

# To the back of Bourke, delivering brain injury rehabilitation to remote areas in New South Wales

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Virginia Mitsch was recently employed as a project coordinator within the Agency for Clinical Innovation NSW—Brain Injury Directorate to complete the rural and remote brain injury rehabilitation project. Virginia currently works as an occupational therapist for the South West Brain Injury Rehabilitation Service in Albury, NSW providing brain injury rehabilitation within rural and remote areas. Her speciality is within acquired brain injury (ABI) where she enjoys working with individuals and their families as they navigate their journey following ABI. Virginia has been a key investigator in a number of research projects including:

- Participation following traumatic brain injury for people residing in rural and regional areas of NSW
- Diary use following traumatic brain injury: Issues for generalisation (a study that included completion of a Master of Occupational Therapy)
- Evaluation of a memory program within a transitional living unit following ABI.

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## Introduction

Rural disadvantage extends beyond health to areas of injury and disability with people with disabilities in rural areas experiencing significantly more social problems than their urban counterparts, but have access to fewer resources including rehabilitation services.<sup>1,2</sup> Given that many Aboriginal people live remotely, and have poorer health outcomes compared to the non-Aboriginal population,<sup>3</sup> they face a double disadvantage. Living with disability such as acquired brain injury (ABI) presents challenges for those living remotely, which are only intensified for Aboriginal person within the same context.

Acquired brain injury (ABI) referring to a sudden onset injury, is the result of external trauma such as motor vehicle accidents, falls and assaults, or from non-traumatic (internal) causes such as stroke or aneurysms.<sup>4</sup> Prevalence rates across Australia show that 77, 800 people with an ABI (under the age 65) resided within NSW,<sup>5</sup> prevalence rates for more rural and remote areas in NSW can only be estimated.

The challenges of rehabilitation following injury for people from rural and remote areas are complex and ongoing. These challenges include lack of coordination of services, the need to move to metropolitan areas for more complex rehabilitation, the economic and isolation impact of this on families and dislocation from their community.<sup>6,2</sup>

Rehabilitation for traumatic brain injury and sudden onset acquired brain injury (between ages 5-65) in NSW is delivered through a network of 14 services which constitute the NSW Brain Injury Rehabilitation Program (BIRP). Delivery of brain injury rehabilitation to rural and remote areas of NSW by the NSW BIRPs at Dubbo, Bathurst and Albury is highly problematic due to distances and limited resources.

This paper reviews the literature regarding the prevalence and impact of acquired brain injury in rural and remote Australia and the higher prevalence among the Aboriginal population. It will report on a study to address the issue above and improve the delivery of brain injury rehabilitation within rural and remote areas NSW and the resulting action plan.

## Literature background

In 2006 around 38,000 residents in New South Wales (NSW), lived in remote or very remote areas of the state and just under a quarter of these were Aboriginal.<sup>7</sup> In Australia, health outcomes have been shown to become worse as remoteness increases.<sup>8</sup>

Data from the 2006 census notes that within central and far western areas of NSW the incidence of disability in the population under the age of 65 was higher in the Aboriginal community than in the total regional

population (3.9% compared to 2.5%).<sup>9</sup> Hospital data collected in Queensland, Western Australia, South Australia and the Northern Territory for a six year period documents a disproportionately high representation of Aboriginal people hospitalised for head injury due to assaults. For the total population, the rate of head injury due to assault was 60.4 per 100 000 population as compared to the rate among Aboriginal population of 854.8 per 100 000. A rate 21 times higher than non-Aboriginal people.<sup>10</sup> Although this study does not include New South Wales data it raises concerns regarding possible high prevalence rates of head injury due to assault in this state of high numbers of Aboriginal people. The likely impact of these brain injuries due to assault include physical, cognitive and behavioural disorders resulting in a substantial personal and social burden on injured people, their families and their communities.<sup>10</sup>

Hospital data pertaining to all acquired brain injuries within NSW is difficult to obtain. In 2007 a NSW incidence data study recorded a total number of 6,850 people admitted to a NSW hospital with traumatic brain injury (TBI), and 6,886 incidences of TBI.<sup>11</sup> Over 5,000 of the total admissions were aged 0-64 years (73%). Of the total number of incidences recorded, 3.8% were recorded as Indigenous people (n=261). Of the total number of admissions recorded 13% had a length of stay of more than one week indicating a severe injury. Of this group of longer length of stay 5% identified as being an Indigenous person. Although specific data for rural and remote has not yet been identified within this study, in NSW the numbers of TBI identified as significant injury and Indigenous indicate a high representation of people within the 0-65 age range.

Social and emotional issues encountered whilst living in rural and remote communities following an ABI include feeling isolated, needing to find and liaise with rural community agencies, a lack of emotional and family support, travel and financial difficulties linking in with specialised ABI services.<sup>12,13</sup>

An Australian study has compared outcomes of rural and urban NSW residents following a severe TBI.<sup>14</sup> The participants numbered 198 with 147 from urban areas and 51 from rural areas. Measures of disability, impairments, quality of life, emotional functioning, and vocational outcomes were completed on admission to rehabilitation and at an 18 month follow up appointment. Results of this study found a difference in the type of rehabilitation setting with 53% of rural patients (27) treated in non-inpatient setting, compared to 33% urban patients (49). These results suggest an inequity in service provision; best practice standards recommend a period of intensive rehabilitation for TBI clients before accessing community rehabilitation services.<sup>15</sup>

Findings from the NSW study suggest that the current coordinated brain injury rehabilitation program (BIRP) operating throughout NSW provides effective rehabilitation for people with severe ABI regardless of distance from a major metropolitan centre. Difficulties faced by rural people with a severe ABI were acknowledged however and include time spent away from home during rehabilitation, appropriate accommodation and services in the community and support for carers.<sup>14</sup>

Key issues identified in the provision of rehabilitation and resources was that health professionals are required to manage a number of people with ABI over vast geographical distances, placing a large strain on the rural BIRP program and limiting the assistance available to rural health practitioners.<sup>14</sup>

Further to the above Aboriginal people face additional issues in accessing rehabilitation following injury or disability. Rehabilitation is organised in metropolitan and regional areas, but for Aboriginal people from remote areas being sent to the city for rehabilitation can be a devastating experience.<sup>16</sup> Being away from the family and cultural experiences as well as being assessed within an unfamiliar environment can impose added stress, compounding the effect of the disability of quality of life and psychological functioning. The low use of rehabilitation services by Aboriginal people because of these barriers can lead to the inaccurate perception that the need for disability services among Aboriginal people is minimal and increase the risk that vital services may be removed.<sup>16</sup>

Other factors that prevent equitable access to rehabilitation for Aboriginal people with disabilities as well as the cultural importance given to family and families' involvement in rehabilitation, include a low expectation of assistance from services and stereotypes that exist with non-Aboriginal service workers that Aboriginal communities don't want assistance and that Aboriginal people are unmotivated towards rehabilitation.<sup>17</sup>

## The NSW Brain Injury Rehabilitation Program

The delivery of services to people with ABI (predominately traumatic brain injury) residing in rural and remote areas of NSW, including Aboriginal people, currently operates within the NSW Brain Injury Rehabilitation

Program (BIRP). Eight services are located in the metropolitan areas of Sydney, Newcastle and Wollongong. The remaining six services are based in regional NSW (Table 1.).

**Table 1 Structure of the rural brain injury programs**

Rural BIRPs	Inpatient	Transitional	Community	Paediatric
Albury		Yes	Yes	Yes
Bathurst		Yes*	Yes	Yes
Dubbo**		No	Yes	No
Goulburn		Yes	Yes	No
Tamworth		Yes	Yes	Yes
North Coast at Lismore, Coffs Harbour and Port Macquarie		No	Yes	No FTE

\* Opens after client referral received and admission agreed

\*\* Very limited staff FTE

## Background to study

Outcomes and challenges faced by people in rural and remote areas following ABI are consistent with generic disability studies in disparity of outcomes and disadvantages faced, such as access to services and ongoing support. A paucity of information is available specific to Aboriginal people following ABI, and residing remotely following ABI.

In response to the literature identified in the background above and the concerns of rural clinicians regarding inequities in delivery of rehabilitation services to Aboriginal people, further investigation of the delivery of the BIRP services and the models of delivery to best meet the specific needs of Aboriginal people was recommended within the Brain Injury Rehabilitation Directorate (BIRD). Support was obtained from the Hon. R. Meagher MP, then the NSW Minister for Health and the Brain Injury Rehabilitation Directorate secured project funding from the Greater Metropolitan Clinical Taskforce (now NSW Agency for Clinical Innovation). This funding was combined with a grant previously obtained from the Motor Accidents Authority (MAA) of NSW to the Rural Rehabilitation Research on Brain Injury (RRR-BI).

## Methods

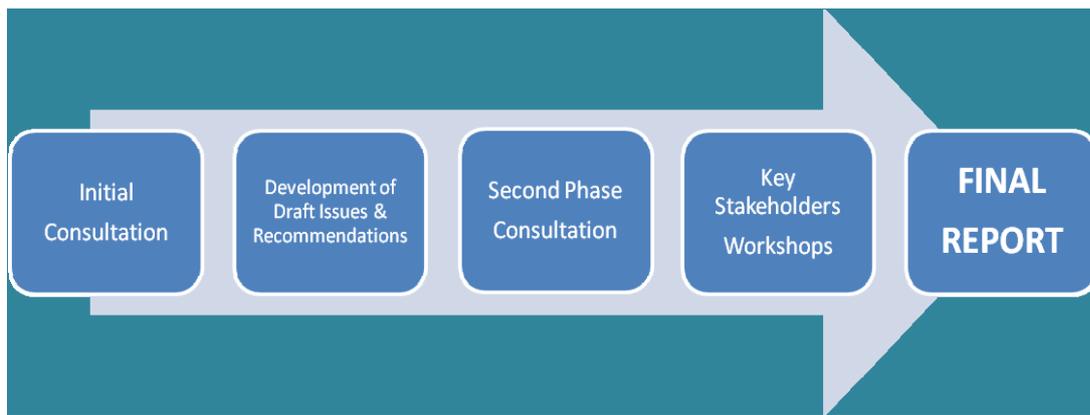
The Remote and Indigenous Brain Injury Rehabilitation Service delivery project emerged from this combination of funds with a steering committee formed in June 2008. The steering committee, comprising representatives from the BIRD, brain injury clinicians and Aboriginal services provided expertise and consultancy to the project in the key areas of community engagement and development of recommendations.

Community engagement commenced within the ethics application for both NSW Health and the Aboriginal Health and Medical Research Council (AHMRC). Connections made within this engagement led to opportunities for consultation once ethics approval was obtained.

The project employed a descriptive qualitative research design utilising the data generating tools of focus groups and semi-structured interviews in two key phases.

Phase one investigated the equity of access to brain injury rehabilitation and services for people aged 5 to 65 years of age, residing in remote areas following ABI with an additional focus on whether Aboriginal people face different or additional barriers to the access and use of brain injury rehabilitation services in remote areas.

Phase two known as the solution phase identified strategies and recommendation for further consultation leading to priorities for action. Figure 1 highlights the consultative process within the project culminating in key stakeholders workshops.



**Figure 1 Consultation process**

Participants for the interviews were drawn from key people within the delivery of brain injury services and rehabilitation (including consumers) in remote areas of NSW and concentrated on central and western areas of NSW. Over thirty services were involved in consultation for this project including NSW Brain Injury Rehabilitation Programs (rural and metropolitan), Ageing and Disability and Home Care (ADHC) provided services, NSW Health funded services, Commonwealth Funded and Non-Government services across the Central, Central West, North West, Western and Far West areas of NSW. The consultations included forty eight interviews. The majority of the interviews occurred face-to-face, at the location of the service or within the home of the consumer participant. This was deemed critical for ensuring representation of the community and identifying the partnerships required for model development.

Eight interviews were conducted with Aboriginal people. All interviews were audio-recorded for later transcription and thematic analysis. Phase one of the project included interview transcription, member checking and initial analysis, followed by group analysis within the steering committee and collective issues emerged.

## Results

Table two identifies the towns and regional centres from phase one of the project and the remoteness rating according to the project definition and the accessibility/remoteness Index of Australia (ARIA) rating<sup>18</sup>

The definition of remote developed in the early stages of the project: places located more than two hours drive from each rural BIRP location (Albury, Bathurst or Dubbo), determined the locations for remote consultations.

**Table 2 Geographical areas involved in consultation**

Town/regional centre	Project definition#	No. interviews conducted	ARIA rating*		
			Score	Rating	Description
Albury		One Group interview	0.99	Highly accessible	<u>ARIA Scores = 0-1.84</u> : Relatively unrestricted accessibility to a wide range of goods and services and opportunities for social interaction.
Bathurst		One Group interview	1.2	Highly accessible	
Tamworth		One Group interview	1.71	Highly accessible	
Dubbo		4	2.4	Accessible	<u>ARIA Scores = &gt;1.84 – 3.51</u> : Some restrictions to accessibility of some goods, services and opportunities for social interaction.
Broken Hill	Remote	2	3.24	Accessible	
Wentworth	Remote	1	3.01	Accessible	
Mildura	Remote	1	2.48	Accessible	
Dareton	Remote	6	2.85	Accessible	
Balranald	Remote	2	4.34	Moderately accessible	<u>ARIA Scores = &gt;3.51 -5.80</u> : Significantly restricted accessibility of goods, services and opportunities for social interaction.
Warren	Remote	1	4.95	Moderately accessible	
Hay	Remote	1	5.39	Moderately accessible	
Menindee	Remote	1	5.530	Moderately accessible	
Coonamble	Remote	3	5.84	Remote	<u>ARIA Scores = &gt;5.80 - 9.08</u> : Very restricted accessibility of goods, services and opportunities for social interaction.
Condobolin	Remote	2	7.69	Remote	
Hillston	Remote	2	5.930	Remote	
Nyngan	Remote	5	6.40	Remote	
Walgett	Remote	2	7.60	Remote	
Lightening Ridge	Remote	2	8.7096	Remote	
Grawin	Remote	1	9.130	Very remote	<u>ARIA Scores = &gt;9.08 – 12</u> : Very little accessibility of goods, services and opportunities for social interaction.
Bourke	Remote	4	10.32	Very remote	

**ARIA Rating\***- Accessibility/Remoteness Index of Australia (ARIA) rating<sup>18</sup>

**Project Definition#**- Remote as defined within this project is a distance of at least two hours from a rural brain injury program.

Five key themes emerged from the consultation data representing a number of issues from the key areas of specialist brain injury services, other health and community services and people with ABI and their families. These themes include:

### 1. The unmet needs of people with brain injury and their families living in remote areas

Living remotely from a brain injury rehabilitation program (BIRP) limits access to specific ABI rehabilitation; at the level of intensity and type required, including staff and services with specific ABI expertise. The lack of transport and support for family are issues of concern and are significant barriers to access to rehabilitation.

A significant finding was that in remote areas people with an acquired brain injury and their families may be left to struggle with the negotiation of their own care needs when returning home from acute care services. These people may not be linked with their nearest BIRP or the distance to this service prevents meaningful participation.

Accessing local services for care coordination and rehabilitation is restricted due to local resources and the lack of local staff with specific knowledge and understanding of ABI. Meeting the needs of children following brain injury in remote areas is of particular concern. Pathways into support services, including school transition, are

often not available when children return home and when problems achieving developmental milestones are identified. Generic services have long waiting periods once problems are identified and the opportunity for enhancing recovery is compromised.

## **2. Additional issues faced by Aboriginal persons following ABI living in remote areas**

In addition to the unmet needs identified for persons with an ABI living in remote areas, Aboriginal people have other specific additional cultural needs and issues related to kinship, gender and shame.

Cultural issues of kinship and connection to community may impact on the acceptance of residential and highly structured environments, such as hospitals and rehabilitation programs which separates an Aboriginal person with an ABI from their family. As a result they may leave early, not engage, and/or not complete rehabilitation programs.

For an Aboriginal person returning back to their community, acceptance of services can be influenced by the issues of shame (bringing attention to one-self), gender of support care worker and trust relationships.

The development of trust and engagement with an Aboriginal community is required for effective brain injury rehabilitation; this is difficult due to large distances between rural BIRP workers and the remote community. This also links to understanding the rehabilitation needs and goals of the Aboriginal person which can be different to the rehabilitation goals of service providers.

## **3. Access and provision of rural brain injury rehabilitation for persons following ABI living in remote areas**

Investigation of the access and provision of brain injury rehabilitation occurred within the central west, north western and far western areas of NSW.

Within these regions there are areas where there is no rehabilitation service or the service provided is limited due to distance from a rural BIRP. However, even where a limited rehabilitation service exists, there are little to no services and support for children who have had a brain injury.

A distance of two hours or more from rural brain injury program compromises availability and intensity of a rehabilitation program to persons and their families living in remote areas. This results in difficulty with key strategies within rehabilitation such as establishing rapport, coordination of services and support to family. Within rural BIRPs with small staff numbers a case coordination model is adopted without clinical input. This essentially means that there may be no access to therapy within a brain injury service or outside.

## **4. Workforce issues**

Variation in skills, knowledge and the numbers of staff within rural BIRPs all impact on the provision of brain injury rehabilitation in remote areas. This along with workforce issues within non brain injury services impact on service equity.

The brain injury rehabilitation service provided in remote areas is not equitable compared with the service provided in regional and metropolitan areas. This is partly to do with the variability of staff resources, skills and knowledge of clinicians within rural brain injury programs. There is no consistency as to whether therapy is provided within a rural BIRP; it is dependent on the model of delivery as defined by resources.

In particular there is limited allied health input for people with an acquired brain injury living in remote communities due to often vacant or poorly resourced allied health positions. The paucity of allied health services for any client base is a familiar issue for communities in rural and remote areas. The current structure of allied health positions provides for low priority afforded to brain injury rehabilitation with input often for assessment only and not for ongoing therapy.

Allied health shortages result in primary health care nurse in remote areas often being the main providers of care coordination and other services for people with acquired brain injury.

## 5. Community understanding of brain injury

People who live in remote areas of NSW usually do not have access to a community rehabilitation model of service provision and to services that understand ABI and the needs of the person returning home following acute care and their families.

People returning home after an ABI can be isolated from specialist services and be unable to access the care and support they need locally. As well as a limited numbers of allied health and rehabilitation physicians available clinicians and service providers located remotely may not have specialised expertise and knowledge of working with people with a brain injury.

### Planning context

In the development of a plan of action to address the issue of equity of brain injury rehabilitation in remote areas NSW when compared with regional and metropolitan services essential data needs to be considered.

Population data highlight significant gaps in brain injury rehabilitation delivery in remote areas of NSW, and contribute essential information and evidence supporting the need for action. The area health services of interest for this project include the Greater Western Area Health Service (GWAHS) and Greater Southern Area Health Service (GSAHS).

The GWAHS serves a total population of approximately 287,481 people, 4.4 per cent of the NSW population.<sup>19</sup> The Mid Western Brain Injury Rehabilitation Program and the Dubbo Brain Injury Rehabilitation Program operate within the GWAHS. As noted in Table 2 below, the Mid Western Brain Injury Rehabilitation Program currently services a population of approx 192,000 with the areas of Condobolin and Lake Cargelligo (total population approx 7,000) experiencing limited service capacity from this BIRP due to remote location and limited resources.

Dubbo Brain Injury Rehabilitation Program is currently servicing an approximate population of 81,000 (see Table 3), including the Dubbo area and surrounding areas up to two hours travelling distance from the BIRP location. A number of central western areas (total population 19,000) are either currently not receiving services from the Dubbo BIRP or service delivery is limited due to remoteness and limited staff (see Table 3).

A rural BIRP service does not operate to the far western area of NSW. A significant population of approx 38,000 which includes the towns of Cobar, Balranald, Wentworth, Dareton, Broken Hill, and the Central Darling area, which do not receive any input from a rural brain injury rehabilitation service (see Table 3). The majority of these towns are rated remote according to ARIA<sup>18</sup> and already experience limitations in services.

In 2006, the Greater Southern Area Health Service (GSAHS) had an estimated resident population of approximately 474,000 people.<sup>20</sup> The South West Brain Injury Rehabilitation Service (SWBIRS) and the Southern Area Brain Injury Service (SABIS) operate within the GSAHS. SWBIRS services a total population of 358,000 including compensable clients in North East Victoria (approximate population of 82,000). SABIS currently services a population of 198,000. Currently both SWBIRS and SABIS are able to provide a service to all areas within GSAHS, however there is only a limited service provided to the north western areas (see Table 3).

**Table 3 Populations serviced and populations not serviced within current service capacity for the following rural BIRPs**

Rural BIRP	Total Population of areas serviced by rural BIRP*	Limitations to service delivery due to remoteness	Areas currently not serviced by the rural BIRP	Total Population With service limitations or no service*
South West Brain Injury Rehabilitation Service	358,000**	Hay and Hillston	-	Total=4,600
Mid Western Brain Injury Rehabilitation Program	192, 000	Lachlan LGA -include Condobolin, Lake Cargelligo	-	Total=7,300
Dubbo Brain Injury Rehabilitation Program	81,500	Coonamble (Pop 4,400) Nyngan (Pop 2,000)	Bourke (Pop 3,300) Brewarrina (Pop 1,900) Walgett (includes Lightning Ridge) [7,300]	Total=19,000
No rural BIRP In Far Western area	No service	No service	Cobar Balranald Broken Hill Wentworth/Dareton Central Darling (Wilcannia)	5,200 2,600 20,000 7,700 2,000 Total=38,000

\* Note figures are approximate figures. Data source-Department of Planning and Statewide Services Development Branch, NSW Health. March 2009

\*\* Includes geographical areas in Victoria

## Action plan

There are three key factors to improving the model of care for brain injury rehabilitation in rural and remote areas NSW, these are critical to the implementation of the report recommendations and include;

- Strengthen the Dubbo BIRP to operate as a hub for the central Western and Northern areas.
- Trial and evaluate BIRP Community Workers in Broken Hill (supported by the Mid Western Brain Injury Rehabilitation program) and Dareton/Robinvale (supported by South West Brain Injury Rehabilitation Service).
- Enhance paediatric services by locating paediatric coordinators in rural and remote areas.

Additional significant recommendations further to these key factors include:

- Develop a network of BIRP Community Workers and ABI Champions to be located in the central and western areas of the state. Integrated with the local NSW BIRP these positions will provide ABI rehabilitation to people living in remote communities and improve the knowledge and understanding of ABI and ABI rehabilitation in the community.
- The development of guidelines within the BIRP network for culturally appropriate services for Aboriginal people following ABI.
- Fund an implementation project officer position at the BIRD for a minimum of three years to develop and manage the action plan arising from project recommendations and development of standards and guidelines to achieve the identified model of care priorities.
- Fund a education and training and paediatric statewide position at the BIRD. This will involve education and training activities for BIRP staff and for increasing ABI knowledge and understanding within rural and remote communities and the development of paediatric rehabilitation guidelines and service delivery.

## Conclusion

This project recommends an enhancement to the existing model of care to improve the equity of brain injury rehabilitation service delivery in remote areas of NSW. Significant gaps and inconsistencies with the delivery of brain injury rehabilitation were identified within the Central Western and Far Western areas of NSW via extensive community and consumer engagement. There were additional issues related to culture and community that are experienced by Aboriginal people following an ABI that can also be addressed by these enhancements.

Recommendations that can be extended to action at a National level include the development of guidelines for working with Aboriginal people following ABI, education on brain injury in rural and remote areas and the funding of rehabilitation community workers.

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