Submission
No 101

INQUIRY INTO SERVICES PROVIDED OR FUNDED BY THE DEPARTMENT OF AGEING, DISABILITY AND HOME CARE

Organisation: NSW Agency for Clinical Innovation - Brain Injury Rehabilitation Directorate

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Position: Director and Chair ACI: BIRD

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ACI NSW Agency for Clinical Innovation

Hon Ian West MLC
Chair
Standing Committee on Social issues No. 1,
NSW Parliament House
Macquarie St
SYDNEY NSW 2000

30th August 2010

Re: inquiry into services provided or funded by the Department of Aging Disability and Home Care

Attached is the response collated by the ACI: Brain Injury Rehabilitation Directorate (BIRD) and developed in consultation with clinicians working in the NSW Brain Injury Rehabilitation Program (BIRP).

The Brain Injury Rehabilitation Directorate (BIRD) is one of 24 ACI networks that involve clinicians and consumers in brain injury rehabilitation services in NSW. The BIRD works closely with other NSW government and non government organisations and is currently engaged in an Interagency Agreement signed in 2008 between NSW Health, ADHC, Housing NSW and the Lifetime Care and Support Authority (LTCS). The purpose of the Agreement is to improve equity across the interface between health and the community to meet the needs of people with ABI. The BIRD has a focus on adults, young people and children with traumatically acquired brain injury (TBI) admitted to the NSW Brain Injury Rehabilitation Program (visit www.health.nsw.gov.au/initiatives/birp). The LTCS operates on a fee for service basis for people with TBI from motor vehicle accidents (visit www.lifetimecare.nsw.gov.au).

The BIRD recognises the progress of ADHC at the senior level with participation in the Agreement and project funding for initiatives that seek to identify and resolve information gaps about ABI, knowledge and skills in ABI for workers and barriers to service delivery. These activities are critical but more change needs to happen at the regional level and with availability of service models and service delivery funding levels. This submission explores the issues experienced and seeks to advocate for people with disabilities from brain injury and their families to access the services and support required to achieve community resettlement and social inclusion.

If you have any questions, please do not hesitate to contact Barbara Strettles, Network Manager,

Regards

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INQUIRY INTO SERVICES PROVIDED OR FUNDED BY THE DEPARTMENT OF AGEING, DISABILITY AND HOME CARE

COMMENTS FROM ACI: BRAIN INJURY REHABILITATION DIRECTORATE, WITH INVOLVMENT OF CLINICIANS FROM THE NSW BRAIN INJURY REHABILITATION PROGRAM (BIRP)

TERMS OF REFERENCE	COMMENTS
a) The historical and current level of funding and extent of unmet need	Traumatic brain injury (TBI) is a common cause of acquired brain injury (ABI) that results in disability for people under 65 years and arising from motor vehicle accidents, falls, assaults, sports injuries etc. Non traumatic causes of acquired brain injury (ABI) include stroke, hypoxia (eg drowning), surgical misadventure, alcohol, drugs etc. Based on analyses of the Australian Bureau of Statistics' (ABS) 2003 Survey of Disability, Ageing and Carers the AIWH report (2007): o Acquired Brain Injury (ABI) is common: around 1 in 45 Australians (432,700 people) had ABI with activity limitations or participation restrictions due to disability including about 20,000 children aged under 15 years with ABI o People with ABI tended to have complex disability. They reported more disability groups and more health conditions than the average person with disability. o More than one in four (26%) people with ABI reported four or more disability groups, compared with one in eighteen (5%) of all people with disability o Age at onset figures suggest 33% sustain their brain injury aged 14 or under and 34% sustain their brain injury whilst aged 15-24 The NSW BIRP was established by NSW Health and the Government Insurance Office (GIO) between the mid 1980's and early 1990's to provide a specialist network of traumatic brain injury rehabilitation services for children, young people and adults to maximise recovery, reduce activity limitation and increase social participation. People with non traumatic brain injury can be admitted based on clinical need and resources. The rehabilitation continuum can occur over a number of years from acute rehabilitation inpatient wards, transition home and living in the community. Research supports early intervention and a continuum of care as key factors for improving outcomes and for many people with brain injury from trauma (TBI) their recovery will continue for some years after hospital discharge. The interface between health and disability services has been difficult. High levels of individual advocacy have been needed, often without success to try and achieve the care required and the access to programs and activities essential to meaningful social participation. Many people with TBI look the same as before their accident/injury but think and behave differently because of changes to how their brain works. They remember their previous life, they will want the same things but not be ble to achieve these same goals. Often they will know what to do but have difficulties putting this knowledge into practice. They will appear socially well informed but have little ability to remember or act on their plans. It is these difficulties and many others that make each person different. Knowing what the brain injury means for each person is essential in making plans, referring to services and identifying how much and what kind of support is needed..

- Before Stronger Together recognised people with acquired brain injury as a target group, clients with acquired brain impairment (ABI) were ineligible for access to majority of ADHC funded services such as attendant care package (ACP), respite services, supported accommodation and/or avocational services.
- No specific funding has been directed towards clients with ABI to manage the individual care and support needs of people currently living in the community or for people newly injured leaving hospital with care and support needs. Historically programs available have not been able to provide the knowledge skills and understanding of TBI to effectively work with this client group or provide the type of services to meet their needs. Services have been developed for people with an intellectual or developmental disability and people with TBI/ABI require a different approach to manage the physical, communication, cognitive and behaviour changes that affect all aspects of their life.
- Extensive waitlist exists for vital ADHC services to enable people moving from hospital home for the first time after their life has changed following severe brain injury. Programs such as the Attendant Care Program (ACP) and supported accommodation services are needed and not available for have insufficient hours available to meet care and support needs. Westmead Brain Injury Rehabilitation Service (WBIRS) is one of 3 Sydney units discharging young adults with disability to the community after traumatically acquired brain injury. This unit makes application for Attendant Care Packages (ACP) for about 5 clients a year. Other clients have access to insurance funding or Lifetime Care and Support Scheme interim participation to assist with rehabilitation treatment and attendant care costs at this vital stage of recovery and community resettlement. Lack of funding from disability services for this service results in extensive stays in hospital (on average up to 6 - 12months) as non compensable patients with TBI/ABI rely on the approval and availability of ACP services in order to be discharged to the community. People may be discharged with family care only if access to needed ADHC funded programs is delayed or not available to support the transition of care to the community. Other clients may abscond from extended inpatient stays and be homeless, be at risk of readmission, vulnerable to other or in trouble with the police.
    - People without ACP or with care hours less than the assessed need rely on informal unpaid care by family members who frequently leave paid employment to obtain the Carer's payment while providing care.
    - People who have a suitable home but need more than 35 hours paid care to manage their assessed level of care and support for a return home to be sustainable cannot go home so are forced to go to a nursing home. These inappropriate environments are a barrier to further recovery. After a TBI people continue to make gains in their rehabilitation and can reduce their care and support needs over time. The provision of appropriate levels of care at discharge can facilitate further recovery and rehabilitation gains with reduced hours of care recurrently.
    - There are insufficient vacancies in supported accommodation for at ADHC funded or ADHC provided services.
    - Extended inpatient hospital stays and discharges to Residential Aged Care Facilities are clearly unsatisfactory (from an age, disability and lack of choice perspective) but are a forced choice for a small number of clients. Sustainable and peer appropriate community living arrangement are required as a discharge option for people with newly acquired disability from TBI/ABI.
    - The NSW BIRP has a network of transitional living programs for people able to live in the community with support.. Extensive delays in accessing this support can be experienced that prevent discharge and can result in the development of challenging behaviours. Delayed discharges prevent the admission of new clients and early

intervention for living skills rehabilitation.

- A large proportion of our clients with ABI/TBI (3-5 per year on average at WBIRS alone) are still inappropriately being placed in an aged care facility/nursing home due to a lack of ADHC funded services and extensive waitlists for existing services. The fact that such placements are still occurring in 2010 transparently highlights the unmet needs of this client group.

- Avocational services that clients with AB/TBII can access have traditionally been services for clients with intellectual and developmental disabilities. This means that while the client with ABI/TBI can access such services, it does not mean it meets their needs or pre injury personal life goals. This often results in refusals to attend and a lack of structured activity to add meaning to changed lives. A person acquires a disability as an adult sees themselves differently to a person who was born with a disability or who acquired their brain injury as a child and has changing needs at different developmental stages.

- There are issues of extensive waitlists, inflexible service definitions and insufficient funding for flexible options, especially for respite packages that are a further restriction to available service provision by ADHC.
    - An example of is a service with intake once per year (referring to the Cumberland Prospect Respite, Intake & Allocation Process (RIAP) who have their intake in March) which further disadvantages the majority of our clients who are not in school when they sustain the TBI/ABI so do not access avocational services from an education/school pathway. They need service access throughout the year.
    - Other services are not yet accepting people with TBI/ABI as they have not changed their policies to align with Stronger Together. Staff is untrained in the needs of people with ABI/TBI and there is a reluctance to accept this new client group, particularly as no additional funding or extra targeted places have become available.

- Paediatric brain injury rehabilitation services report extensive waiting lists
    - Unacceptable wait list - one child waited 2 years for speech therapy – minimal verbal skills and global delay. As with adults, improved outcomes occur for children when rehabilitation I provided as a continuum of recovery and often this window of opportunity is lost when intervention is delayed
    - Inadequate levels of therapy staff to meet demand. Due to long waiting lists, ADHC therapists will not see children who are accessing another therapy service, even at times when it has been explained that the service (when provided by a paediatric BIRP) is a gap service to ensure child does not lose further function whilst waiting for ADHC services.
    - Caseloads are complex & include large numbers. Recommended strategies required for the home or school are often not followed up to ensure that they are integrated with daily living
    - Inadequate professional support of therapist for their clinical caseload (ie complex chronic disability) to understand and implement ABI assessments or treatment and to generate new solutions when therapy plans not working out
    - Pathways into other services eg respite are not readily available as a continuum of service provision
    - Level of family support for hours of care and service referrals may be under represented as the burden impact on family and changes as the child reaches developmental milestones is not easily recognised or understood.

- Access to ADHC case management needs to be available as a continuation of discharge planning for adults young people and children with newly acquired brain injuries and needs to be more proactive to ensure transition of care from hospital to community
- Clients with ABI who make it onto the *Immediate Housing Needs* register are clearly not seen as a priority. They need to wait for an NGO who takes clients with ABI to have a vacancy – almost impossible. Clients currently are waiting YEARS for a vacancy. Out of over 200 NGO's in NSW (funded by ADHC) who provide supported accommodation only a small percentage take Clients with ABI/TBI. Therefore it is almost impossible to get our clients into an ADHC funded (either direct or indirect) supported accommodation service with the appropriate levels of care and support. This is further restricted by the current exclusionary criteria in many supported accommodation services that the injury has to be sustained prior to age of 18 years, (a very small number of our clients) and until recently an emphasis on assessed IQ. Most of our clients in need of supported accommodation sustain their ABI/TBI as young adults and their IQ score is not sufficiently reduced (individual IQ abilities eg their memory, planning and organisation skills are affected) to meet this entry criteria.

Possible solutions:

- ADHC needs more funding allocated SPECIFICALLY to the client with ABI group across all programs and service types
- Expand the supported accommodation criteria to people 16 – 65 years.
- Fund and support more NGOs to take people with an ABI/TBI or tender out funding to NGOs who will build and run supported accommodation (i.e. current Acquired Brain Injury Services NSW (formally Wareemba Community Living) project in Bathurst or Supported Housing Development Group Pty Ltd in Western Sydney.
- Provide a 'funding package' to people with severe ABI/TBI so money can be used flexibly (to minimise current guidelines and restrictions in providing attendant care in the home or to pay for supported accommodation).
- Increase ACP funding recurrently so that new ACP's are available to be allocated to people with ABI/TBI to enable them to leave hospital as a continuation of recovery and rehabilitation with a transition to the community that is timely and exusres a successful/sustainable discharge.
- Consider ACP or similar to have access to a higher number of hours for the initial transition to the community phase than would be available recurrently where further recovery is expected that potentially reduces over time.
- Provide increased access to existing and appropriate activities and programs as part of the transition of care process from hospital to disability/community. This involvement may reduce the hours of individual care required.
- Consider innovative ways of mixing people with different disability support needs so people with an ABI/TBI can access current NGO supported accommodation services
- Consider all areas in NSW as the shortage of age and disability appropriate services is universal in both metropolitan and rural/remote NSW.
- Clients with ABI/TBI benefit from 1:1 flexible respite packages, where the funding can be used and tailored to the specific needs of this client group and the person in the context of their family.
- Clients with challenging behaviours are not able to access current ADHC behaviour management programs which are primarily for people with intellectual disabilities. People with ABI do access the Integrated Services Project (ISP) for an intensive residential challenging behaviour program but it is so difficult to access that your current care arrangements have

	to totally fail and your behaviour needs to be so difficult that you become a management priority for the Interagency Partners before you can get a place funded. NSW Health referrals are from Area Mental Health Services. There is no opportunity for families or other areas of NSW Health to make referrals. o Clients with challenging behaviour after TBI/ABI could benefit from early intervention programs prior to this level of dysfunction and cost. Funding of a challenging behaviour support and development program would provide a similar model to that available to people with intellectual disabilities but have staff with the specific knowledge and expertise about TBI/ABI to assess and include cognitive impairments in program development. This type of program is being considered by the partner agencies in the Interagency Steering Committee. (add correct name here) Although it is acknowledged that funding for attendant care workers required by adults with brain injuries has increased, there is still significant unmet need. • People who do not access the NSW BIRP (eg adults with stroke) require access to case management services to make sense of the ADHC services and identify services that are appropriate and useful in achieving quality of life and social participation.
TERMS OF REFERENCE	**COMMENTS**
b) Variations in service delivery, waiting lists and program quality between: ➢ services provided, or funded, by ADHC ➢ ADHC Regional Areas	Many adults with brain injuries require assistance and supervision with multiple tasks to enable them to live safely in the community. Generally they require a different approach that provides support to do things themselves rather than support for someone else to do things. This assistance and supervision is required for home and community based tasks including: personal care eg showering, dressing; domestic tasks eg cooking & cleaning; community activities eg shopping, catching public transport, visiting the library & participating in leisure activities. Adults with brain injuries require this assistance and supervision as a result of the cognitive impairments eg memory difficulties and/or physical impairments, and/or mood/behavioural difficulties they have as a direct result of their brain injury. Consequently they require attendant care services with appropriately trained attendant care workers. AC staff generally has an aged care, physical or intellectual disability background that does not easily translate to the skills required working with people with ABI/TBI. • An additional essential role for attendant care workers which requires further funding is to assist adults with brain injuries to increase their skills in home and community based tasks and activities in a graded manner, with training and guidance from therapists. • In the absence of increased funds for the ABI target group ADHC appears to be struggling with the increased service demands and equity of access is reduced. There is a marked need for increased funding for programs that provide attendant care services for adults with brain injuries to enable them to live safely in the community in a sustainable manner. • The lack of access to readily available attendant care worker services increases the length of stay for some adults with brain injuries in the Transitional Living Unit and creates a bed block for the Inpatient Unit, and restricts access to clients referred who are living in the community. ADHC provides funding for specific programs (eg Headstart Newcastle and Headway Bankstown and Illawarra) that provides a good community access services for people with ABI in the community. This is a service that is flexible to clients needs within the financial limits of the service. Unfortunately these programs have a waiting list and are not available in all ADHC regions in NSW. Existing programs would benefit from additional funding to increase capacity and additional funding to establish additional services across NSW. Currently, each program has a core surrounding area based on their location and do not extend to the whole of the ADHC

	region within which they are located. Headstart is an example being located in Newcastle and unable to provide services past Singleton in the Hunter Valley. • The further from ABI/TBI specific services clients are located, the less ABI specific services or knowledge is available in the community and disability sectors. The need is greater in rural areas. Some areas of NSW have no access to ABI/TBI specific services eg The Manning area and the far west of NSW and regional offices continue to limit access for people with ABI to existing services. Brokerage funding would be useful for special circumstances, particularly when services required are not locally available or the available services are not appropriate to the person. Brokerage funding would provide the flexibility to purchase needed services and break the cycle of people just not being able to access the support and or therapy they need or waiting extremely long periods of time during which problems can develop and outcomes can be compromised. Generally brokerage is short term one off funding and has limited usefulness in providing recurrent sustainable alternatives but can play an extremely important role in solving problems in a timely manner and preventing deterioration or other problems.
TERMS OF REFERENCE	**COMMENTS**
c) Flexibility in client funding arrangements and client focused service delivery	The current process of applying for ADHC services is confusing, complicated and lengthy. It requires the skill of an experienced social worker or case manager to navigate and advocate on the clients behalf. If a client does not have this service/advocate available to them they are significantly disadvantaged and at risk of missing out on a service all together. There is no current flexibility in funding arrangements for our clients with an ABI/TBI. Many services are block funded and so cannot easily meet individual needs that are different from the primary client group. The result is that our clients are forced to fit into existing ADHC funded service models. Additionally, our clients are often assessed for program access on criteria that does not include recognition of the impact of TBI/ABI (especially cognitive and behaviour changes after ABI/TBI) or service providers do not understand the importance of rehabilitation and promoting independence. Where there is some flexibility, (i.e. ACP and ability for clients to choose their service provider and negotiate how there care will be delivered) there are extensive waitlists and a complete lack of funding for the current demand. This is particularly evident at discharge from hospital and for people living in the community when care and support needs change. One community based ADHC funded Brain Injury Respite Options (BIRO) program in Newcastle provides a good service to the carers of people with ABI that is flexible in that it provides respite in the client's home, in the community, or in a house in the community, as well as group days periodically throughout the year. This service type is not available in all ADHC regions. This model of care could be expanded across NSW. Some pockets of NSW have access to ABI specific services that are able to meet the needs of people with disability from ABI/TBI better than the generic disability services. This has been obvious with the provision of attendant carers who are not ABI specific in their training or familiar with the concept of ongoing goals and the potential for gains to be made even after the formal

	rehabilitation has ceased. There is a need to increase the availability of specific ABI services as a way of improving service response to this target group especially in the short to medium term. Overall there are good intentions at the senior levels of ADHC to respond to Stronger Together by improving access and services for people with ABI/TBI. However, more needs to change at the regional service delivery level to ensure equity of access and improved service capacity to meet the different and changing needs of people with ABI/TBI.
TERMS OF REFERENCE	**COMMENTS**
d) Compliance with Disability Service Standards	• There are disability rights issues for people with TBI when they are unable to access the services and programs they need to live where they want to live, to live with people of their choice and do the things that give their life meaning. For many people with TB I and their families they are forced into situations not of their choosing because of a failure of the disability services to understand what is needed why it is needed and how it can be funded and provided.
TERMS OF REFERENCE	**COMMENTS**
e) Adequacy of complaint handling, grievance mechanisms and ADHC funded advocacy services	– ADHC has not made it clear what their grievance mechanisms/complaints handling procedures are for non funded services. Their web site is confusing and ineffective. We are unable to locate adequate information about services, who to contact, instruction about how to apply for services or any other support information such as grievance/ complaints handling process. This information is usually known by a senior BIRP team member (eg social worker or case manager)
TERMS OF REFERENCE	Comments
f) Internal and external program evaluation including program auditing and achievement of program performance indicators review	• ADHC has never to our knowledge requested feedback regarding the quality of their service delivery to our client group. • Information about public consultations is not disseminated directly to rehabilitation providers in NSW Health.

TERMS OF REFERENCE	COMMENTS
f) **Other matters**	An issue that is becoming increasingly problematic is for access to supported accommodation (as opposed to periods of respite) for older carers. Some carers of people with ABI/TBI are now well past retirement age and are fearful about the future for their children with ABI (children young people and adults). Carers would like to be able to plan ahead and start the change over from the person living at home with their families to living in supported accommodation. The transition needs to occur in a planned way while families are available to assist with resettlement rather than when a crisis occurs and family can no longer provide care in the home environment or support the life changes. Current supported accommodation priority is for the homeless. This prevents transition planning for aging carers and new initiatives to meet increasing demand are extremely slow to develop. Few new options have been provided in NSW as an outcome of the young people in aged care (YPIACF) initiative or in future service planning when living at home is no longer an option. Joint programs with NSW Housing for somewhere to live and receiving the care required are limited, particularly for location, staff skills in clients with ABI and care hours. ADHC have moved to a functional assessment of care and support need. However ADHC appears to be moving towards providing more generalist services, rather than having a general standard of disability service provision with additional specialist knowledge. It has been the experience of BIRP staff that a general approach to care and support has not always been successful with our clients. For example, we have tried on a number of occasions to involve younger ABI clients in the Peer Support type programs but ABI clients have been reluctant to engage. Behaviours that result from cognitive and behaviour change after an ABI/TBI are misinterpreted (eg difficult, resistant, not interested, not trying etc) when the problem is directly related to the brain damage (eg not able to remember, slowed information processing, poor attention and impulsive etc.). The life long strategies that are essential in supporting the person with ABI to achieve their goals are not introduced or not supported in an environment with little or no understanding by staff and the agency responsible (ADHC provided or ADHC funded).