attendant care. If family members have been involved with direct support and then are unable to continue, there is no entitlement for the individual to ensure ongoing support. Conversely, families may decide not to become more involved in support at various times for fear that the available resources will be lost and never be available again. This is both unfair and poor use of all the available formal and informal resources.

How to fairly support individuals with or without family carers must be considered.

Universal ‘no fault’ access would mean that all people would get early intervention and timely access to rehabilitation and disability support. In the long-run this should cost the community less because it would prevent more costly recovery of capacities (and sometimes preventable life-long conditions) which frequently occur when people miss out on timely supports while a liability is being sorted out. An insurance model of assessing long term financial liabilities would be motivated to ensure the most cost effective interventions were researched and available.

Summary points:

- Different systems for people with the same impact of an ABI, but a different cause, is unfair
- The existing system does poorly when people need assistance from various sectors
- Family members are disadvantaged for varying how much direct support they provide

4. Who gets the power to decide?

There are several points in the proposed NDIS where clarity about the responsibility for decision making is critical. The NDIS requires independent processes for decisions to ensure fairness and equity. Processes and decisions are required about:

- Determining eligibility for the scheme i.e. to receive direct funding related to degree of functional impairment (see section 3)
- Ensuring appropriate responses to people's needs, including service options, whether that be to the NDIS care and support system, or another sector/non-disability support area
- Determining capacity of an individual to be self directing regarding lifestyle options and disability supports and self management of any individualised funding packages
- Review of any of these decisions.

Such decision-making should be based on a commitment to individuals and to the viability of the scheme overall. At present considerable effort is invested in a tussle between referring people for as much disability support 'as you can get' and the staff required to gate keep and reduce an overall budget. The NDIS implies the need for a different operating culture from all parties if the system is to be successful.

4.1 General comments

VCASP and VBIRA endorse the guiding principle for the NDIS that individuals with disabilities should direct and control how their disability support funds are used to the maximum extent possible. We also note that some people need help to do this and some people can't do this. We recognise that disability affects families and not just individuals and the NDIS needs to balance the rights of the individual and the importance of family (where there is one available and able). This direction means more choice by individuals, rather than service providers, about what is possible and available, more individualised opportunities and more direct say by individuals and their families over what happens in people's lives.

The role of service providers is to provide functions not typically available within families and society. Those services potentially have a lot of power, even in a climate where the intent is to increase decision making by people with disabilities. As such service providers need monitoring, accreditation and review particularly in relation to ensuring that they have the skills to enable people with ABI and their families to set the goals of support programs as far as is possible. Currently there is marked variability in the quality of providers. Families who want to undertake the role of service providers for payment also need guidance and monitoring.

The essence of self directed funds is not the administrative tasks involved with funds management. Directing how funds are used ie that funds are directed towards supporting the person to work towards his/her goals, should be distinguished from the administrative task of accounting for the funds. There should be administrative mechanisms for people who want to directly manage their own funds, with appropriate levels of accountability in keeping with the scale of packages. We suggest that there is a much larger group who don’t want to, or can’t, directly manage their funds but are keen and able to direct how those funds are used. This is consistent with a system promoting self directed funding arrangements.

Self-directing is less straightforward when someone has a cognitive injury after ABI, or in addition to ABI (such as people with ABI and mental illness or intellectual disability). There are not currently ways such competency is systematically ascertained, despite the significance of such as decision. The less frequent exceptions are in more extreme situations requiring guardianship through the legislated processes of the Supreme Court or Office of the Public Advocate.

It is posited that deciding most people’s capacity t decide for themselves will be straightforward, and it is the ‘by exception’ situations which are in need of clarification. The processes adopted should reflect such differential complexity. The existing compensable schemes process of mediation prior to formal appeals has proved successful in resolving issues and not proving resource intensive. When a decision is less straightforward, practice experience has shown a panel approach to be the most reliable and fair method of assessment. Such a panel would comprise an advocate, suitable professionals and key others as appropriate for an individual situation. There will be disagreements and differences between individuals, their family members and involved professionals. Decisions from such a panel would need to be reviewable with judgements for close decisions being biased towards people being able to self manage rather than not.

However, such panels adopted more widely may introduce unnecessary delays and hurdles. A framework is needed outlining who should be an alternative decision maker on someone's behalf and on what basis, if someone is deemed to not be competent to self manage their funds, and where guardianship is not needed,

> *'The issue is most vexed for adults with decision making impairments. There is an understanding of delegated authority and decision making in adult-children relationships which is lacking with adult-adult relationships (except for formal guardianship arrangements, which are applicable to the minority of people). 'Deciding for' is not adequately defined for families, friends or formal support services and exists with the seemingly inconsistent public policy back drop of individual rights and promotion of community living and an individualised way of life. That is, the implicit assumption of each person's autonomy. This has left delegated decision making assigned to family members, friends and staff members who are often lacking information to undertake these decisions.'* (Fyffe et al 2010)

4.2 Decision making and people with ABI

VCASP and VBIRA strongly endorse the rights of people with ABI to manage their own lives (as outlined in the previous section). We stress that good decision making requires good information for people to be able to make decisions about their life choices and the disability and other support requirements. We also recognise that some people cannot make all decisions affecting their lives. An over-riding consideration for people with an ABI is the contribution of rehabilitation and disability support to recovery. Some people's ability to make good decisions will improve, so any arrangements for delegated decision making need to be reviewed over time.

People with ABI who require arrangements for delegated decision making are likely to be individuals in the following situations:

- Up to 2 years post severe acute brain injury. Typically the delegated decision making role is undertaken in the acute and rehabilitation settings, but without a framework for such decision making including how to incorporate the relationships and roles between family members and staff.
- People who are not cognitively able to make decisions or be responsible for decisions with major (and at times lesser) life implications, such as:
    - At key transition times (such as school to work; moving from family home to independent housing; moving from corrective to community services)

  - During significant changes in needs and services (such as cessation of or re-involvement with rehabilitation; loss of employment)
  - With complex care arising from a range of interacting physical, social and emotional issues, (such as homelessness or housing instability, criminal justice issues, alcohol and other drugs dependency, child welfare issues, relationship breakdown and significant health issues).
- People who need assistance to support their developing capacity to make their own decisions. This point again recognises the importance of supporting recovery for people with an ABI.

SUMMARY POINTS

- NDIS needs to start with the assumption that most people with disabilities self direct how their disability support funds are used.
- However, some people with ABI have decision making impairments
- Processes are needed to support delegated decision making which also recognise that with recovery, some people may be better able to self manage.

5. What services and how they should be delivered

VCASP and VBIRA endorse the importance of identifying what people with ABI need and then those disability supports which are effective in improving people's lives. This means how people can be assisted to a new and meaningful life post-ABI, often with a new identity. The system for supporting people with a disability must be founded on a long term view, over people's life times and life stages, which can be maintained while still allowing flexibility and responsiveness to emerging issues at the level of both the individual and the service system's ability to respond. People with disabilities and their families need reasonable expectations of a disability support system and their role within it. This point again recognises the importance of the NDIS introducing cultural change so that the aim is not 'to get as much as possible' but to get the most effective supports.

This section outlines the components of a disability support system and the additions or variations which are particular to people with an ABI and their families.

5.1 Components of a disability support system

The nature of people's impairments, life stages and personal circumstances and preferences determine what will be appropriate for each individual and their family. What is funded within disability support needs to be associated with improving people's quality of life in demonstrable ways. The NDIS will be starting in a context where there is an uneven spread and scope of rehabilitation across states/regions, and lack of clinical staff to do the 'by exceptions' assessments in some areas. This is particularly true in regional, rural and remote regions as well as indigenous communities.

a. Support for eligible individuals

A disability support system requires the following responses organised in an accessible way and with multiple entry points:

- Information about effective service provision promoting recovery, independence and community re-involvement.
- Advocacy and self help initiatives for individuals and family members
- Capacity to plan, fund and coordinate, with the emphasis to maximise potential and plan transitions over the life course. This means beyond only service-based responses to include individuals, family, friendships and community roles and responses. Many people do need skilled and

comprehensive case management which is understood as a professional role not an administrative, process-driven task. Possible variations include:
  - Some people can self manage and can effectively be their own case manager.
  - More limited funding and case administration roles where someone's needs and circumstances are stable.

- Support which maximises independence and a life in the community typical for that life stage. This includes:
  - Rehabilitation, but not in the short term form it is typically understood in acute settings. The rehabilitation approach incorporates evidence based practice attending to cognitive, psychosocial and behavioural issues and pre-ABi skills, as the basis of relearning and developing new skills. This is active and long term rehabilitation, nursing and therapy to achieve personal outcomes.
  - Personal care (attendant care), direct support for physical, communication, behavioural and/or cognitive needs.
  - Specialist services and programmes to achieve functional gains, facilitate independent living and community participation
  - Specialist links to the health system and monitoring of health status
  - Specialist and mainstream employment services to find and sustain paid work
  - Education support (teacher aide and/or special education consultant with expertise in ABI and education to liaise and intervene regarding the educational program development and review)
  - Specialist youth service to facilitate transition from secondary school to further education, training or employment
  - Education including continuing education and retraining
  - Access to workers skilled in assisting people with ABI and their families when health, mental health and/or substance issues exist
  - In home and residential care and support
  - Parenting support when the parent with ABI has young children
  - Home help and (extended) child care
- Secondary consultation by specialist ABI staff involved wider staff training, information dissemination, modelling of practice, supervision of staff in other

agencies, mentoring, problem solving and expert assessment and intervention.

- Aids, equipment and modifications, including:
    - Equipment, aids and appliances.
    - Consumables
    - Housing modifications
    - Maintenance, repair of equipment
    - Support to access highly modified vehicles
    - Access to reliable and secure means of transport
    - Technology to support memory (for example, iphones), planning, safety etc (based on Dyson, 2010)

b. Support to their caring families

The person with a disability is not the same as their family. There is confusion in practice in the current disability support policy and practice about who the priority is and what are the distinctive roles and activities when supporting people with a disability compared with their family. All initiatives need to be underpinned by the rights of the person with a disability and the potential for different views from their families. This is not to ignore the reality that family members are extremely important for many people with a disability. However, the distinctive support issues require separation or the fragile voice of people with a disability may be lost or ignored (see also section 4, about decision making). It is important to consider together the needs of family carers and the person with a disability. The current system considers these needs independently with separate organisations supporting family carers and the person with an ABI. The NDIS is an opportunity to create a single system supporting individuals and their family carers.

Programs needed to support families include:

- Information and peer support with information about community living and effective service provision.
- Coordination and contact with the service system
    - Support to the family to plan for the long term as well as initially immediate post injury; ways to introduce individuals and families to system, options etc
    - Transition and issues-based support eg preschool to school, leaving home etc
    - Monitoring of the physical and emotional health of family carers
- Counselling:

    - Grief and personal
    - Financial
- Information and training about the support requirements for their family member at home or in the community, such as
    - Managing behaviours of concern
    - Physical assistance and lifting
- Opportunities to return to work and study

c. What to say about respite?

It's difficult to know what to propose about respite as much of the demand for respite at present is a consequence of the pervasive system shortfalls. If there are adequate opportunities for a family member with a disability to be well supported, logically the need for respite as we know it will diminish. Hopefully this allows resources to be re-directed to the family support areas outlined in (b) above, while still retaining some notion of flexible respite services both in-house and out-of-house.

5.2 What else is needed for ABI disability support

The ultimate goal for a person with ABI is to be participating and involved as much as possible as a valued member of their family and community. However, re-entering the community can be very challenging. People with ABI may need support to help them build relationships and establish a new identity, achieve independence and autonomy in day-to-day life, locate community resources and services, build confidence and self-esteem, develop or re-develop skills, and find work or meaningful pastimes.

Since the establishment of a specialist ABI service sector in disability in the mid-1990's in Victoria, largely in the non-government sector and involving secondary consultations as well as direct support, there has been an increase in the understanding of ABI within generalist disability providers, including in government services. However, current evidence indicates that despite policy changes to ensure ABI is treated equally to other disabilities, there still remains a need to support generalist providers to have access to the knowledge and skills of the ABI specialist providers, in identification of ABI, and the design and implementation of appropriate service responses. This is especially so in rural and remote communities.

This means that in broad terms disability support for people with an ABI has the same components relevant to people with other disabilities, with several major variations. These variations are:

- The importance of rehabilitation tied to outcomes to maximise recovery of function and minimise secondary disabilities developing. This is often needed intensively for the initial years post injury and extending for many years after with attention to further functional development. The absence in the current system of 'dedicated disability beds' for such rehabilitation is limiting possibilities for recovery (VBIRA 2007).
- The need for post injury identification for those who are diagnosed long after injury or with substance related brain injury but who need assessment of functional impairments, interventions, equipment etc. A rehabilitation focus is still important but is not occurring after an acute injury.
- The importance of specialist research, knowledge and skills which ensure best longer term outcomes for people with ABI. The notion of recovery from ABI is a relatively new understanding from research and practice. Specialist ABI skills and knowledge are twofold: in response to particular people with an ABI (such as children; people with catastrophic injury, people who misuse alcohol; people who have lost contact with the service system) and the systemic issues arising because of the requirements for cross sector working (such as links needed with mental health, rehabilitation, community health etc).
- A coordinating role provided by specialist ABI case managers who emphasise the maintenance of each individual's lifestyle, community re-integration, crisis intervention, and sustainability of approach.
- Attention to the transition of people with an ABI from specialist disability to general disability to wider community support wherever possible.
- Recognition that people with ABI don't always identify with having a disability and don't want to be with others with disabilities. This has implications for any assumptions about group-based disability support models such as shared housing, disability supported employment. The exception to this can occur in indigenous communities.

Due to the importance of a recovery, rehabilitation and transition framework for disability support in ABI these issues are discussed further in the following section.

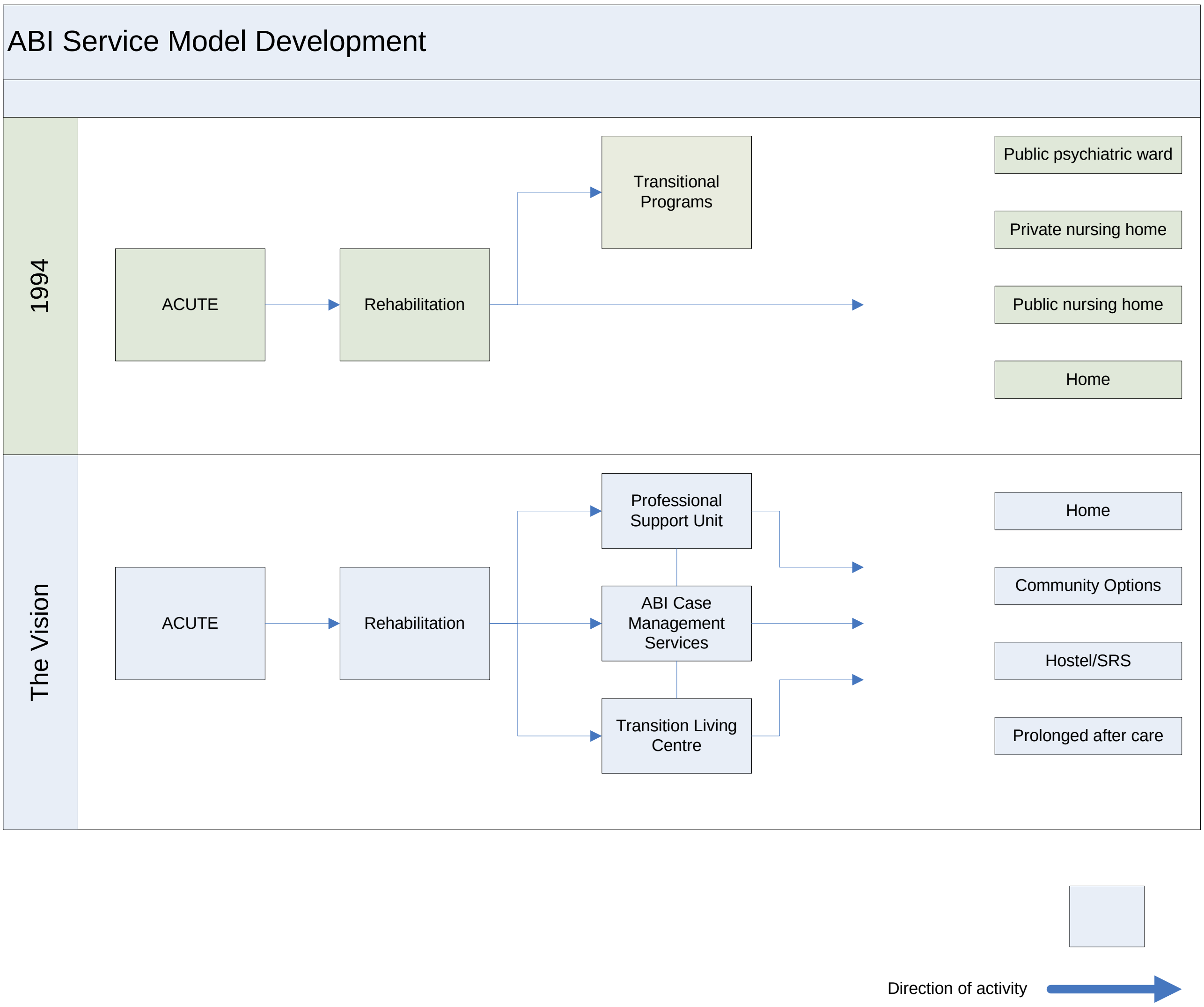
a. A recovery, rehabilitation and transition framework

Unlike many other disabilities, a rehabilitation framework is a key concept in the thinking about how people with an ABI get re-involved in their communities (for example, Galea, 2004; Ewing, 2004). This incorporates two key ideas: a medical concept involving targeted allied health support and other 'therapeutic' interventions, and another concept that involves ongoing social re-engagement activities. The intensive phase after injury, where acute conditions often require substantial medical interventions, give way to rehabilitative frameworks, and these to community integration systems, and ultimately to self-management. Maximising opportunity for citizenship and community participation, while often incorporating therapy oriented programs, focuses on re-learning a role in family, community and location. This is a lifelong process and takes place in the 'real' world.

In Victoria ABI case management has been recognised as central to assisting people with ABI move though the various stages post injury, which are depicted in diagram one.

> *Diagram 1 describes the Victorian service system in 1994 and the vision for the future. In 1994, people with a traumatic ABI moved from acute hospital to rehabilitation, and then either to transitional programs or directly to alternative living arrangements, perhaps with little assistance. The vision recognised the importance of various transition arrangements as people moved from acute hospital and rehabilitation and envisaged coordinated contributions from various specialist professional staff, ABI case managers and the transition living centre (which was never developed) to support people moving to longer term living arrangements, be they at home, or in various staff residential settings. That is, the importance of specialists to support transition from the recovery phases of acute hospital and rehabilitation to the establishment of longer term community living arrangements. One implication of this model was that all people with an ABI transitioning from acute hospital/ rehabilitation to community arrangements would be supported by an ABI case manager (Stringer 2006).*

Diagram one: Changing relationships between acute, rehabilitation and community supports for people with an acute brain injury (Stringer 2006)



The process (in diagram one) is neither linear nor easily predictable, despite the wealth of knowledge and research that has been done into the recovery of the brain. Overall evidence seems to indicate that the earlier the introduction of life goals back into a person's routines, rather than goals that are only therapeutically-accurate, the better the recovery potential. It is also clear that every individual's recovery process is unique and is built upon a whole range of pre-injury skills, connections, family supports (or lack of them), and is highly aligned to the age when the injury was received (paediatric, juvenile, and adult injuries are very different in the way they effect recovery patterns).

The rehabilitation framework is not the same as acute, short term rehabilitation. Nor is it the same as the developmental framework, which has been the basis for much of the development of disability services although the particular supports engaged may be similar. If effective community participation is the goal, anecdotal evidence shows that using developmental concepts has not been a success for people with an ABI. The key features of a rehabilitative approach are:

- The restoration of capacities lost through an ABI and acknowledges the person's pre-injury identity and experience
- Establishing the functional implications of the ABI and what needs to be done to ameliorate and support these
- Planning for lifelong improvements in abilities (no matter how incrementally small)
- Shaping an encouraging environment, with supplementary aids and tools (for example, memory prompts)
- Addressing the onset of delayed depression (frequently 2-5 years after injury)
- Addressing post-traumatic responses, in the individual and his/her family and carers
- Family centred where possible because family breakdown is a frequent outcome and families are affected and important in their own right – particularly where it is a child who has incurred the ABI
- Encouraging new identity exploration, where previous roles (for example breadwinner, professional etc) are unable to be continued (Stumbo, Worsnop & McNamara, 2009).

b. Implications for cross sector relationships and generic providers

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.

There are two aspects to cross sector arrangements for people with an ABI. First, the new arrangements for the disability support system need to maximise where possible the transition of people with an ABI from specialist ABI providers, to general disability providers, to wider community sector providers. Transition (as depicted in diagram one) assumes the willingness and skill of all parts of the service system to be involved. Difficulties with entry to generic services have emerged as a significant barrier to community re-integration. The experience of

ABI case managers is that generic services are reluctant to accept referrals given the specifics and range of the presentations needing attention and frequent associated behaviours associated with the ABI group. Secondary consultation and brokerage funds can assist this transition.

Second, ways are needed to ensure co-contributions for people with ABI who require support from other sectors, such as education, mental health, alcohol and other drug, justice and homelessness services. This has already been referred to in relation to eligibility for the NDIS direct funding and people over 65 years of age.

SUMMARY POINTS

- Based on long term outcomes studies – people with ABI do improve and recover functional abilities with timely and early rehabilitation and disability support.
- The NDIS can maximise this potential by incorporating a rehabilitation, recovery and transition framework in disability support.
- Components of a disability support system for people with an ABI and their families have been proposed.
- People with an ABI are best supported through cooperation between ABI specific, generalist disability approaches and community supports, and often require all three over time.

c. Employment support

Employment is emphasised in the NDIS papers. Appropriate employment support is a significant gap in the current systems for people with an ABI. Evidence is that many people with an ABI can gain entry back to work arrangements but frequently have difficulty maintaining work without targeted supports. Currently there is no specific support to employment for people with an ABI, except through Traffic Accident Commission where a specialist program has assisted people with mild to severe ABI to return to and stay in work.

There are few people with ABI in the disability employment system and probably many people with ABI undiagnosed or not identifying with having a disability in the general unemployment system. They may be receiving inappropriate support (often through ignorance of the cognitive challenges they face) and therefore experience prolonged unemployment or frequent job change over. Currently the emphasis in employment is physical adaptation rather than the need for ongoing support and review relevant to assisting someone with a cognitive and behavioural impairment. The following case study outlines the pattern of job changing and inadequate feedback and support experienced by someone with an ABI.

Case study six: Neville: Employers not happy with work – but why?

Neville lives a rural town, is a parent, and receives the Disability Support Pension. He experienced an accident in 1976 when he was a first year tertiary student. He had such major physical injuries that no-one seemed to notice any acquired brain injury. His medical report at this time stated at the top 'Neville suffered extensive brain damage at the time of his accident' but the whole of the rest of the report was on his physical injuries.

When Neville was up and walking after hospitalisation and physical rehabilitation he went back to tertiary study. After his injury he could manage essays when he was able to work at his own pace, but he failed his exams. Later he worked in a human service, completed further study and worked for a government department. After about a year, the supervisor informed Neville that they were not happy with his work (without clearly saying why) and he was transferred to another office where the same story happened. At this time he worked in a warehouse job. He was unemployed for a while and then moved to a country town and gained employment in human services again. The story was similar – at his review he was told they were 'concerned with the way he operated' but were not specific. He was eventually made redundant.

Twenty two years after his injury, the first professional mentioned the possibility of acquired brain injury. When he applied for the Disability Support Pension, the Centrelink doctor did not ask any questions about his acquired brain injury and he was told he was not eligible for the Disability Support Pension. A neuropsychological assessment was eventually completed and Neville was told that no employer could provide the time required for training in this situation and was granted the Disability Support Pension. Neville currently works 12 hours a fortnight and completes home duties.

Neville's story is typical of many people with ABI and physical injuries. The physical injures heal and no one pays attention to the long term impact of the ABI. There was no link at initial diagnosis with the ABI support system. Neville was effectively lost from the system.

The features of an effective disability employment service for people with acquired brain injury are:

- A 'whole of life' approach to employment. This means the capacity to tackle the issues which will jeopardise employment, such as conflict with family members, someone who is losing friends or has no friends, has an alcohol and/or drug problem, has little pre-injury work experience, has mental health problems, has budgeting problems, or is struggling to cope with their cognitive impairments.
- Specialised understanding of how to support people with acquired brain injury seeking employment, such as peer feedback at the pre-employment stage can greatly assist people's perceptions of their employability
- Various partnerships between agencies including those involved with non-work issues. Supporting employment means attention to transport options,

strategies to promote independence to complement the assistance provided by open employment services, advocates to represent people with acquired brain injury, and support groups for people with acquired brain injury or their family members. Specialist support is needed, for example, enough trained employment support staff, counselling services to assist with dealing with the acceptance of the disability and the lack of community acceptance, and support for people with an alcohol and drug problem. Support in these non-work issues is fundamental to achieving and sustaining employment outcomes.

- Practices which promote the participation by people with acquired brain injury and their families (based on McCubbery et al 2002).

Rather than a model of career development, disability employment services have evolved with a view of job placements as permanent and job change as a reaction to a problem or failure. The incorporation of disability employment support into mainstream employment support is unlikely to greatly affect the employment prospects of people with an ABI unless there is active case finding of those people not recognised as having an ABI and recognition of the nature of support required, before, during and while planning future employment.

As a final comment, it is important not to imply all people with an ABI could work. However, all people do need a range of meaningful activities in their lives. In common with the lack of appropriate employment support, there exists a stark shortage of appropriate services for people with an ABI.

SUMMARY POINTS

- Many people with an ABI would benefit from appropriate employment support
- There are models of appropriate support for employment for people with an ABI
- Ways are needed to identify and assist people with ABI in the unemployment system. Some of these people will not have been diagnosed with an ABI.
- Not everyone with an ABI can be supported to work. Everyone needs meaningful activities in their lives.

6. Funding and how the system could work

The current funding system lacks a long term view and therefore the incentive to progressively achieve personal outcomes over the longer term. VCASP and VBIRA are interested in an insurance model which is understood to be liability based and future oriented. An insurance scheme is logically motivated by wanting to reduce the costs from eligible people while meeting the legislated requirements for entitlement for lifelong support. This would seem to create incentives which are currently significantly under-resourced, to:

- Determine which intervention truly results in individual outcomes related to increasing independence, employment, and capacity to steer one's own life
- Minimise the numbers of people with ABI through prevention strategies (such as existing compensable schemes and their road safety education roles)
- Work to increase the capacity of other sectors to provide support and maximise independence of all people with ABI
- Educate and inform the community to better understand and support people with disabilities. This has potential to increase natural and informal supports from community members and so reduce formal supports.

This submission supports a general no fault insurance scheme linking or incorporating existing compensable schemes, Workcover etc. These arrangements need to ensure everyone who is eligible has care and support which is:

- Lifelong
- Allows expenditure on family support or individual preferences for support such as the costs of carers on holidays, for modified recreation equipment, for family counselling support, and the travel fees for specialist staff in a remote consultative model.

These comments do not apply to common law claims for pain and suffering, loss of income etc.

It is assumed that direct funding will be allocated based on long term disability impairment and support costs for particular levels of functional impairment. Difficulties with funding bands have been experienced in the current system due to gate keeping imperatives and reductions in people's available direct funds as a consequence of service provider/ fund manager on costs for administration. In the NDIS allocated funds are presumed to be based on the assessment of impairment which follows from the assessment of eligibility.

What the funds can be used for should be tied to the principles of the NDIS (to ‘facilitate independence and maximise potential’) and the options for disability support, and not be directed to wider lifestyle support or income subsidy. The NDIS needs to be clear about ‘choice’ within what is provided and that it is not unfettered choice which is on offer. Current arrangements and practices in Victoria confuse this issue, and therefore can make it more difficult to meet the policy goals of maximising independence and community involvement.

6.1 How it could work

a. Preferred features of the NDIS

At an individual level, the preferred features of the NDIS are:

- Clearer statements about the purpose of disability support (for example, maximise independence, increase in functional performance across all life areas, productivity, social participation) and how that is determined and reported, for example, Quality of Life Scale, Sydney Psychosocial Outcome Scale.
- Application of funds to disability support activities which demonstrably improve people’s long term outcomes
- Separation of the funder and assessor; and the funder and service provider. (This implies government would not be a service provider).
- Funding by need, not service-type. The best responses may be within the family or community for some needs but these do not replace circumstances where specialist staff are needed.
- Assistance through information or case management to explore initial expressed needs and all other possibilities.
- Some flexibility for the use of funds.
- Ability to vary arrangements people’s needs or circumstances fluctuate, such as ‘carry over’ funds. The current system struggles to respond as people’s needs change and increase as a consequence of living longer with given disabilities. This is not the same as ageing-related disabilities. Profiling of people’s lifetime costs given certain functional impairments should allow for both decreases and increases in people’s support needs.
- Potential for responses to sudden changes in capacity (such as the MS ‘sudden deterioration’ fund), or if family members take on a direct support roles start and then can’t continue at same level

- People being confident that if they don't spend the allocated funds in a given year they will get that level of assistance again if needed. A system people can trust – a system that is secure.
- The potential for a mix of public and private funding for disability, as occurs in education and health. People with resources should be able to use services (which isn't the case at present) or supplement what is funded through NDIS.
- A review system or independent body such as an expert panel including people with ABI expertise
- A system of feedback and reporting on progress at an individual and systemic level.

b. Proposed process

The following processes are suggested in the light of points raised throughout this submission:

- People deemed eligible for NDIS would be allocated an individual package based on a profile of different functional impairments and estimates of costs. It is assumed that lifelong profiling allows for increases and decreases in support costs at different life stages and lengths of time living with particular disabilities.
- Everyone would be assisted by a case manager initially to ensure a reliable link to the system, determine responses to needs, and educate about possibilities. Some people may ultimately be ready to direct their own arrangements.
- As long as people's costs for disability supports are within the model there would be no need for the funding scheme to intervene and approve each transaction (as currently occurs with TAC). That is, the allocation of a single package with all family/ individual supports in one and if costs remain within these estimates the person can choose how funds are spent. This allows potential for individual to choose variations to disability supports as long as expenditure does not inflate.
- If costs increase then how funds have been spent would be reviewed against recommended disability supports.

6.2 Reducing the administrative burden and overlap

There is a risk that the NDIS simply adds another layer to what exists already. Implementation must involve abolition or re-working of existing accountability and monitoring requirements. Ensuring that unnecessary administrative hurdles to access are streamlined is important. Currently significant bureaucracy is in place because the existing system has to ensure priority needs are being met in a rationed resource pool. This bureaucracy should not be needed to perform these activities under NDIS. The likelihood of this occurring is increased when the funder is not the assessor. Such separations avoid internal conflicts of interest about resource allocations which quickly translate to more bureaucracy.

There are several ways administration is hoped to be reduced with the new NDIS scheme as a consequence of lifelong entitlement:

- The NDIS logically eliminates the requirement for people to keep re-qualifying and being re-assessed each time they want services, as eligibility is for life.
- Time would not be wasted when staff searching for funds for someone. This would make case managers and others more available to the individual with ABI and their family and for secondary consultation and education to the mainstream and community providers.
- Not all individual transactions need to be approved by the NDIS if the pattern of expenditure is within estimates (see 6.1 above).

There are additional ways the NDIS can reduce bureaucracy and by implication use funds more effectively. The current system wastes money through:

- The absence of a national disability plan with a research and evaluation component. What are we trying to achieve and how will we know?
- Lack of systemic reform. The NDIS has a role and incentive to make cross sector initiatives and interfaces work. Currently a lot of time is wasted in attempts to build cooperation and no one has the mandate or motivation for successful implementation
- Tender processes that don’t expect or critique the performance of organisations applying to undertake support roles. People assessing tenders may not be skilled about the requirements for disability support.
- For people with ABI non attendance at any appointment is a major issue. There need to be incentives to attend or funds are wasted as practitioners/ agencies private or public can reasonably expect payment.

There are expectations that NDIS, through a social insurance model can improve the current system. However, it is important to report difficulties practitioners have with existing compensable schemes, namely:

- If there is to be an incentive to reduce costs per person (and there should be) this must be driven by more effective interventions leading to fewer high costs crisis, better independence etc and not by reducing services based on the personal views of care managers.

- Burden of paperwork has increased for staff and families
- There are delays in responses
- System tending to limit creativity, innovation and flexibility. A narrow emphasis on measurable outcomes can restrict possibilities and become rigid and prescriptive.
- Rigid (non evidence–based) time-based milestones for rehabilitation goals, in particular, no recovery expected after 2 years, and support funded accordingly, despite increasing evidence to contrary.
- Appealing a decision can become a ‘lawyer-fest’. Mediation through TAC has been an improvement.
- Many competent organisations cannot afford to provide trained and supervised attendant carers/ direct support staff at the rates funded by the insurer. The training of staff can be directly tied to achieving personal outcomes and needs to be recognised in the funding.
- If person is NDIS eligible, KPIs are needed for a timely response for services/ system to make contact and for a meaningful decision. Without this there can be waiting lists by default.

6.3 Transition and making it happen

It will take years for a new scheme to be fully implemented. It is likely that the transition will be very confusing. There needs to be a balance between supporting people currently in the system ‘in the new way’ and responding to new people. In Victoria the challenge for service reorientation continues the limitations introduced through rationing of the currently available resources. New initiatives need to be trialled and their efficacy demonstrated prior to changes to existing services, or the consequence is resistance to change.

The NDIS needs to be implemented in the context of a national disability strategy, rather than the current fragmented state and territory initiatives. Leadership in creating new cross-sectoral arrangements has proven essential in breaking down existing silo based interests (eg STR program in Victoria)

Further, it is essential that everything does not ‘go on hold’ until the new scheme. Resources must continue to be attracted to the disability system as it currently exists. This is important both in terms of the resources ultimately available to the NDIS but more immediately, support responses are needed now for many individuals and families. The existing processes for attracting additional funds must not be sacrificed as a consequence of planning for an improved system. Both strategies are needed.

The initial thoughts about how people begin to move in to the NDIS are:

- Current services continue as NDIS switches over
- People on waiting lists for ABI disability support and new people to move to the NDIS first
- Case finding process to commence to identify people in less appropriate systems or circumstances

As the implications of the proposed scheme become clearer, VCASP and VBIRA want the opportunity to contribute to the thinking on the implementation and transition issues in later submissions to the Productivity Commission.

SUMMARY POINTS:

- Social insurance offers incentives for long term financial and disability support planning
- This submission supports one no fault disability scheme for Australia as the basis for the provision of disability care and support
- Preferred features and processes for the NDIS have been identified
- There are lessons to be learned from how the current system doesn't use funds effectively and the experiences from existing compensable schemes.

7. Examples of successful ABI support initiatives

There are aspects of the current system which work well and could be retained and built on. For example:

- Slow to recover program of people with catastrophic injury.
- Multiple and Complex Needs Initiative panels for people with complex needs

This section describes aspects of the current system which work well.

7.1 Flexibility and coordination

Currently in Victoria the ABI service system is flexible and responsive to variations in support needs. There is a sound recognition that ‘one size (of service response) does not fit all’. Many people with an ABI are understood as ‘complex’ due to the frequent concurrence of risk factors for poor outcomes such as alcohol and drug use, homelessness, family breakdown and mental illness. It must be noted that, while flexible, the ABI service system is not equally distributed across Victoria and varies across geographical areas in terms of resources and services.

In Victoria there has also been progress towards a coordinated approach to service access through ABI case management. ABI case management agencies can be distinguished by target group and by geography and work together to create a single system. There are:

- Statewide case management agencies with designated target groups within the ABI population: STR (post catastrophic injury), arbias (AOD and mental illness), MCM (post rehabilitation referral from rehabilitation/hospital).
- Geographic specific case management agencies – regional or subregional (eg rural) agencies and these may include designated target groups, such as rural AOD case managers.
- Case management funded in rural regions through DHS in Victoria. Small funding packages enable some ABI specific case management to be provided.

Specialised case management depends on the capacity to refer to general case management as people’s circumstances stabilise. A key role for specialist ABI case management is resourcing other sectors and disability case managers about ABI. DHS has assisted in supporting other sectors through funding ABI specific Information, Training and Secondary Consultation workers in each Victorian rural region.

7.2 Active case finding

Many people with an ABI are not diagnosed and this is contributing to their unemployment, lack of appropriate housing and poor quality of life. A more assertive model has been used for some people with more complex needs in Grampians region at Ballarat Health Services. People have been discharged from the detoxification unit to the Health Service for a neuropsychological assessment. The diagnosis of ABI has explained concerns about cognitive competency and high risk behaviours. Several of these people have proceeded to VCAT and were appointed guardians. Another example is where the Traffic Accident Commission have staff at acute hospitals to ensure people post injury are appropriately identified and referred.

7.3 Statewide ABI Paediatric team: Secondary consultation

The Victorian Statewide Acquired Brain Injury Paediatric (SAPC) team works with people living or working with children and young people with ABI who do not receive compensation. It has been very effective based on a secondary consultation model. SAPC undertakes to:

- Provide information about paediatric ABI
- Link people to workplace training about ABI
- Provide one-to-one mentoring with a case manager or worker
- Provide resources
- Assist the worker to find you suitable case management services, funding packages, behaviour management, education and training, doctors and specialists
- Go to meetings where the child’s situation or program will be discussed, for example school support groups, clinical team meetings.

7.4 CBDATS: Cross sector funded initiative

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.

7.5 Compass Clubhouse: Employment support program

Compass Clubhouse is part of the International Brain Injury Clubhouse Alliance, which was founded in 2004, as a collaborative network of Clubhouses that serves people with brain injury and stroke through the use of the Clubhouse Model. ‘A Clubhouse is a community of people who have sustained devastating life altering events and need the support of others who believe that healing is possible for all’. Sustainable funding remains a challenge, as the Clubhouse model does not fit with any of the activities currently funded through government (although there are mental health clubhouses in operation elsewhere in Australia).

Piloted using a small philanthropic grant in 2006, and the Transport Accident Commission, and then through a grant by the Lord Mayor’s fund in 2007/08, this initiative provides a more substantial opportunity for people with an ABI to move from support and service emphasis to developing independence in life goals, with a particular emphasis on ‘work-ordered’ days. Current operation is three days per week, with the following work groups operating:

- Administration, which includes membership processing, newsletter and event coordination
- Catering group, which provides both in-house meals for members who attend, and for events such as the recent open day held in brain Injury Awareness Week;
- Gardening group, which now supplies herbs and vegetables for the catering group, and also supports skills development
- IT working group which is offering a range of opportunities to learn computer skills and also supports the IT system development.

7.6 Darcy model for rural and remote areas

This is model of service delivery for people with severe acquired brain injuries, who reside in rural and remote locations, involves a tailored daily therapy program by attendant carers. This model was first implemented in rural Victoria and now has been successfully implemented in far north Queensland. This model can and has been used to implement programs for people with acquired brain injury who have either severe physical impairment as well as those people with minimal physical impairment but significant cognitive impairment. The difference is the focus of therapy. This model has proved itself to be cost effective and very successful while providing a tailored program to people with ABI and developing local skill and knowledge. So far the demonstrated benefits of this program have been:

- The person is able to return to their home environment and location;
- Clear and agreed setting of goals;
- The development of a tailored program reflective of goals;
- The person and their family own the programs. The program becomes ‘their’ program they own and implement the program with assistance and support from others (i.e. therapists and attendant care workers);
- The development of local skills and knowledge;
- The move away from the expectation of therapists being the only people able to implement an appropriate therapy program;
- Maximisation of available funding;
- Cost efficient method of delivery of specialist ABI services to clients and their families in rural and remote areas of Australia

8. Queries and uncertainties

VCASP and VBIRA remain uncertain about some aspects of the proposed scheme's implementation.

8.1 Sufficient and appropriate housing is essential

The proposed NDIS locates responsibility for affordable housing with the housing sector not the disability sector. It makes sense to reframe housing for people with disabilities so that it is part of the private or affordable housing markets leaving people with disabilities to have control over their support provider wherever they live. Unlike the present where options are limited when they are available, there needs to be housing products to meet the various needs of individuals and families, as the following case study demonstrates.

Case study seven: the importance of stable housing

Peter sustained a hypoxic brain injury as a result of a heroin overdose when he was 32 years of age. Peter was aware of his environment and could express his needs by repeating short words (i.e. "drink, drink, drink") however his ability to do this fluctuated depending on his level of fatigue and pain.

Upon Peter's discharge from hospital after a fractured hip he lived in his parent's home, which had had some minor modification completed for wheelchair access for Peter and a bedroom and bathroom set up for his needs. A wheelchair accessible van was funded by the family due to them living in the outer suburbs so they felt they could bring a quality of life to Peter by accessing the wide community.

Peter lived at his parents' home successfully for five years with the support of his family (parents and siblings) and attendant care workers, until his mother was diagnosed with a terminal illness. As a result, Peter moved out with his older brother into an Office of Housing house. At this time the home was not wheelchair accessible and a number of interim modifications were made so Peter had somewhere to live. Over the next two years, Peter and his brother were required to move house a number of times and each time the house was set up with minimal home modifications.

Each time Peter was required to move house therapy input had to be increased due to the modifications required at each house and an equipment review occur. Peter also experienced anxiety each time he was required to move house, which resulted in an increase in his muscle tone, fatigue and screaming, and an overall decrease in his comfort. As a result increased input was required at each of these transitions.

Currently the disability sector has purpose built some housing on the basis that specialised design was needed. If all housing goes to the housing sector and modifications stay with disability support, there need to be ways to build specialised housing if that proves to be needed and there needs to be ways for housing and disability support to work together to maximise housing relevance and minimise costs.

However, regardless of how the housing stock is developed, there is a major shortfall between demand and supply across Australia which will presumably take many years to overcome. It is likely family carers will have a continuing role well in to the future which needs to be recognised and resourced. Opportunities for co-contribution to housing development and support provision are needed. Many families are able to consider funding housing stock but can't undertake the staff support costs.

8.2 Recognising the limits of the market

The NDIS adopts the principle that the market and choice are the best ways for people to maximise their well-being, recognising that in some cases people with disabilities will need support, through advocacy, in their decision making. However, VCASP and VBIRA have concerns that disability support is not a typical commercial market and the sector actually needs strengthening. Examples are already emerging where people have individual support packages but there is no availability of relevant supports in a given local area. Continued regulation and intervention into the market is needed to ensure supply where there are market failures. There is a need to recognise that the concept of a market driver in the supply of disability supports has limitations.

There is the capacity for some market driven aspects of this system to keep public value at its maximum, where there are significant demands for services such as attendant support, accommodation provision and some aspects of transport and regular respite. However, with regard to specialist services and in rural and remote areas, there is simply not sufficient evidence that market forces are effective, and quality of care is often compromised. In general, service providers must be accredited, effective and relevant to people with disabilities. Quality of product is essential in human service provision, and the market drivers for efficiency and lower costs can compromise quality, particularly in specialist areas. Quality of care and support can't be compromised by the narrow use of market forces in determining a price for all disability supports.

The roles for the NDIS in longitudinal research, sector development and quality assurance are an essential aspect of the proposed new scheme.

8.3 Organisational capacity and workforce development initiatives

Organisational capacity is so much more than workforce. How to improve the capacity of disability support providers individually and collectively has been neglected. This includes governance; practice expertise; expectations for performance and reporting; and management development. A flaw in the current tendering process occurs when e the funder does not determine an organisation's capacity to implement what was intended. In these situations, there is no scope for discussion beyond 'you're funded to do it'. Tender processes must incorporate research/ evaluation components in regard to service quality as well as financial viability.

There is a need to develop further what support means for people with ABI, and cognitive impairments generally. Currently disability support is built around non-specialised attendant care/ direct staff support which is most apt for people with physical and sensory disabilities. Support for people with cognitive impairments requires specialised attendant care/ direct support and better use of technology.

There is no recognition of attendant care staff's specialist skills and training. In contrast, USA has schemes with credentialing of staff to work with people with ABI. The implications of a better trained and specialised workforce for the cost of care at an average of $30 (DIG 2009b) needs to be researched to ascertain the 'savings' as people recover. This figure currently suggests an unspecialised workforce.

Attendant care/ direct support staff will be the major budget item for NDIS – staff need to be as well trained, supervised and managed as possible to maximise outcomes for people with disabilities. For example, within the funding for a disability support system there needs to be recognition that the cost of service delivery is more than the hourly rate for direct support staff if staff are to be adequately trained, supervised and managed. Without staff training and management an individual's lifestyle choices may be at risk in complex situations. This submission stresses the importance of training and supervision for attendant care/ direct support staff. Individuals and family members may choose their own staff, but staff training needs to be monitored and accredited. Where family members undertake these roles for payment, the same expectations must apply. In addition, there are obvious blurring of boundaries when family members formally take on staff support roles which can make problem solving very difficult.

The disability sector has a major challenge ahead to create and maintain jobs people stay in, as staff consistency is so important to an individual's long term outcomes. There is an obvious loss of efficiency and effectiveness when casual and direct support staff remain employed for short time periods. The costs of training and retraining, and the disruption of support perhaps jeopardising recovery and outcomes, all suggests a new analysis is needed of the workforce issues. A work force plan requires more than consideration of career structures and payment levels, although these are important. There is a need for an improve cycle over the years of pay, status, competence of applicants, increased roles and training, increased expectation particularly for attendant care/ direct support staff.

When professional staff are needed, for example, assessments, program design and review and evaluation, the design of those roles must attract experienced people. Basic assessments in existing compensation schemes are undertaken by external and private therapists. However, due to administrative requirements more experienced people simply won't do the roles.

Staff are not the only solution. There has been limited development of aids for people with cognitive impairments, despite significant recent technology development in the community with. More research is needed about alternatives to staff support created though technology, such as timing, memory, location, and warning devices, and assist dogs. New ways to increased independence should remain a persistent policy goal for the NDIS.

9. Concluding comments

VCASP and VBIRA strongly support the directions of the proposed National Disability Insurance Scheme. The long term support needs of people with ABI can only be met with a system based around long term funding and effective support options. Many questions remain about the details of a new system and the transition process. We look forward to contributing to the next stages of the Productivity Commission's deliberations.

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