



**ACI** NSW Agency  
for Clinical  
Innovation

# Acquired Brain Injury Rehabilitation Service Delivery Project

Developing a Model of Care  
for Rural and Remote NSW



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Firstly we would like to express sincere thanks to the large number of people involved in consultations for this project who gave willingly of their time, experience and stories so that this report can truly reflect current issues by developing actions to achieve change.

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The ACI provided strategic and financial sponsorship for this project. The ACI was established by the NSW Government as a board-governed statutory health corporation in January 2010, in direct response to the Garling Report into Acute Care Services in NSW Public Hospitals. Building on the work of the Greater Metropolitan Clinical Taskforce (GMCT) and its predecessors, the ACI uses the expertise of its clinical networks to improve patient care within the NSW health system.

Thanks to the Motor Accidents Authority and Rural Rehabilitation Research on Brain Injury (RRR-BI) for their financial contributions to the early development of this project. Their support was instrumental in the formation of the project.

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Virginia Mitsch  
*Author and Project Officer*

# FOREWORD

The Agency for Clinical Innovation (ACI) takes seriously its responsibility to identify inappropriate variations in care and promote equity of access and outcomes for NSW patients. The divide between access to city services and those available to people in rural and remote communities – particularly indigenous communities – is one of the most significant challenges facing Australia. The Rural and Remote Brain Injury Rehabilitation Project was established by the ACI's Brain Injury Rehabilitation Directorate (BIRD) to investigate brain injury needs, including the needs of Aboriginal people and services in rural and remote NSW, with a focus on Central-western and Far-western areas.

The NSW Brain Injury Rehabilitation Program (BIRP) provides specialist services to rural and remote areas from Dubbo to Bathurst and Albury. However, the spread of population across vast areas means health professionals are required to manage brain injury patients over great distances, and access to rehabilitation and support can be problematic and in some areas non-existent. The issues are more pronounced for Aboriginal communities, which comprise a significantly higher proportion of the population in remote areas and have a higher incidence of brain injury.

The ACI project explored in detail the experience of consumers and service providers within 45 consultations, with follow-up consultations and key stakeholder workshops to help develop an improved model of care and recommended strategies for action. How best to utilise the report as a blueprint for future planning and service developments and the feasibility and costs of specific recommendations, remains to be determined. The project developed four key principles and six primary areas of change to achieve an improved model of care for people with acquired brain injury (ABI) in rural and remote areas. Improvement to the model of care is based on a simple but important proposition: people with ABI should be able to access the services they need regardless of where they live. Culturally appropriate rehabilitation should be available for Aboriginal people with ABI.

Key areas for change to improve the model of care services in remote areas of NSW include:

- Strengthening the Dubbo Brain Injury Rehabilitation Program as a hub for remote communities in the central-west and northern areas of NSW.
- Developing a new program at Broken Hill as a hub for the far west.
- Supporting the expansion of paediatric ABI services to rural and remote areas by appointing paediatric coordinators and improving access to metropolitan specialists.
- Develop a network of BIRP community workers and ABI champions located in the central and western areas of the state, to provide ABI rehabilitation to people living in these remote communities in addition to improving knowledge of ABI rehabilitation.

Brain injury is a big problem right across Australia. Nationally there are around 2,500 new cases of moderate or severe brain injury as a result of trauma each year. In NSW alone there were over 6,000 recorded incidences of traumatic brain injury (TBI) in 2007. The effects can include long term physical and neurological disability and significantly higher risk of premature death. In addition to personal and family devastation, the total cost to the Australian community through direct care and lost productivity has been estimated by Access Economics (2009) at more than \$8.6 billion a year. Almost two thirds of the cost is shouldered by individuals and families either directly or through insurances.

This major ACI project, led by clinicians and drawing on the hands-on knowledge of doctors, nurses, allied health professionals and consumers, offers practical solutions to real problems facing individuals, families and health services, particularly in rural and remote NSW.

We recommend the report as a guide for action around a challenging issue and welcome any suggestions you may have for further improvements.



Dr Hunter Watt  
*Chief Executive, Agency for Clinical Innovation*

# EXECUTIVE SUMMARY

Rehabilitation in NSW for people aged 5-65 years with sudden-onset traumatic (eg motor accidents, falls) or acquired brain injury (eg stroke, tumors) is delivered through a network of 14 specialist services which constitute the NSW Brain Injury Rehabilitation Program (BIRP). The Brain Injury Rehabilitation Directorate (BIRD) is one of 24 clinical networks within the Agency for Clinical Innovation and provides clinician and consumer involvement in the planning and delivery of these services, located both in metropolitan and regional areas of NSW.

Delivery of brain injury rehabilitation to rural and remote areas of NSW by the NSW BIRP at Dubbo, Bathurst and Albury is highly problematic due to distances and available resources. Following a brain injury, a person residing remotely will have difficulties with coordination of services, availability of rehabilitation, access to specialist services and feelings of isolation (Murphy, 2004; Fyffe & McCubbery 1996).

The Rural and Remote Brain Injury Rehabilitation Service Delivery Project was instigated by the ACI BIRD to investigate what was happening in remote areas of NSW, with a focus on central-western and far-western areas. The project sought to identify if inequities existed in service delivery, including the issues for a person with a newly acquired brain injury returning home to live remotely or already living in the community and in need of rehabilitation services, and any additional issues faced by Aboriginal people. From this investigation real solutions, with a framework for models of care to provide access and equity in brain injury rehabilitation services for people living in remote areas of NSW, have been developed.

The approach to this project was focused on broad consultation so that varied experiences ranging from the service delivery perspective to the personal lived experience could be documented.

The project comprised two key phases:

**Phase 1:** Project planning and consultations.

**Phase 2:** Solution phase – follow-up consultations for validation of issues and draft recommendations, key stakeholders' workshops and final report.

## Key issues

In Phase 1, over 45 consultations occurred with both consumers and service providers. These interviews explored the issues both of the delivery and the experience of brain injury rehabilitation and support in remote areas of NSW. Analysis of these interviews identified a number of issues, summarised within five main themes:

- Living remotely from a brain injury rehabilitation program (BIRP) will limit access to specialised ABI rehabilitation at the level of intensity and type required, including staff and services with expertise about ABI. Transport issues and adequate support for families of the person with the ABI create additional barriers.
- Aboriginal people have specific additional cultural needs and issues related to kinship, gender and shame. The development of trust and engagement with an Aboriginal community is difficult when practitioners within the rural BIRP are not based within that town/community.
- Some areas do not receive a specialist ABI rehabilitation service, or the BIRP service provided is limited due to distance and workforce. Paediatric brain injury rehabilitation services are primarily located in metropolitan NSW with limited specialist support in rural and remote NSW.
- Variation in skills, knowledge and the numbers of staff within rural BIRPs have an impact on the provision of brain injury rehabilitation in remote areas. The limited skills, knowledge of ABI and availability of staff within non-brain injury organisations have a further impact on a lack of service equity in rural and remote NSW.
- People who live in remote areas of NSW typically 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.



## Project processes

Follow-up consultations and key stakeholder workshops were utilised in the development of recommendations arising from the issues and strategies for action. Population data, TBI hospital incidence data (Tate, Cameron, Mathers, Rosenkoetter & Genders, 2010), prevalence data and remote resource data assisted in developing the specific strategies for the final recommendations and the underlying principles of the model of care.

## Principles of the project

The principles of the model of care that underpin the recommendations are:

1. That people with ABI in NSW should be able to access the essential services they need whether they are living in urban, rural or remote areas.
2. That the NSW BIRP is committed to providing rehabilitation service delivery across all of NSW.
3. That culturally appropriate rehabilitation for Aboriginal people should be embedded in all services provided by the NSW BIRP.
4. That families are integral to the process of rehabilitation service delivery.

## Recommendations of the project

With these principles central to the recommendations for the project, the following priorities for enhancing the current NSW BIRP model of care are essential:

1. Strengthen the Dubbo BIRP so it can operate as a hub for the central-western and northern areas of NSW. This is essential for making the strategies below feasible and effective.
2. 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 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.
3. Support the expansion of paediatric ABI services to rural and remote NSW by appointing paediatric coordinators and improving access to metropolitan paediatric medical specialists and clinicians in BIRP services. This will ensure that essential ABI rehabilitation services are available to children returning to live in rural and remote areas of NSW following ABI, as well as their families.
4. Develop a brain injury rehabilitation program at Broken Hill so it can operate as a hub for far-western areas of NSW.
5. Fund an implementation project officer position at BIRD for a minimum of three years to develop and manage the action plan arising from project recommendations to achieve the identified model of care priorities.
6. Fund a statewide position at BIRD to identify and support education and training activities for BIRP staff and enhance community ABI knowledge and understanding within rural and remote communities.

How best to utilise the report as a blueprint for future planning and service developments and the feasibility and costs of specific recommendations, remains to be determined through consultation between the ACI, Ministry of Health and local health districts.

# CONTENTS

|   |    |
|---|----|
| Chapter 1: Acquired brain injury and rehabilitation in rural and remote NSW .....                                 | 3  |
| Current health service models in rural and remote Australia .....   | 5  |
| Development of the brain injury rehabilitation program for people with traumatic brain injury in NSW .....        | 6  |
| The additional issues faced by Aboriginal people .....  | 11 |
| Current pathways for people with severe traumatic brain injury in NSW .....                                       | 11 |
| <br>  |    |
| Chapter 2: Project methodology .....  | 12 |
| The project .....   | 12 |
| Phase 1: Consultation interviews and analysis .....   | 13 |
| Phase 2: The solution phase .....   | 16 |
| <br>  |    |
| Chapter 3: Consultations .....  | 17 |
| Consumers involved in consultation .....  | 18 |
| Services involved in consultation .....   | 18 |
| 3.1 NSW Brain Injury Rehabilitation Programs .....  | 18 |
| 3.2 Government-provided services .....  | 19 |
| 3.3 Non Government Organisations .....  | 22 |
| <br>  |    |
| Chapter 4: Issues emerging .....  | 23 |
| 4.1 Specialist brain injury services .....  | 23 |
| 4.2 Other health and community services .....   | 26 |
| 4.3 People with ABI and their families .....  | 32 |
| <br>  |    |
| Chapter 5: Themes and preliminary recommendations .....   | 35 |
| 5.1 The unmet needs of people with brain injury and their families living in remote areas .....                   | 35 |
| 5.2 Additional issues faced by Aboriginal people following ABI living in remote areas .....                       | 37 |
| 5.3 Access & provision of rural brain injury rehabilitation for people following ABI living in remote areas ..... | 39 |
| 5.4 Workforce issues .....  | 40 |
| 5.5 Community understanding of brain injury .....   | 40 |
| <br>  |    |
| Chapter 6: The planning context .....   | 42 |
| Population data .....   | 42 |
| Prevalence rates according to population data .....   | 42 |
| TBI incidence data 2007 .....   | 43 |
| Remoteness .....  | 44 |
| Aboriginal Medical Services/Aboriginal Community Controlled Health Service .....                                  | 44 |
| Transport .....   | 44 |

|  |        |
|--|--------|
| Chapter 7: Recommendations: A plan of action .....   | 49     |
| 7.1 The strategic context .....  | 49     |
| 7.2 The principles .....   | 49     |
| 7.3 The broad strategy .....   | 50     |
| 7.4 The specific strategies .....  | 51     |
| 7.5 The operational details .....  | 51     |
| 7.5.1 Dubbo Brain Injury Rehabilitation Program (BIRP) – Greater Western Area Health Service ..... | 51     |
| 7.5.2 Broken Hill BIRP – Greater Western Area Health Service .....                                 | 55     |
| 7.5.3 Mid Western BIRP (Bathurst) – Greater Western Area Health Service .....                      | 57     |
| 7.5.4 South West BIRP (Albury) – Greater Southern Area Health Service.....                         | 58     |
| 7.5.5 Paediatric brain injury rehabilitation services in remote areas .....                        | 60     |
| 7.5.6 Brain Injury Rehabilitation Directorate (BIRD) .....   | 62     |
| <br>Appendices .....   | <br>65 |
| Appendix 1: ICD – 10 AM Codes for 2007 hospital admissions in NSW* .....                           | 66     |
| Appendix 2: Rural Rehabilitation Research on Brain Injury (RRR-BI) .....                           | 67     |
| Appendix 3: Steering committee membership .....  | 68     |
| Appendix 4: Service providers’ information sheet .....   | 69     |
| Appendix 5: Consent form – service providers .....   | 71     |
| Appendix 6: Consumer participants – information sheet .....  | 72     |
| Appendix 7: Consent form – consumer participants .....   | 74     |
| Appendix 8: Interview format – rural BIRP clinicians .....   | 75     |
| Appendix 9: Interview format - service providers .....   | 76     |
| Appendix 10: Interview format – family members .....   | 77     |
| Appendix 11: Interview format – consumers .....  | 78     |
| Appendix 12: Participant organisations – key stakeholders workshops .....                          | 79     |
| Appendix 13: Consumer participants .....   | 80     |
| Appendix 14: Service consultations .....   | 81     |
| Appendix 15: Fly-in professional team proposal .....   | 83     |
| <br>Acronyms list .....  | <br>85 |
| <br>Reference list .....   | <br>86 |



# CHAPTER 1: ACQUIRED BRAIN INJURY AND REHABILITATION IN RURAL AND REMOTE NSW

## Background data

In 2006 around 38,000 NSW residents lived in remote or very remote areas of the state, just under a quarter of whom were Aboriginal. Aboriginal people comprise approximately 3.2% of the population in central-western NSW, compared to 2% in the total NSW population (Andrews, Simmons, Long & Wilson, 2002). The far-western area of NSW, with 13% of the population being Aboriginal, has been classified as entirely remote and rated as having the highest level of socioeconomic disadvantage in Australia (Perkins, Roberts, Sanders & Rosen, 2006).

In Australia, health outcomes have been shown to become worse as remoteness increases (Phillips, 2009). Compared to people living in major cities, people who live in remote and very remote areas have a lower life expectancy, are more likely to die prematurely and are more likely to die in a motor vehicle accident (NSW Department of Health, 2008).

Data from the 2006 census notes that within central and far-western areas of NSW the incidence of disability in people under the age of 65 was higher in the Aboriginal community than in the total regional population (3.9% compared to 2.5%) [National Disability Services, 2010]. Organic brain impairment has been reported at seven times the prevalence in the Aboriginal population than the non-Aboriginal population (Human Rights and Equal Opportunities Commission [HREOC], 1993).

Hospital data describing rates of hospitalisations for head injury due to assaults in Queensland, Western Australia, South Australia and the Northern Territory for a six-year period show a disproportionately high representation of Aboriginal people. While the rate of head injury due to assault was 60.4 per 100,000 population overall, the rate among Aboriginal populations was 854.8 per 100,000 – 21 times higher (Jamieson, Harrison and Berry, 2008). Although this study excludes NSW data, it raises concerns regarding possible prevalence rates in this state of high numbers of

Aboriginal people and the burden of impact of injuries due to assault.

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 (Brain Injury Association of NSW, 2008). Prevalence rates across Australia inform that 77,800 people with an ABI under age 65 resided within NSW (Australian Institute of Health and Welfare, 2007). Data, obtained from South Australia Health, of hospital admissions with ABI codes and a NSW postcode inform that in the 23 months from January 2006 to December 2007 39 patients were admitted to SA hospitals with a remote NSW postcode and stayed for more than seven days. Thirty of these patients had a Broken Hill postcode (data extracted from South Australia Health Information Portal, 2009).

Hospital data pertaining to all ABIs within NSW is difficult to obtain. In 2007 a NSW incidence data study recorded a total of 6,850 people admitted to NSW hospitals with traumatic brain injury (TBI), and 6,886 incidences of TBI (Tate, Cameron, Mathers, Rosenkoetter & Genders, 2010). Refer to Appendix 1 for ICD codes. Of all TBI incidences, 3.8% were recorded as Indigenous (n=261) and the remainder (n= 6625) were either not stated [n=180 (2.6%)] or not of Aboriginal or Torres Strait Islander origin [n = 6445 (93.6)].

Of the 6,886 incidences recorded in NSW hospitals, 4,835 were males (70%) and 2,051 (30%) females. Over 5,000 of the total admissions were aged 0 – 64 (Table 1.1). Altogether, 36 people had two head injuries in 2007, one of these from the Aboriginal but not Torres Strait Islander origin group.

A total of 897 (13%) had an admission of more than one week, with 5% of this group identified as being Indigenous (Table 1.2).

**Table 1.1 2007 TBI Incidence data, NSW**

|            | INDIGENOUS n=261* | NON-INDIGENOUS OR NOT STATED n=6625** | TOTAL      |
|------------|-------------------|---------------------------------------|------------|
| Male       | 194               | 4641                                  | 4835 (70%) |
| Female     | 67                | 1984                                  | 2051 (30%) |
| 0-14yrs    | 57                | 930                                   | 987        |
| 15-19yrs   | 37                | 693                                   | 730        |
| 20-64yrs   | 161               | 3146                                  | 3307       |
| Over 65yrs | 6                 | 1856                                  | 1862       |

*Incidence of TBI in NSW hospitals = 6,886*

*Total number of people admitted to a NSW hospital with TBI in 2007 = 6,850*

*\*260 Indigenous people had one TBI in 2007 and one person had two TBIs*

*\*\*6,850 non-Indigenous/not stated people had one TBI in 2007 and 36 people had two TBIs.*

**Table 1.2 2007 TBI incidence data, NSW – length of hospital stay**

| LENGTH OF STAY     | INDIGENOUS n=261* | NON-INDIGENOUS OR NOT STATED n=6,625** | TOTAL |
|--------------------|-------------------|--|-------|
| Less than one week | 218               | 5,771                                  | 5,989 |
| One week or more   | 43                | 854                                    | 897   |
| 1-2 weeks          | 23                | 458                                    | 481   |
| 2-4 weeks          | 9                 | 222                                    | 231   |
| More than 4 weeks  | 11                | 174                                    | 185   |

### **Living in rural and remote areas following ABI**

Social and emotional issues encountered while 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, and travel and financial difficulties linking in with specialised ABI services (Fyffe & McCubbery, 1996; Sample and Darragh, 1998). A person's rural and remote status can influence decision-making around referral to rehabilitation and can influence a person's length of stay in acute rehabilitation (Foster, Fleming, Tilse & Rosenman, 2000). Differences in health care status of people from rural and urban centres following TBI can also be due to economic and geographic factors such as funds availability for maintenance programs and availability of specialist services (Murphy, 2004; Sample & Darragh, 1998; Schootman & Fuortes, 1999). This lack of availability and access to services is concerning given research has shown that individuals who receive interdisciplinary services from

initial injury to rehabilitation are re-integrated into the community more successfully (Murphy, 2004).

American studies have discussed the positive aspects associated with living in rural communities following an ABI, such as greater social supports, openness to seeking social support and greater community acceptance (Farmer, Clark & Sherman, 2003; Johnston, Nossaman, Schopp, Holmquist & Rupright, 2002). This was supported in Kuipers et al. (2001) study examining the needs of a sample of rural Queenslanders who had sustained serious disabilities, with participants reporting high levels of social assistance from neighbours and considerable support from the community. A contrasting view from participants in a rural TBI participation study was a fear of disclosing their ABI within their rural community due to stigma, which limited their social support. Some participants in this study chose not to return to their communities (Curtin et al., 2008). A lack of support from members of their own community can be experienced by people from rural areas, possibly due

to a lack of understanding of brain injury (Huntly and Perlez, 2008).

An Australian study has compared outcomes of rural and urban NSW residents following a severe TBI (Harradine et al., 2004). The participants numbered 198, with 147 from urban areas and 51 from rural. Measures of disability, impairments, quality of life, emotional functioning and vocational outcomes were completed at rehabilitation admission and at an 18-month follow-up. The results of this study include a difference in the type of rehabilitation setting, with 53% of rural patients (27) treated in a non-inpatient setting compared with 33% of 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 (British Society Rehabilitation Medicine, 2003). Although sample size was an issue, similar rehabilitation outcomes were noted between the two groups. This finding contrasts with the Schootman and Fuortes (1999) study; however comparison may be difficult due to the higher numbers in this American study of people with mild brain injury, and the difference in the coordination of the rehabilitation programs between the two cohort populations.

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 included time spent away from home during rehabilitation, appropriate accommodation and services in the community, and support for carers (Harradine et al., 2004). Key issues identified in the provision of rehabilitation services and resources were that health professionals are required to manage a number of people with ABI over vast distances, placing a large strain on the rural BIRP program and limiting the assistance available to rural health practitioners (Harradine et al., 2004).

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 (Gething, 1996). 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 on 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.

As well as the cultural importance given to family and families' involvement in rehabilitation, other factors that prevent equitable access to rehabilitation for Aboriginal people with ABI include a low expectation of assistance from services, and stereotypes that exist among some non-Aboriginal service workers that Aboriginal communities don't want assistance and that Aboriginal people are unmotivated towards rehabilitation (Kendall and Marshall, 2004).

## Current health service models in rural and remote Australia

The availability and use of many health services and programs decrease as rurality increases (Humphreys, 2002). For residents of small rural or remote communities, primary health care is the first point of contact within the health system, and they are then usually required to travel to larger centres for more secondary and tertiary health care, such as accessing a specialist medical provider or rehabilitation (Humphreys, 2002; Humphreys, 2009). Models within primary health care for rural and remote communities include discrete services, integrated services, comprehensive services, and outreach and virtual outreach services (Wakerman et al., 2006). Discrete services refer to primary care services delivered from an identifiable site within the community with a goal of sustaining a general practitioner service. In comparison, integrated services involve the integration of primary health care sites located within the community, such as general practice with multidisciplinary primary health care teams. Outreach models include the delivery of services from one location to another location which doesn't have services. Outreach services are usually delivered via a 'hub and spoke' model, where services are rotated through a central hub to target areas/locations (spokes). Embedded in the outreach model is the use of technology to provide an outreach service known as virtual outreach (Wakerman et al., 2006).

### **Delivery of disability and rehabilitation services to rural and remote areas**

Rural disadvantage extends beyond health to areas of injury and disability. People with disabilities in rural areas

experience significantly more social problems than their urban counterparts but have access to fewer resources, including rehabilitation services (Kuipers, Kendall and Hancock, 2001; Humphreys, Hegney, Lipscombe & Gregory, 2002). Specialist rehabilitation, such as for TBI, is centralised in large regional and metropolitan centres (Brownlea and McDonald, 1981, cited in O'Callaghan, McAllister and Wilson, 2009).

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 isolation and economic impact of this on families, and dislocation from their community (Queensland Health 2000, cited in Pashen, Grant, Veitch, Sheehan & Chalmers, 2002; Kuipers et al., 2001). Existing models of service delivery for rehabilitation to rural and remote areas include those discussed by Wakerman et al. (2006), such as specialised outreach services (including the 'hub and spoke' model), fly in-fly out services and telehealth. Further to these is the community-based rehabilitation model.

Outreach and visiting services are the most common forms of service provision in rural Australia. The 'hub and spoke' model was recommended as the most feasible model for distribution of rehabilitation services in rural and remote areas at a meeting of the Australasian Faculty of Rehabilitation Medicine in 2006 (Graham & Cameron, 2009). This model advocates the development of large metropolitan centres (hubs) providing support to smaller rural and remote centres. A further development on this is the recommendation that centres in rural and remote regions develop special interests in relevant areas such as Aboriginal issues, vocational rehabilitation and community-based rehabilitation. This will ensure that the provision of support and expertise is multi-directional and that clinical networks develop beyond the 'hub and spoke' model to a more flexible model (Graham & Cameron, 2009). A criticism of the outreach model is that it is susceptible to high staff turnover, staff burnout and inadequate rapport between outreach service providers and consumers (Humphreys, Matthews & Rolley, 1996, cited in Kuipers et al., 2001). Ineffective communication between specialist and community services, and not addressing the interface between community and disability, are further challenges for this model of delivery (Kuipers et al., 2001).

The use of telehealth has been identified as a cost-effective and time-efficient strategy for rehabilitation service delivery within rural and remote areas, in particular within the ABI population (Murphy, 2004; Johnstone et al., 2002). This includes the delivery of services via phone,

videoconferencing or computer directly into the home or at a community-based facility.

The emerging model of rehabilitation for rural and remote areas in Australia – that of community-based rehabilitation – provides an approach whereby service delivery is integrated within the community structure.

Community-based rehabilitation (CBR), according to Kuipers et al. (2001), places emphasis on developing partnerships and promoting community participation, supporting initiatives taken by people with disabilities, their families and communities, and maximising existing formal and informal services. Rehabilitation is implemented through the combined efforts of people with disabilities, their families and communities, and the appropriate formal services (Kendall, Buys & Lerner 2000). Concerns exist about the implementation of a CBR model within rural and remote areas of Australia due to geographical barriers, low population densities, limited numbers of trained rehabilitation professionals, especially with community development knowledge, and the handing over of responsibilities to vulnerable and overstretched individuals, families and communities. For these reasons it has been suggested that is unreasonable to base a CBR model in rural and remote Australia based on volunteerism (Bonner et al., 2009).

Based on a project completed within NSW which sought to identify and recommend optimal approaches for CBR in rural and remote areas of NSW, Bonner et al. (2009) suggested a 'network of community-based rehabilitation coalitions', designed to embrace new and existing services and programs associated with rehabilitation in the home. The core components of a CBR coalition are the individual and their family/supports, health care professionals, community rehabilitation facilitator, community rehabilitation database and community rehabilitation assistants.

## Development of a brain injury rehabilitation program for people with TBI in NSW

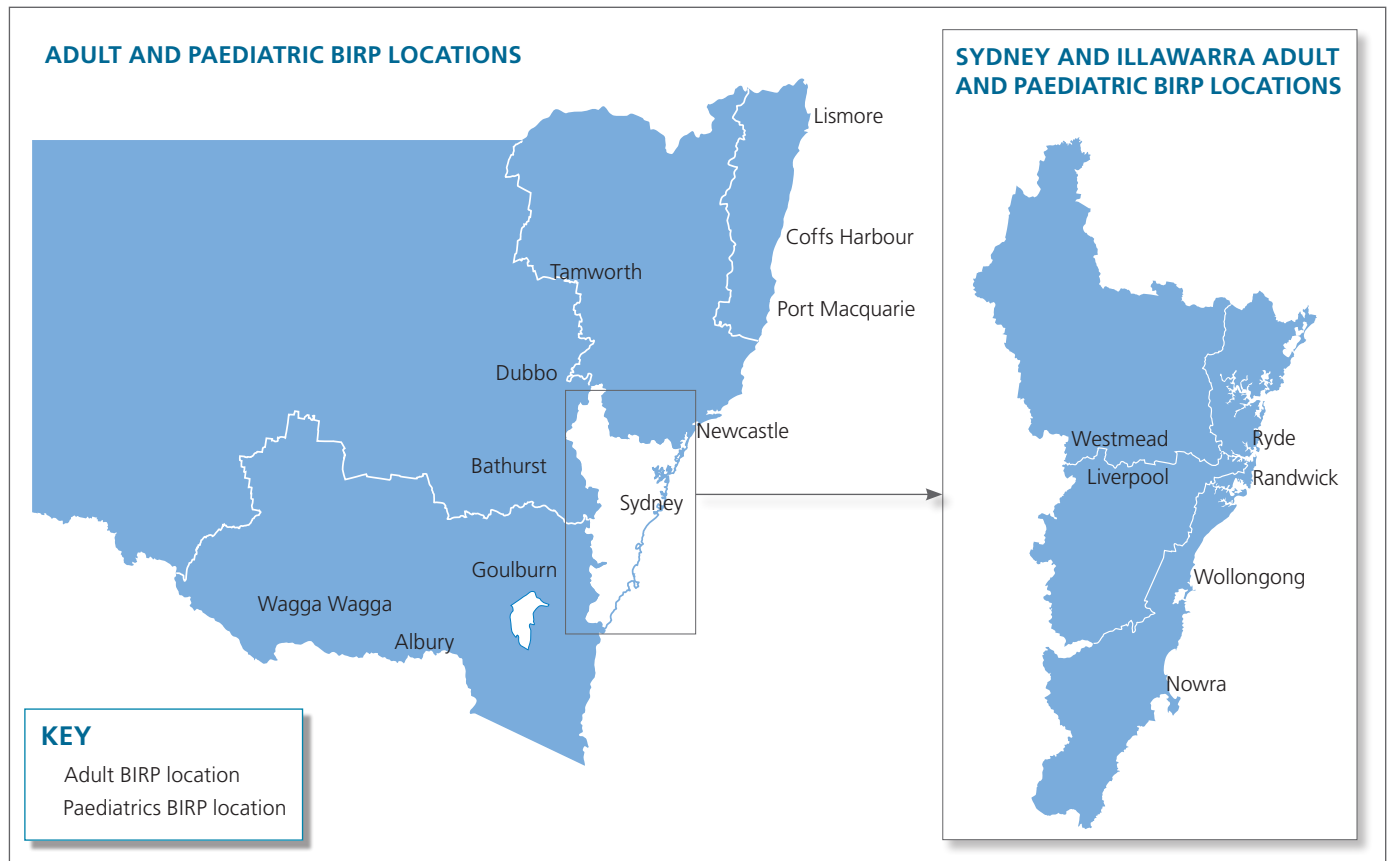
The NSW Brain Injury Rehabilitation Program (BIRP) was established in the early 1990s as a joint initiative between NSW Health and the Motor Accidents Authority to provide a comprehensive state-wide network of specialist multi-disciplinary inpatient and community-based brain injury rehabilitation services. All people aged up to 65 who sustain a TBI are able to

access the program, with no barriers related to cost or compensation status. In practice, the great majority of people who access the program have severe to extremely severe injuries, and few people with mild or moderate injuries are seen. The network comprises 14 services – 11 adult units and three paediatric units. Location of the BIRPs is shown in Map 1.1.

Eight services are located in the metropolitan areas of

Sydney, Newcastle and Wollongong (Table 1.3). The remaining six services are based in regional NSW (Table 1.4). In the late 1990s an initial capital investment was provided by the NSW Government Insurance Office (GIO) in partnership with NSW Health to provide structural, physical and staffing resources (Cuff Consultants 1987). Recurrent funding was organised by NSW Health, providing block funding to each Area Health Service with

**Map 1.1 NSW Brain Injury Rehabilitation Program locations**



**Table 1.3 Structure of the metropolitan BIRPs**

| METROPOLITAN BIRP               | INPATIENT | TRANSITIONAL | COMMUNITY | PAEDIATRIC |
|---------------------------------|-----------|--------------|-----------|------------|
| Children’s Hospital at Westmead | –         | –            | –         | Yes        |
| Hunter                          | No        | Yes          | Yes       | –          |
| Illawarra                       | No        | No           | Yes       | Yes        |
| Kaleidoscope PBIRT, Newcastle   | –         | –            | –         | –          |
| Liverpool                       | Yes       | Yes          | Yes       | –          |
| RRCS Ryde                       | Yes       | Yes*         | Yes       | –          |
| Sydney Children’s Hospital      | –         | –            | –         | Yes        |
| Westmead                        | Yes       | Yes          | Yes       | –          |



**Table 1.4 Structure of NSW rural BIRPs**

| RURAL BIRP   | 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

a partial self-funding model on a fee for service basis.

The primary objective of the NSW BIRP is to provide rehabilitation services from as early as possible after brain injury, and address the cognitive, behavioural, physical (including communication) and psychosocial needs of people after TBI. Characteristics of these rehabilitation services have been described as:

- goal-directed
- person-focused
- providing rehabilitation in the least restrictive environment
- having a commitment to community integration
- using a case management process to coordinate the rehabilitation program.

In 2002, NSW Health commenced funding for specialty network managers to provide clinician and consumer involvement in governance, coordination and development of specialty health services. These specialty network managers promote clinician and consumer engagement to improve clinical services across NSW (Agency for Clinical Innovation, 2010). The Brain Injury Rehabilitation Directorate (BIRD) has permanent staff and project staff to provide these services for the

network of 14 brain injury rehabilitation units.

The coordinating agency for the 24 clinical networks is the Agency for Clinical Innovation, which is board-governed and reports directly to the Director-General of NSW Health and the NSW Minister for Health.

### NSW BIRP

Within NSW, brain injury rehabilitation for people with a severe TBI and under 65 years primarily occurs in the NSW BIRP. Severity of injury for the purposes of BIRP admission is primarily measured by the duration of post traumatic amnesia (PTA) or assessment of the injury and resulting impairments. Generally people with acquired brain injury from other causes will only be admitted based on assessed need, complexity and availability of resources.

In 2007 there were a total of 1169 new admissions to the NSW BIRP. Of these new admissions, 4.8% of patients were Indigenous (Table 1.5), which is comparable to the 3.8% in the TBI 2007 incidence data (Tate, Cameron, Mathers, Rosenkoetter & Genders, 2010). Table 1.6 refers to injury type and cause, with the majority due to motor vehicle accidents.

**Table 1.5 BIRP 2007 clinical data – admissions by sex and indigenous status**

| GENDER     | INDIGENOUS n=56 | NON-INDIGENOUS OR NOT STATED n=1113 | TOTAL n=1169 |
|------------|-----------------|-------------------------------------|--------------|
| Male       | 46              | 778                                 | 824          |
| Female     | 10              | 264                                 | 274          |
| Not stated | –               | –                                   | 71           |



**Table 1.6 BIRP 2007 clinical data – injury by cause and type**

| CATEGORY   | CAUSE                         | NUMBER    | TOTAL |
|------------|-------------------------------|-----------|-------|
| TBI        | MVA-related                   | 451 (46%) | 982   |
|            | Fall (other than sport)       | 215 (22%) |       |
|            | Assault/non-accidental injury | 171 (17%) |       |
|            | Sport/leisure-related         | 58        |       |
|            | Other TBI                     | 51        |       |
|            | Pedal cyclist/pushbike        | 32        |       |
|            | Gunshot                       | 4         |       |
| Non-TBI    | Hypoxia/stroke                | 122       | 180   |
|            | Other non TBI                 | 58        |       |
| Not Stated | –                             | –         | 7     |

### Services within NSW BIRP

The three Sydney metropolitan brain injury rehabilitation units provide adult inpatient rehabilitation services for the state as well as transitional and community services for defined geographical areas. If residing rurally, a person with severe to extremely severe brain injury may complete the inpatient rehabilitation program within one of these three metropolitan units and then be referred to their rural BIRP and/or local hospital. These metropolitan units are purpose built and located in the more traditional hospital environment with dedicated and expert staff. The focus of rehabilitation intervention is improving body function, reducing activity limitations and facilitating social recovery.

### Transitional living units/programs (TLU/TLP)

The aim of a transitional living program is to give an individual with ABI the experience of living in shared accommodation within the community to which they wish to return (Ponsford, 1995). The emphasis is on functional skills to make the transition to community living (Boake, 1990). Simpson et al., (2004) reported an evaluation of one Sydney metropolitan TLU in the NSW BIRP that included a description of the individual and group therapy programs and efficacy of standardised TBI-specific outcome measures. Key features of the program included an emphasis on social participation both within the TLU and broader community, as well as developing functional skills and enhancing executive functioning for goal-directive activities. Results of outcome measures showed that the majority of residents made gains during their

participation in the residential program or attendance at the TLP.

BIRD completed a two-stage research project to describe the TLP service model operating across NSW, and to implement clinically relevant standardised outcome measures. The TLP Stage One Evaluation report (Hopman, 2006) identified differences in how the eight TLPs operate and staff resources for achieving rehabilitation outcomes (refer to Table 1.7)

The delivery of rehabilitation in the community in conjunction with a TLP is the recognised model of care for service delivery for four of the six rural BIRPs. For those who live more remotely, a centre-based program within a TLP may not be possible or appropriate due to the lack of availability of the TLP, family or cultural issues and transport barriers related to distance from home, or poor understanding of the benefit of an admission. People who live in Dubbo and surrounding areas have no centre-based residential TLP option, with the closest TLP located at Bathurst. This means that the services from the Dubbo BIRP are provided in the community.

Participation in a residentially based TLP is a choice for the client and their family. Barriers to admission can include travelling distance and operating hours. The majority of clients will be referred to their local community BIRP team when discharge is being planned to continue rehabilitation and manage community integration.

All BIRP programs offer community rehabilitation, incorporating case management principles to assist people following ABI to identify goals and develop

**Table 1.7 Transitional Living Programs (TLP) within the Brain Injury Program NSW**

| TLP           | CORE STAFF  | OPERATING HOURS           |
|---------------|---|---------------------------|
| Hunter        | Residential care workers (RCWs)   | 5 days                    |
| Liverpool     | RCWs, 0.5 manager, 1 FTE OT<br>P/T physio, SW, rehab specialist, neuropsych, recreation officer | 5 days                    |
| RRCS at Ryde* | P/T OT and rehab assistant  | 7 days                    |
| Westmead      | 0.5 Manager, RCW  | 5 days                    |
| Albury        | 0.2 Manager, RCW  | 5 days                    |
| Bathurst      | Rehabilitation assistants as needed.<br>P/T OT as needed  | As needed, usually 5 days |
| Goulburn      | Manager, RCW  | 4 days                    |
| Tamworth      | RCW   | 5 days**                  |

\*TLP is four beds in a separate wing of the brain injury ward so has full-time nursing staff cover

\*\* Residents need to be able to stay overnight with monitoring from night nurses.

strategies for achieving goals, as well as the broader tasks of service coordination for community re-integration (Mid Western BIRP, 1999). Community rehabilitation services for people with TBI include a holistic approach to assessment and management (Tate, Strettles and Osoteo, 2004) through a combination of regular face-to-face support, individual and group therapy, phone contact and provision of education and support to the person, family and friends. Community rehabilitation within a BIRP has been described as needs-driven, community-based and largely individually focused (Tate, Strettles and Osoteo, 2004). A BIRP community rehabilitation program may be incorporated into a TLP program, follow a TLP program or operate without involvement of the TLP.

The configuration of BIRP community teams varies across the network, with case management being a core activity. Core service delivery also includes community education on brain injury and community development. This includes educating people who have personal contact with brain injury as well as educating service providers who may, or will, provide services to people with brain injury and their family. Community development includes fostering skills within a community to assist in supporting a person with a brain injury, as well as establishing services in a community to meet the re-integration needs of people with brain injury (Mid Western BIRP, 1999).

Paediatric BIRPs are located in three metropolitan areas (Newcastle, Randwick and Westmead) and do not have dedicated inpatient beds in a purpose-built facility. Generally children have a much shorter inpatient stay than adults so the dedicated team of specialist staff works acutely in both inpatient (general rehabilitation or medical beds) and community settings. Following discharge from acute care, therapy in the early stages post-discharge can be quite intensive and involve a high number of BIRP staff.

The Sydney teams provide a range of clinical services post-discharge for children returning to rural areas (rehabilitation specialist clinic assessments with specific allied health services, such as neuropsychology, are not available locally). Metropolitan paediatric services are supported by dedicated paediatric coordinators in four of the six rural BIRPs; Albury is the only rural unit with a paediatric team combining coordination, case management and clinical input.

## The additional issues faced by Aboriginal people

The leading causes of ABI, including motor vehicle accidents, falls, violence and suicide attempts (Keightley et al., 2009), are all evident in Aboriginal communities. Despite this, research into injury rates and intervention in Aboriginal people remains neglected, with few attempts to study brain injury intervention or rehabilitation within Aboriginal populations. The rehabilitation needs of Aboriginal people with an ABI within the Australian health system require further investigation.

The delivery of rehabilitation to Aboriginal people following an ABI has not been addressed nationally. In 2005 the North Coast Brain Injury Service (NCBIS) attempted to identify how many local Aboriginal people with ABI were accessing rehabilitation services and community support services by utilising an Aboriginal Support Worker and completing an extensive consultation with Aboriginal services. Specific issues identified related to how the NCBIS worked with Aboriginal people following brain injury, and the difficulties Aboriginal people experienced attending appointments and engaging with a rehabilitation program even with the use of an Aboriginal Support Worker.

Other issues (housing, financial or legal matters) took a higher priority over rehabilitation goals and acted as barriers to accessing both rehabilitation and support services. Subsequently the NCBIS targeted these issues as part of their service delivery and achieved a significant increase in the rate of referrals and admissions for Aboriginal people, and the development of community networks to solve environmental issues. It also raised the image of the NCBIS within the Aboriginal community (North Coast Brain Injury Service, 2005). In 2006-07, 65 Indigenous people (6%) were admitted to the NSW BIRP (total n=1169) [Brain Injury Rehabilitation Directorate, 2007].

The challenges for service delivery to Aboriginal people identified by the NCBIS project were also identified by the rural brain injury clinicians servicing the central and western areas of NSW (Greater Western Area Health Service, 2005).

Many of these issues reflect the broader issues in Aboriginal health and impediments to Aboriginal people accessing services and receiving services appropriate to their needs (Australian Government, 2007).

## Current pathways for people with severe TBI in NSW

In NSW rural areas, the primary retrieval network is to Level 1 trauma hospitals located in metropolitan Sydney, Newcastle, north to Brisbane, across the border to South Australia (Broken Hill areas) and to Victoria (Murray River areas). The majority of severe TBI clients retrieved to NSW metropolitan hospitals are then admitted to metropolitan BIRPs before returning home either directly or via their local hospital with the involvement of the rural BIRP. People who return to their community from across state borders may return directly home, or if this is not an option because of high care and support needs, they may not return at all or return to their local hospital without the involvement of a rural BIRP.

# CHAPTER 2: PROJECT METHODOLOGY

Inequities in the delivery of brain injury rehabilitation in remote areas of NSW, including the delivery to Aboriginal people following ABI, was initially identified by BIRP clinicians and given priority by the BIRP Directors and Managers to investigate possible action for addressing these issues. Support was obtained from the Hon. Reba Meagher MP, then the NSW Minister for Health, and BIRD, which 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) [Refer to Appendix 2].

The project employed descriptive qualitative research design to investigate brain injury rehabilitation in remote areas of NSW. This included access to services and current service delivery for people aged 5-65 with a severe ABI. It was decided to investigate severe ABI in addition to TBI due to smaller numbers within remote areas.

The project was conducted over three years from 2008 - 2010. Twelve months of MAA funding to RRR-BI supported the literature review, ethics application, formation of the steering committee and initial consultations. The completed literature review will be available on the MAA web site. Two years of ACI funding supported the expansion of project consultations and involvement of key stakeholders, analysis, development of the recommendations and completion of the project report. The initial consultations were included in phase one, the consultation phase of the expanded project. The analysis, development of recommendations and final report formed phase two of the expanded project.

## Steering committee

A steering committee supervising the project commenced meeting in June 2008. It included representation from the BIRD (NSW Agency for Clinical Innovation), RRR-BI and Aboriginal Services. Meetings have occurred monthly via

videoconference and teleconference links. The steering committee has provided expertise and consultancy to the project in the areas of consultation within Aboriginal communities, consultation with BIRP and service workers, methodology development, analysis and development of recommendations.

A list of the members of the steering committee over the life of the project can be found in Appendix 3.

## Ethics

The project concentrated on rural BIRPs and remote areas within what were then known as the Greater Western Area Health Service and Greater Southern Area Health Service, including central-western and far-western areas of NSW. These areas were selected due to their geographical remoteness, and the known scarcity of brain injury services to these areas. It was expected that the recommendations and actions stemming from the project could be transferred to other rural BIRPs servicing remote areas.

Ethics approval was obtained from NSW Health through the Greater Western AHS Lead HREC Committee in December 2008. This included approval for multi-centred research at both Greater Western and Greater Southern AHSs. Approval was also obtained from the Aboriginal Health Medical Research Council ethics committee. Appendices 5 to 11 provide the interview and consent forms required for ethics approval and used in the consultation phase.

## The project

The project was structured into two phases: Phase 1 commenced in January 2009 and continued to completion of consultation interviews and analysis in November 2009. The aim of Phase 1 was to investigate the following:

*Equity of access to brain injury rehabilitation and services for people aged 5 to 65, residing in remote areas following ABI.*

*Do Aboriginal people face different or additional barriers to the access and use of brain injury rehabilitation services in remote areas?*

Phase 2 was the solution phase, using findings from Phase 1 to identify strategies and recommendations for the development of sustainable models of delivery of brain injury rehabilitation in remote areas of NSW, and through to report completion. The steering committee played a vital role in this phase, meeting to discuss and structure identified issues into key themes, (and draft recommendations to address these issues), key stakeholder consultation and the final report.

In April 2010 follow-up consultations commenced with the initial consultative group to validate the identified issues and the draft recommendations for addressing the issues. Follow-up consultation with service providers and key consumers occurred via email and phone contact. A summary of the consultation process within the project is found in Figure 2.1 below.

Feedback from the initial consultative group was included in a document outlining the final themes, issues and draft recommendations. This document was presented and discussed at two key stakeholders' workshops in May 2010. The key stakeholder workshops attracted 25 participants representing nine NSW agencies, with an additional 17 participants from the ACI executive, BIRD and NSW BIRPs. Appendix 12 includes a list of services represented.

## Phase 1: Consultation interviews and analysis

### Definition of remote

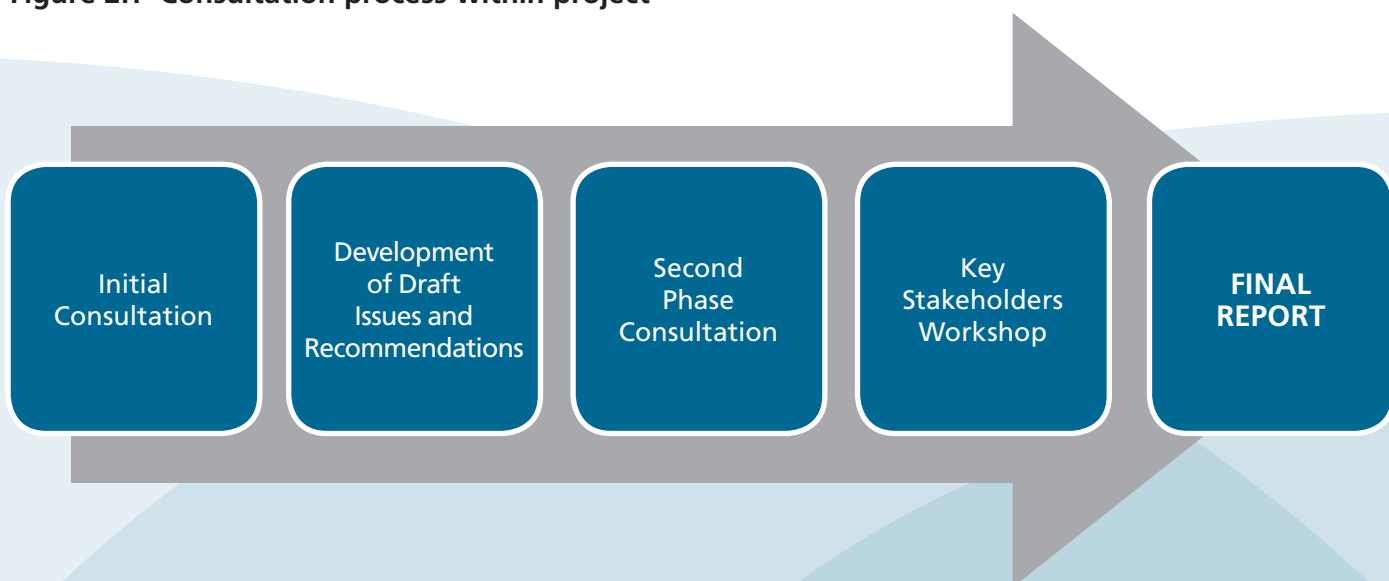
A definition of remoteness was required for this project and determined before the commencement of consultation. Rural brain injury practitioners noted the difficulties in providing a regular and intensive rehabilitation service to people with ABI and their families beyond a distance of two hours from the rural brain injury program. Taking into account this information it was decided to define remote for this project according to distance (travelling time) from a rural brain injury program. The project therefore defined remote as being a distance of at least two hours from a rural brain injury program.

Along with the above definition, remote was further defined according to the Accessibility/Remoteness Index of Australia (ARIA). ARIA is a geographical approach to defining remoteness based on access to road networks. Localities that are most remote have least access to service centres; those that are least remote have most access to service centres (Department Of Health and Aged Care, 2001).

### Participants

Participants for the interviews were drawn from key people within the delivery of brain injury services in remote areas of NSW and concentrated on central and western areas of NSW. They included:

**Figure 2.1 Consultation process within project**



- Practitioners within the brain injury rehabilitation programs in NSW.
- Individuals representing health and community services in rural and remote NSW.
- Practitioners outside the NSW brain injury programs providing services to people with an ABI in remote areas.
- People with a severe brain injury and/or their families residing in remote areas.

Potential participants within health and community services were discussed at steering committee meetings and a participant list generated. These participants were approached by phone or email by the project coordinator, inviting them to be part of the project. Project information, including a participant’s information sheet and consent form, was sent to these potential participants (Appendices 4 and 5). Once informed consent was obtained interview times and venue were arranged.

The BIRPs involved in consultations were approached directly by the project coordinator and group interviews organised.

Contact was made with potential consumer participants through staff within the rural brain injury programs and through service providers, utilising purposeful sampling. Staff sent project information to potential consumer participants (Appendix 6), asking if they would be interested in taking part in a face-to-face or phone interview. Once informed consent was gained (see Appendix 7) the project coordinator made contact to arrange interview times and venues.

Forty-eight interviews occurred within the consultation phase for this project. Eight were group interviews and the remaining were individual 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 included Aboriginal representation. Individual interviews took between 60 and 90 minutes and group interviews 90 to 120 minutes. All interviews were audio-recorded for later transcription.

Chapter 3 outlines the services and consumers involved in consultation.

### Consultation timeline

The consultation phase occurred in blocks representing geographical areas for ease of organisation. Refer to Figure 2.2 for a timeline for consultation. Phone interviews occurred concurrently with consultation blocks.

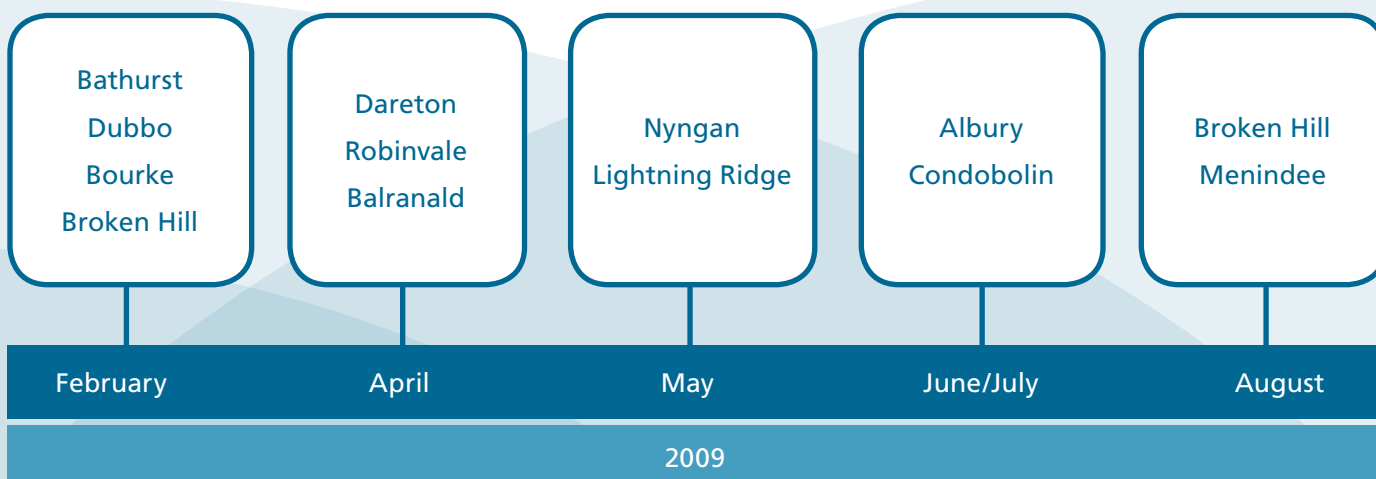
### Areas involved in consultation

Consultation occurred throughout central and western areas of NSW. Table 2.1 identifies the towns and regional centres from Phase 1 of the project and the remoteness rating according to project definition and ARIA.

Using the definition of remote developed in the early project stage, areas determined for consultation were located two hours’ drive from each BIRP location in Albury, Bathurst or Dubbo.

When comparing the BIRP remote definition to ARIA classification, towns that are rated accessible or moderately accessible under ARIA, for example Balranald and Hay, don’t receive a regular service from a rural BIRP and were therefore termed remote under the BIRP definition.

**Figure 2.2 Timeline for consultation**





There were a number of towns classified remote under both ARIA classification and project definition (refer to Table 2.1) such as Condobolin and Walgett, indicating lack of access both to rural BIRP services and general service centres.

### Analysis procedure

After each block of consultations, all interviews were transcribed verbatim and a copy sent back to participants for checking. Following checking, the transcripts were analysed for consistent issues by different members

of the steering committee as well as the project coordinator. This included reading and re-reading of the transcripts, noting issues and then collating into key issues. Each individual transcript and issues emerging within the transcript were then discussed within the steering committee. Individual analysis followed by group (steering committee) analysis occurred after each consultation block and modifications to interview questions and identification of key consultation participants occurred as required.

**Table 2.1 Geographical areas involved in consultation**

| TOWN/<br>REGIONAL<br>CENTRE | PROJECT<br>DEFINITION | NO. OF<br>INTERVIEWS<br>CONDUCTED | ARIA RATING* |                         |  |
|-----------------------------|-----------------------|-----------------------------------|--------------|-------------------------|--|
|                             |                       |                                   | SCORE        | ACCESSIBILITY<br>RATING | DESCRIPTION  |
| Albury                      | –                     | 1 group interview                 | 0.99         | high                    | <b>ARIA Scores = 0-1.84</b><br>Relatively unrestricted accessibility to a wide range of goods and services and opportunities for social interaction. |
| Bathurst                    | –                     | 1 group interview                 | 1.20         | high                    |  |
| Tamworth                    | –                     | 1 group interview                 | 1.71         | high                    |  |
| Dubbo                       | –                     | 4                                 | 2.40         | moderate                | <b>ARIA Scores = 1.84-3.51</b><br>Some restrictions to accessibility of some goods, services and opportunities for social interaction.               |
| Broken Hill                 | remote                | 2                                 | 3.24         | moderate                |  |
| Wentworth                   | remote                | 1                                 | 3.01         | moderate                |  |
| Mildura                     | remote                | 1                                 | 2.48         | moderate                |  |
| Dareton                     | remote                | 6                                 | 2.85         | moderate                |  |
| Balranald                   | remote                | 2                                 | 4.34         | low                     | <b>ARIA Scores = 3.51-15.80</b><br>Significantly restricted accessibility of goods, services and opportunities for social interaction.               |
| Warren                      | remote                | 1                                 | 4.95         | low                     |  |
| Hay                         | remote                | 1                                 | 5.39         | low                     |  |
| Menindee                    | remote                | 1                                 | 5.53         | low                     |  |
| Coonamble                   | remote                | 3                                 | 5.84         | remote                  | <b>ARIA Scores = 5.80-9.08</b><br>Very restricted accessibility to goods, services and opportunities for social interaction.                         |
| Condobolin                  | remote                | 2                                 | 7.69         | remote                  |  |
| Hillston                    | remote                | 2                                 | 5.93         | remote                  |  |
| Nyngan                      | remote                | 5                                 | 6.40         | remote                  |  |
| Walgett                     | remote                | 2                                 | 7.60         | remote                  |  |
| Lightning Ridge             | remote                | 2                                 | 8.71         | remote                  |  |
| Grawin                      | remote                | 1                                 | 9.13         | very remote             |  |
| Bourke                      | remote                | 4                                 | 10.32        | very remote             | <b>ARIA Scores = 0-1.84</b><br>Very little accessibility to goods, services and opportunities for social interaction.                                |

ARIA Rating\* – Accessibility/Remoteness Index of Australia (ARIA) rating

Project Definition# – remote as defined within this project is a distance of at least two hours from a rural BIRP

## Phase 2: The solution phase

This commenced when the collective issues emerging within the analysis were then clustered by the steering committee. Development of five key themes emerged from this clustering of issues. These issues and themes were further structured and defined by the steering committee during a one-day workshop, and draft recommendations developed. Feedback and verification of final issues and themes and draft recommendations occurred during April 2010 via email and phone contact

with the initial consultative group. Feedback regarding the issues was considered and further changes made to the final issue and themes document (refer to Table 2.2)

Feedback from the consultative group pertaining to draft recommendations was incorporated into a final recommendations document presented and discussed at two key stakeholders meetings in May 2010. These key stakeholder meetings provided valuable feedback for additional information to include in the report and for structuring the recommendations. The report completes the solution phase.

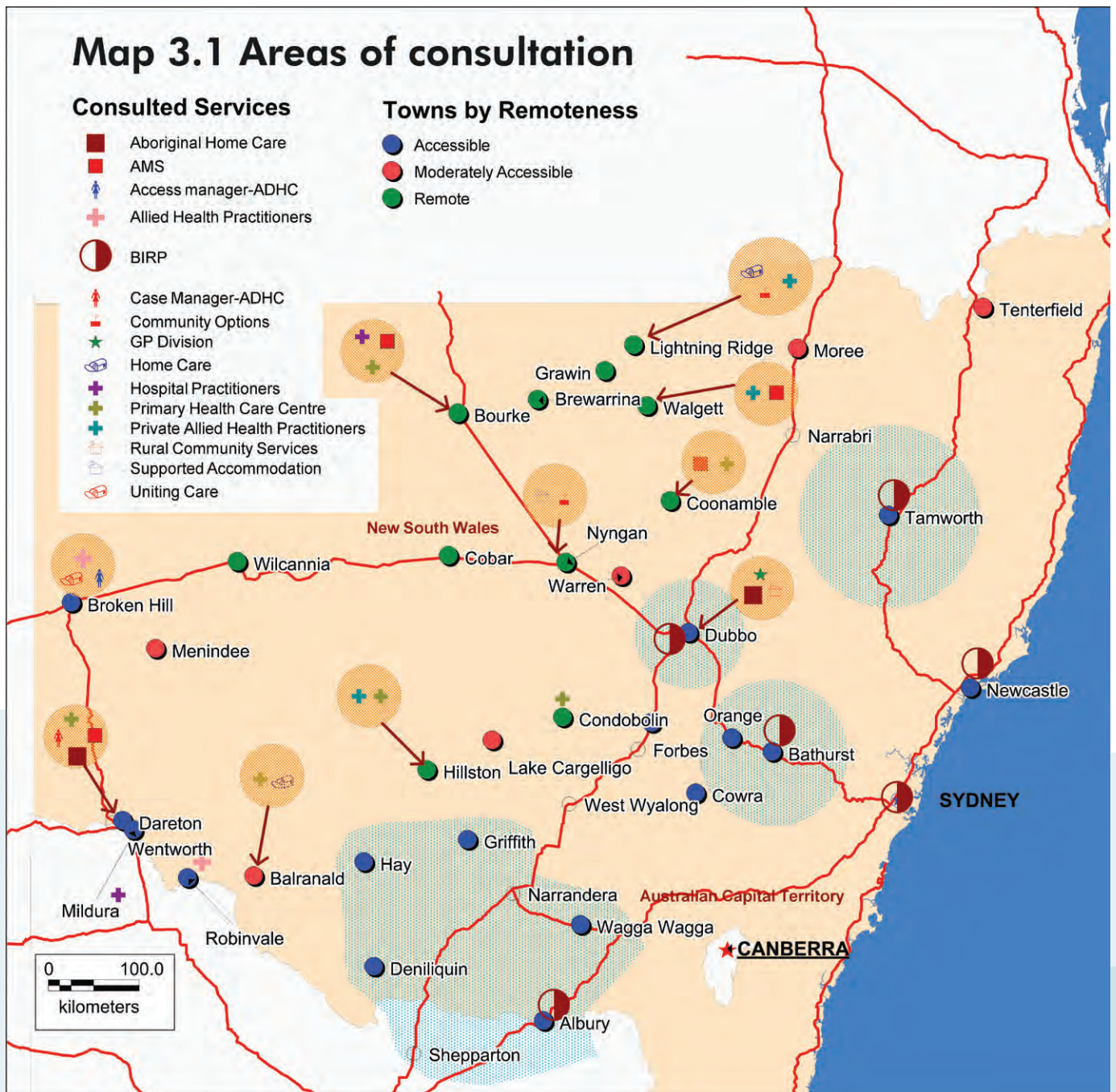
**Table 2.2 Theme development**

|                              |   |   |  |  |   |  |
|------------------------------|---|---|--|--|---|--|
| <b>KEY ISSUES IDENTIFIED</b> | Limited availability of rehabilitation, respite, leisure, transport, psychology, – and allied health. | Identification of brain injury within Aboriginal population. The impact of cultural issues on rehabilitation. | Delivery of rehabilitation within BIRP. Workforce differences within the rural BIRPs.                      | Issues within services:- workforce, use of rural BIRPs, expertise for ABI. | Understanding and responding to brain injury in general community. Knowledge of role of rehabilitation. | Environmental issues.*<br>Includes wheelchair accessible infrastructure within remote towns. |
| <b>CLUSTERING OF ISSUES</b>  | Needs of the person with the brain injury and their families.   | Specific Aboriginal issues.   | Service issues within BIRP.  | Workforce issues.  | Knowledge of brain injury in general community.   |  |
| <b>THEMES</b>                | The unmet needs of people with brain injury and their families living in remote areas.                | Additional issues faced by Aboriginal people following ABI living in remote areas.                            | Access and provision of rural brain injury rehabilitation for people following ABI living in remote areas. | Workforce issues.  | Community understanding of brain injury.  |  |

*\*Wheelchair access for people with disabilities to buildings in remote towns and wheelchair-accessible transport in remote towns is not within the scope of this project. As no other environmental issues emerged during additional analysis, this theme was not pursued although is noted within 4.3 People with ABI and their families.*

# CHAPTER 3: CONSULTATIONS

Over 45 consultations were completed as part of the project. This chapter will provide a summary of the consumers and services involved.



## Consumers involved in consultation

A table summarising the consumer participants is presented in Appendix 13, with pseudonyms used to protect the identity of the participants.

Thirteen consumer participants were involved in the consultation phase of this project. Six were individuals who had sustained an ABI and the other seven were family members of a person with an ABI and in a carer role.

Two of the carer participants were mothers of participants with a brain injury; the remaining consumer participants had no relationship to each other.

Three of these consumer participants identified themselves as Aboriginal. Within these consumer consultations, the following geographical areas were represented: the central, central-west, north-west, western and far-western areas of NSW.

## Services involved in consultation

Refer to appendix 14 for summarised details.

Over 30 services were involved in consultation for this project representing NSW BIRPs (rural and metropolitan), Ageing, Disability and Home Care (ADHC) services, services funded by NSW Health, Commonwealth-funded and non-government services. The central, central-west, north-west, western areas and far west areas of NSW are represented by these services. This chapter will describe the services involved in consultation.

### 3.1 NSW brain injury rehabilitation programs

Service consultations included the rural BIRP programs located at Albury, Dubbo and Bathurst for adult services and Albury and Tamworth for paediatric services.

Map 3.1 indicates these rural BIRP locations with shaded areas identifying current service capacity for intensive rehabilitation input. The three metropolitan paediatric units (Randwick, Westmead and Newcastle) were consulted with specific reference to community resettlement in rural areas.

#### **Mid Western Brain Injury Rehabilitation Program (MWBIRP)**

Located in Bathurst, MWBIRP is one of six rural brain injury programs within BIRD, providing community transitional rehabilitation and case management services for people aged 5-65 following ABI, with clinical priority afforded to TBI. Refer to Map 3.1 for current geographical service distribution.

A total of 6.9 full-time equivalent (FTE) staff are located at the MWBIRP, with clinical input including occupational therapy, a shared manager/social work position, clinical psychologist and speech therapy. The paediatric coordinator position is currently only a 0.5 part-time position. A Transitional Living Unit (TLU) is located in the Bathurst community for clients to undertake independent living programs. Due to resource limitations, use of the TLU is restricted to people who are independent overnight. (Refer to Appendix 14 for summary.)

[http://www.health.nsw.gov.au/initiatives/birp/services\\_midwesternbirp.asp](http://www.health.nsw.gov.au/initiatives/birp/services_midwesternbirp.asp)

#### **South West Brain Injury Rehabilitation Service (SWBIRS)**

Located within the community in Albury and with an office in Wagga, SWBIRS provides community transitional rehabilitation and case management services for people aged 5-65 following ABI, with clinical priority afforded to TBI. Refer to Map 3.1 for geographical service distribution.

A total of 16.5 FTE staff are located within this program, providing both adult and children's services. Service delivery includes centre-based TLP, community rehabilitation and case management service. Staff use flights coordinated by the Royal Flying Doctor Service (RFDS) on a monthly basis to access more remote areas.

Clinical input within the adult program includes living skill educators, physiotherapy, neuropsychology, occupational therapy, speech therapy and rehabilitation coordinators. The TLP has permanent staffing attached to its unit and is operational all year except during the Christmas closure period. The TLP provides a 4.5 day a week program.

The children's service at SWBIRS, known as the Kids Team, includes a 2.3 FTE and is non-centre based, providing both intervention and case management within each child's community. Therapy and case management positions operating within this team include occupational therapy, speech therapy and neuropsychology.



[http://www.health.nsw.gov.au/initiatives/birp/services\\_swbirs.asp](http://www.health.nsw.gov.au/initiatives/birp/services_swbirs.asp)

### **Dubbo Brain Injury Rehabilitation Program**

Located at Lourdes Hospital in Dubbo, this program is auspiced under Catholic HealthCare. The Dubbo unit is the smallest of the rural brain injury programs with only three FTE positions, however has the largest geographical responsibility. This program provides case management service delivery to adults only. Current resources limit clinical coverage to within a one-hour radius (refer to Map 3.1).

[http://www.health.nsw.gov.au/initiatives/birp/services\\_dubbobirp.asp](http://www.health.nsw.gov.au/initiatives/birp/services_dubbobirp.asp)

### **New England Brain Injury Rehabilitation Service (NEBIRS) – children’s program**

The children’s program of NEBIRS is co-located with the adult program at Tamworth Hospital. This one FTE position provides a case management service to children aged up to 16 with a brain injury and their families, utilising available therapy staff within community services.

[http://www.health.nsw.gov.au/initiatives/birp/services\\_nebirs.asp](http://www.health.nsw.gov.au/initiatives/birp/services_nebirs.asp)

### **BIRP, Sydney Children’s Hospital**

This program provides state-wide inpatient, outpatient and outreach services following brain injury for children until they leave school. Clinical and outreach support is available as an outreach service to both city and rural areas. Referral occurs to rural paediatric coordinators and therapy teams based at SWBIRS, Southern Area Brain Injury Service, NEBIRS and North Coast Brain Injury Rehabilitation Service.

<http://www.sch.edu.au/services/services.asp?id=53>

### **BIRP, Children’s Hospital at Westmead**

This service is located within the rehabilitation ward of The Children’s Hospital at Westmead. The Brain Injury Service supports and assists children and young people who have sustained a brain injury, through inpatient and outpatient case management and clinical service. Referral occurs to rural paediatric coordinators and therapy teams based at SWBIRS, Southern Area Brain Injury Service (Goulburn), NEBIRS and North Coast Brain Injury Rehabilitation Service.

[http://www.chw.edu.au/rehabilitation/brain\\_injury/?print](http://www.chw.edu.au/rehabilitation/brain_injury/?print)

### **Kaleidoscope Paediatric Brain Injury Rehabilitation Team (PBIRT)**

This inpatient and community program located within Newcastle provides a rehabilitation service for children from birth to adolescents attending school following brain injury. Referral occurs to the paediatric team based at NEBIRS.

<http://www.kaleidoscope.org.au/services/pbirt/index.htm>

## **3.2 Government services**

### **NSW Department of Human Services: Ageing, Disability and Home Care (ADHC)**

#### **Home Care**

The Home Care Service of NSW is a major provider of the Home and Community Care (HACC) Program in NSW to help young people with a disability, older people and their carers to live independently in their own homes. Services include domestic, personal and respite support. A high-need pool service is available for Home Care Service clients who require between 15 and 35 hours of service per week.

Access and intake for the majority of Home Care’s HACC-funded services are through the Referral and Assessment Centre (RAC) located in Sydney. Assessors located in key rural areas complete the assessment for Home Care to be processed within RAC. Home Care coordinators are located throughout a number of rural areas in NSW, coordinating programs for eligible Home Care clients.

[www.dadhc.nsw.gov.au/dadhc/Older+people/Home+Care+Service.htm](http://www.dadhc.nsw.gov.au/dadhc/Older+people/Home+Care+Service.htm)

#### **Aboriginal Home Care**

Aboriginal Home Care is part of the Home Care Service of NSW that provides services to help younger Aboriginal people with a disability, older Aboriginal people and their carers to remain independent in their own home, with Aboriginal Home Care service outlets across rural NSW. Eight Aboriginal Home Care Service branches in NSW undertake their own intakes and assessments rather than using the central RAC in Sydney.

## **Children's services provided by ADHC**

The following services are funded by ADHC for eligible clients:

- Local support coordination. This is offered in specified rural and regional communities, and aims to increase the links between people with a disability, their families and their local community,
- Disability services provided directly by ADHC,
- Community support teams,
- Respite services,
- Behaviour intervention,
- Accommodation support services.

Children and young people are eligible to access these services if they are:

- under 6 years of age and have a developmental delay in at least two areas of functioning, or
- over 6 years of age and have a significant intellectual disability (where intellectual functioning is two or more standard deviations below the mean or equivalent) and significant deficits in adaptive functioning in two or more areas.

[www.dadhc.nsw.gov.au/dadhc/People+with+a+disability/Supporting+Children.htm](http://www.dadhc.nsw.gov.au/dadhc/People+with+a+disability/Supporting+Children.htm)

## **Other NSW/Victorian health services**

### **Broken Hill Base Hospital and Health Service**

This 88-bed hospital is located within the remote cluster of Greater Western Area Health Service (GWAHS). Broken Hill Hospital has four rehabilitation beds located within acute wards in the hospital. These beds can be used for people who have sustained an ABI for transitional rehabilitation following discharge from a metropolitan hospital (i.e. Adelaide).

An outpatient rehabilitation program in Broken Hill is available but is limited. For outlying areas, hospital-based staff provide some services with the assistance of the Royal Flying Doctor Service.

<http://www.gwahs.nsw.gov.au/index.php?select=Facilities&orderby=&option=Hospitals&Id=1>

## **Mildura Base Hospital**

Victoria's Mildura Base Hospital provides both an inpatient and outpatient rehabilitation service. Referrals for neurological rehabilitation (including ABI) are received from both Melbourne and Adelaide acute rehabilitation services. The rehabilitation ward is co-located with palliative care beds. The Community Rehabilitation Centre provides a multidisciplinary rehabilitation service on an outpatient basis.

<http://www.mildurabase.com.au/>

## **Robinvale District Health Services**

Located at Robinvale on the Victoria/NSW border, this service provides primary health care and community-based services to Balranald, Wentworth and Dareton in NSW. This service is made possible due to the Commonwealth Rural and Regional Health Services Program. As well as allied health input of physiotherapy, occupational therapy, speech pathology, social work and dietetics, this program also funds a community health nurse based within the community health services.

<http://www.rdhs.com.au/>

## **Aboriginal Liaison Officers (ALO)**

ALOs are located within hospitals in NSW to advocate and provide support for Aboriginal patients and their families, assisting with communication between medical staff and families. ALO positions within GWAHS include Broken Hill (2), Bourke, Brewarrina, Orange, Bathurst, Walgett and Dubbo.

## **Primary health care centres**

Primary health care centres provide generalised primary health care to residents of all ages within a shire. Services include care of chronic diseases, health promotion, child and family services, and Aboriginal primary health care.



## Commonwealth funded

### Dubbo Plains Division General Practice

Located within Dubbo, this general practice division provides programs in rural and remote areas surrounding Dubbo, such as the 'The Coonamble Family Wellbeing Project', which is a 12-month funded partnership between the Commonwealth Department of Health and Ageing and Dubbo/Plains Division of General Practice. This project has been created to foster family and community environments that promote family wellbeing and reduce the negative impacts of alcohol and substance misuse, and family violence.

<http://www.dubboplainsdgp.com.au/index.php/programs/ab>

### NSW Outback Division of General Practice Ltd

Funded by the Commonwealth, this division serves the shires of Bourke, Brewarrina, Cobar and Walgett. Services include general practice, allied health, early intervention and prevention, nursing and medical specialist services.

<http://www.outbackdivision.org.au/site/index.cfm>

### Aboriginal Medical Services (AMS)

An Aboriginal Medical Service is a health service funded principally to provide services to Aboriginal and Torres Strait Islander individuals (National Aboriginal Community Controlled Health Organisation, 2010).

If community controlled, an AMS will be eligible to be a member of a National Aboriginal Community Controlled Health Organisation (NACCHO). This control is through a locally elected board of management. There are over 130 Aboriginal Medical Services in Australia, varying greatly in size and staffing levels. These services are unique in their management, funding structure and community base.

Within NSW over 48 Aboriginal Community Controlled Health Organisations (ACCHO) operate. Within the GWAHS a regional group of AMSs, known as Bila Muuji, meaning 'river friends', was established in 1995 (Walgett Aboriginal Medical Services, 2010). Bila Muuji meets bi-monthly at the six locations of the AMSs (see Table 3.1 Bila Muuji members).

<http://www.walgettams.com.au/bilamuuji/>

**Table 3.1 Listed members of Bila Muuji Aboriginal Health Services Incorporated (Walgett Aboriginal Medical Services, 2010).**

| MEMBER   | LOCATION   |
|--|------------|
| Balranald Aboriginal Health Service                            | Balranald  |
| Bourke Aboriginal Health Service                               | Bourke     |
| Brewarrina Aboriginal Health Service – auspiced by Walgett AMS | Brewarrina |
| Coomealla Health Aboriginal Corp                               | Dareton    |
| Coonamble Aboriginal Health Service                            | Coonamble  |
| Orana Haven Aboriginal Corporation                             | Brewarrina |
| Orange Aboriginal Health Service                               | Orange     |
| Thubbo Aboriginal Medical Co-op Ltd.                           | Dubbo      |
| Walgett Aboriginal Medical Service                             | Walgett    |
| Wellington Aboriginal Corp Health                              | Wellington |

Location of other ACCHSs within GWAHS not within Bila Muuji:

- Broken Hill
- Cobar
- Condobolin
- Forbes
- Lake Cargelligo
- Menindee
- Menindee
- Parkes

Location of ACCHSs within GSAHS :

- Albury
- Barmah
- Griffith
- Wagga Wagga

[http://www.mja.com.au/public/issues/184\\_10\\_150506/armstrongIntro\\_fm.html](http://www.mja.com.au/public/issues/184_10_150506/armstrongIntro_fm.html)

## 3.3 Non-government organisations

Refer to Appendix 14 for summarised details.

### **Community Options**

Community Options is a program for people eligible to receive assistance under the HACC scheme who have complex and fluctuating needs. Assistance includes coordination of services, personal and domestic assistance. This is a non-government organisation funded by ADHC to provide community services.

### **Yarrabin services**

Yarrabin Outreach Inc has been providing ADHC-funded services in Western NSW since 1990. In more than 20 years the service has expanded to cover seven local government areas and provides 16 separately funded projects. Yarrabin Outreach Inc has one group home in Nyngan, western NSW; the target population is intellectual disability, however it does provide accommodation for people with an ABI.

### **Mackillop Rural Community Services**

This non-government organisation, under the sisters of St Joseph of Sacred Heart, provides supporting programs to promote and develop the wellbeing of rural communities. In places such as Balranald in western NSW this service provides ADHC-funded living skills and support programs to adults with disabilities.

<http://www.sosj.org.au/being-involved/index.cfm?loadref=97>

### **Uniting Care Ageing Community Care Far West Miraga**

This non-government community care service in Broken Hill focuses on enabling, empowering and promoting independence so people can remain active members of their community for as long as possible. The target population includes aged care. Packages can include domestic personal assistance and case management, respite care, assistive equipment and home modification. Funding for individual programs is through Community Aged Care Packages.

[http://www.agedcareguide.com.au/facility\\_details.asp?facilityid=13900](http://www.agedcareguide.com.au/facility_details.asp?facilityid=13900)

### **Employment Works**

This job support agency aims to help unemployed people with a disability within the community to obtain and maintain jobs within the open labour market. Employment Works has offices in the rural and remote areas of Kerang (Victoria) and Hay (NSW).

<http://www.employability.org.au>

### **Private practice**

Businesses providing private allied health services, such as occupational therapy, were represented within consultation. These services operate on a fee for service basis as well as utilising the Medicare Primary Care Scheme, where some consumers can receive five funded allied health services as part of the chronic care program.

# CHAPTER 4: ISSUES EMERGING

This chapter will present the findings from the consultation phase of this project within the sections of specialist brain injury services, other health and community services, and people with ABI and their families.

## 4.1 Specialist brain injury rehabilitation services

This section will present issues identified in consultations with the BIRPs described in Chapter 3.

Brain injury services to people with an ABI living in remote areas provided by BIRPs include centre-based transitional living programs (TLP), community/outreach and case management services.

### 4.1.1 Centre-based transitional living programs (TLP)

Challenges were identified in the use of a TLP in rural BIRPs as a model of delivery of rehabilitation for people living in more remote areas. One significant challenge is the TLP only operates five days a week and, in the case of the Mid Western BIRP, is not always operational 24 hours a day due to staff resources. This five-day-a-week program results in residents within the TLP having to travel home on weekends or find alternative accommodation. This is difficult for people who live in remote areas, a possible four-hour trip away, or who require assistance for weekend leave. In addition, many potential users of the TLP who live in remote areas may have limited transport options, even with the support of community transport programs.

Encouraging people with a brain injury to complete a TLP can be problematic if they have returned home from a metropolitan hospital having already completed a lengthy acute rehabilitation program. According to

TLP staff, continuing cognitive issues affecting their community integration, self-awareness of these issues and family support are often the impetus for accepting a placement in the TLP rehabilitation program. It was felt that the best outcomes occur when admission is a continuum of the hospital stay. This requires the referring service to provide education and information on the TLP, specifically emphasising the important role the TLP can play in continuing rehabilitation goals and assisting the person to transition back home.

TLP staff indicated that it was important to follow-up a person once they had left the TLP to provide support while the person adjusts to re-entering the community. This is important if the person is going to generalise the skills and strategies learnt in the TLP, increasing the possibility of living and participating in the community independently. However, it was recognised that the current capacity to provide this support in a person's community following a TLP program is limited when the community may be over two hours' travel away from the location of the rural BIRP, and home visits by BIRP staff are limited by distance.

Rural brain injury rehabilitation practitioners expressed concerns that the TLP delivery model may not be meeting the needs of an Aboriginal person with a brain injury. The structured environment, time orientation and goal-focused nature of a TLP, together with limited accommodation space, may not be ideal for an Aboriginal person who usually resides with a large supportive extended family. In addition, the current model of individual goal setting with the person and their family may not encompass the goal of community and family living, which may be the priority for an Aboriginal person.

## A summary of findings related to centre-based TLPs

- The distance to travel to a rural TLP located regionally for a person with a brain injury living remotely can be extensive, and is a barrier to the engagement and completion of a program.
- It is difficult to engage a person with a brain injury who resides remotely to complete a TLP following an already lengthy metropolitan program.
- With the current resources within rural BIRPs and limited capacity, it is difficult to provide intensive follow-up to support the transition of skills to the person's home and local community.
- Additional issues for TLP service for Aboriginal people:
  - The environment and structure of a TLP may not be meeting the needs of Aboriginal people with a brain injury.
  - Distance from family can be barrier to admission and completion of a program.

### 4.1.2 Community based/ outreach

Delivery of a rehabilitation program within the community requires visits to a person's home or school. This model of delivery as reported by rural BIRP workers enables skill building and rehabilitation to occur in a person's natural contexts, promoting generalisation of strategies and adjustment after brain injury. As explained by staff, however, this model is problematic if intensive input is required and the person is located remotely to the service base. A fortnightly rehabilitation service is a possibility; however, this is difficult to sustain for more than a few months. Overnight travel for staff is possible within some units and used as a strategy to enable staff to spend more time in a person's community; however, this option is dependent on staff availability.

As well as the resource intensity of this model, the issues of staff fatigue and the reduced number of hours available for intervention present challenges. All units identified that driver fatigue affects service delivery in terms of the number of outreach visits that can occur within a week. The time available to provide input, whether it is therapy, case management or a combination of both, is lessened the more remote the location.

The provision of brain injury rehabilitation intervention within the community is resource-intensive when two staff members are required for each trip for occupational health and safety requirements and to maximise benefits for the client and their family. For a small unit this can mean that the entire team and resources are involved in an outlying remote visit that will take at least two days, which then severely restricts service capacity and may warrant program closure until staff return. Even brain injury programs that are better resourced are affected when remote visits occur, especially when there is no discipline specific therapy service remaining at the unit. This affects the capacity of the unit to respond to service demands.

Working collaboratively with other services based in the community, such as schools, home care or mental health staff, is embedded within this outreach model. However, this is problematic the more remotely the person with the injury is located. The problems include identifying appropriate services to collaborate with, coordinating services to meet when many services are operating within an outreach model, and visiting that remote area infrequently.

While there are difficulties in the provision of consistent and intensive rehabilitation and case management services to some remote areas of NSW, some areas in NSW receive no input from a rural BIRP. These areas include Broken Hill, Wentworth, Dareton and Balranald in far-west NSW. The cessation of regular non-commercial flights to Broken Hill means there is no input from a BIRP in that region. Broken Hill is over 600km from Dubbo and would require a minimum three-day road trip for at least two staff members. Balranald and Wentworth, due to their proximity to the Victorian border, receive allied health input from Victorian Health services based in Robinvale; however, they receive no specialty rehabilitation brain injury input from Victorian or NSW services.

Two common strategies used by rural BIRP staff to provide services to people who live remotely include health flights and telehealth. The use of regular health flights is available to some areas of NSW, such as Bourke, Griffith and Deniliquin. Within the Greater Southern Area Health Service flights to remote areas such as West Wyalong and Hay occur on a monthly basis. These flights are used within the Albury BIRP to provide a more regular service to clients as well as increase client contact time during a remote visit. However, for more remote outlying areas, such as

Walgett and Lightning Ridge, no health flights are available. The Flying Doctor Service provides flights to Bourke and Moree, but the use of this service by rural BIRPs is limited as priority is given to medical services. Other limitations include the available flight times, especially if outside of school terms, and access to a car to visit clients in their home and community once at a remote location.

All programs consulted used telehealth to provide intervention and case management to more remotely located clients. This includes the use of videoconferencing facilities linking up to units in the community to provide therapy to clients via the monitoring screen. Examples of telehealth include: discussion of goal attainment, meetings with families and support psychological adjustment. The use of telehealth by rural BIRPs had mixed success. More success was noted when videoconferencing was used with supporting services for education rather than for one-on-one client intervention. Videoconferencing is not always available in some remote areas or may be not operational. If working, its use by rural brain injury workers can be limited due to issues of confidentiality, as a staff member from the local health centre may have to be present with the client. Successful use of videoconferencing requires coordination from services, both the rural BIRP and community services, yet the staff input required to ensure this coordination is often not available.

The Medical Specialist Outreach Assistance Program (MSOAP), an initiative to provide visiting specialist programs to rural areas, has been utilised within the rural units to provide regular neuropsychology, rehabilitation specialist and neuropsychiatry input. This offers a capacity for review and monitoring of more remote clients. For clients who receive little brain injury rehabilitation intervention and case management due to the distance they live from a rural BIRP the MSOAP can provide a mechanism for review, although input from the rural program for follow-up remains limited.

Rural BIRP practitioners discussed the challenges of working with an Aboriginal person under this outreach model. Early discharge from an acute metropolitan hospital frequently occurs as the Aboriginal person with an injury needs and wants to return to their family and community. Having the time to develop trust and rapport with an Aboriginal person within their community was also identified. Within the current structure of the rural BIRP, service provision on a weekly basis for an individual who

lives in a remote area is not a possibility. Often rehabilitation within regional centres such as Dubbo and Orange is also not an option. BIRP practitioners expressed concerns that families are not given enough information before discharge regarding the lack of rehabilitation services available for a person living remotely and the impact of this on recovery.

The identification of ABI within Aboriginal communities and subsequent referral to a rural BIRP was raised as an issue. If co-morbidities or complex family and social issues are present, then the brain injury may not be seen as the priority to address for intervention.

Medical and support services may not identify the brain injury, especially if other issues, such as safe housing, need to be addressed. Brain injury that results in a physical presentation such as hemiplegia is more often identified for follow-up than a cognitive presentation such as memory difficulties.

### ***A summary of findings related to community/outreach services***

- A distance of two hours from a rural BIRP compromises availability and intensity of a rehabilitation program for people with a brain injury and their family.
- Intensive rehabilitation and case coordination from rural BIRPs within a person's own community is limited when they reside remotely.
- Support for children and their families following brain injury is often not available within their own remote community.
- Input to family members and services supporting a person with a brain injury, located remotely, is resource-intensive and therefore limited due to distances and resources within rural BIRPs.
- A large area of NSW is not receiving services from a rural BIRP.
- Additional issues for community/outreach services for Aboriginal people:
  - Developing trust and engaging with an Aboriginal community is difficult when practitioners within the rural BIRP are not based within that town/community.
  - The early discharge of an Aboriginal person from an acute hospital following brain injury has an impact on appropriate follow-up.



- The numbers of Aboriginal people with brain injury within a community may not be identified among competing co-morbidities.

### 4.1.3 Case management

Both Dubbo BIRP and NEBIRS have identified that case management as simple coordination of interventions by other services may not be adequate. Cognitive therapy and strategies are often requested as part of the case management role. For example, a school may ask for specific cognitive strategy-based training for a child with ABI and their teacher.

A BIRP model based purely on case management is often not able to deliver this intervention nor to engage community allied health, as clinical skills and experience within a unit may not include cognitive therapy or a range of allied health professionals. Even when experienced staff (within a case management team) provides intervention, such as cognitive therapy, they may not be recognised within the compensation system for this expertise and, therefore, not funded to provide it.

Case management that is only phone-based provides fewer opportunities to address education, support and adjustment issues. Face-to-face service delivery was identified as a requirement for building rapport with clients and their families for the development of goal-driven case management. However, staff reported that funding may be allocated for only two face-to-face visits per year.

A coordinated case management program for children and their families following brain injury does not exist within the Dubbo BIRP and is limited within the Mid Western BIRP. Paediatric rehabilitation coordinators were established with MAA funding in some rural BIRPs, however not all these programs have been able to obtain funding for the continuation of this service (for example, Dubbo BIRP).

Children's brain injury rehabilitation services identified restrictive pathways for children and their families following brain injury when a coordinated approach is not operational. This includes metropolitan services not accessing and coordinating local services before children are discharged from Sydney hospitals, which is further complicated by short length of stays. Care coordination following discharge from Sydney BIRPs can often be left to very busy GPs or the nearest paediatrician, with brain injury coordination and education occurring only when reviews take place in Sydney.

Finding services and allied health practitioners to see children with brain injury in the more remote areas of NSW is a challenge. Often, families are left to provide their own rehabilitation, monitored from afar from the metropolitan units. Metropolitan units expressed concerns that with current resources, review and monitoring at critical developmental points for the child and their family, such as transition to high school, do not occur.

### Summary of findings related to case management services

- Delivering transitional rehabilitation is less effective when the model used by the rural BIRP is a case management model only, and when there are minimal allied health practitioners and support services to collaborate with.
- Dubbo BIRP does not offer brain injury transition rehabilitation to children and their families and the Mid Western BIRP can only offer a limited service.

## 4.2 Other health and community services

The health and community services interviewed for this project included hospitals, community health centres, Aboriginal Medical Services (AMS), Home Care, Community Options and non-government support agencies. This section will present issues and strategies related to the support and rehabilitation provided by these services to people with a brain injury living in remote areas of NSW.

All services reported that they deal with only a small number of people with an ABI under 65 years of age. Most services focused on supporting the frail aged as their priority. A more severe TBI may only occur in a community once every few years. In the larger remote areas, such as Broken Hill, staff reported that it is likely that people could be living in the community with an ABI acquired several years ago and not be known to health or support services.



## 4.2.1 Allied health services within community and hospitals

Allied health delivery outside rural BIRPs to people with a brain injury in remote areas was discussed during consultations with allied health practitioners and community services. Allied health practitioners consulted included occupational therapists, speech pathologists, dieticians and physiotherapists representing the areas of Broken Hill, Balranald, Walgett, Lightning Ridge, Condobolin and Hillston.

These practitioners identified the issues of a paucity of allied health services in remote areas of NSW, low priority placed on rehabilitation for ABI and the need for specialty skills to engage in brain injury rehabilitation.

For areas more remote from the regional centres of Dubbo, Bathurst and Orange, allied health services are often transient. In Forbes and Condobolin it is very difficult to access a psychologist, occupational therapist and speech pathologist. Allied health services provided by Lourdes Hospital in Dubbo to surrounding areas are dependent on funding and often take the form of assessment only.

A physiotherapy service is available in Walgett, however it is limited to one position for the whole town and surrounding district as far as Lightning Ridge. The physiotherapist is not funded to travel, therefore clients from Lightning Ridge have to travel to Walgett. Occupational therapy input for the areas of Coonamble and Walgett leading up to Lightning Ridge is limited. At the time of consultation there was a two-day OT service in Walgett in addition to an eight-hour OT service funded via the Community Options program, which can only be accessed by Community Options clients.

For areas around Bourke and Cobar, allied health funding is available through government initiatives such as the MAHRA (More Allied Health for Rural Areas) program; however, attracting and sustaining staff is an issue. Allied health staff based at Broken Hill Hospital provide a limited outpatient service for people following ABI but frequent vacancies in allied health positions result in limited resources, meaning that inpatient input is given priority over outpatients. Outreach allied health programs to areas such as Wilcannia utilise the Flying Doctor Service but priority again is given to home safety and mobility, rather than to rehabilitation for people with brain injury.

The NSW areas of Wentworth, Dareton and Balranald are serviced by allied health practitioners through a Victorian Health Program based in Robinvale on the Victorian /NSW border (see 3.2).

An advantage of this program is that it allows a number of allied health staff to be co-located in Robinvale, assisting with recruitment and support of staff. Staff within Robinvale explained that despite the positives of this program difficulties still arise in recruitment and retention of staff, especially social work positions. Travel time places demands on staff and limits consultation times. Involvement of visiting allied health practitioners in program development within specific community health centres is limited.

Even if allied health services are available in areas, clients with a brain injury are often considered a low priority due to other competing demands such as people who are elderly, frail or at risk of falls or injury. HACC-funded allied health services are limited by eligibility criteria.

Being aware of what is available in the surrounding areas, knowing who to contact, and coordinating services within this transient environment were also identified as issues.

The possibility for allied health practitioners in more remote areas to provide a therapy program to people with an ABI is restricted by their limited knowledge and expertise in this specialised area. When there are competing demands, allied health practitioners will not usually choose to engage in therapy for which they do not think they have the skills.

Local therapists can also find it challenging to adapt their framework and model of therapy to work with children with ABI, particularly when numbers are small and exposure to this client group limited, and the input and consultation required to up-skill the therapists is time intensive for BIRP practitioners.

The use of private OTs from Sydney from compensation funding such as within the NSW Life Time Care Scheme, is often only for assessment rather than ongoing therapy. One-off assessments can and do occur; however ongoing therapy for skill development requires local and consistent input.

For one private occupational therapist, rehabilitation input to people under 65 following brain injury is limited to the Medicare Primary Care Scheme. As this is restricted to five consultations, the costs of any further consultations then become entirely the person's responsibility. The costs for further private

intervention are more often than not unrealistic for people on limited incomes.

Although there are advantages to being located within the town, living and practising locally also brings an expectation of being available for consultation at all times of the day and week. Many also experience difficulties developing appropriate professional boundaries.

*I get phone calls on Sundays and things like that from people, just because I grew up here and people know me and I'm happy to take them, and it would just allow me to do those jobs that I wouldn't get paid for.*

As there are only limited funded hours therapists tend to provide people with a brain injury assessment only for school and employment reasons. Therapists do not often have the funding to provide comprehensive services. Therapists who provide an outreach service are unable to expand their role to providing more comprehensive rehabilitation for a person with a brain injury, and relevant training of support workers and family members. As one occupational therapist who works remotely explains:

*The perfect thing would've been able to pop in there and get a bit more of a living skill program ... It would have been nice to have a more regimented routine for him. There was a lot he could've been doing, but he lacked that internal drive. Even visiting regularly, we would have struggled with that. It would have been nice to have some sort of community service.*

With a high turnover of staff within support and allied health services, it is understandable that effective follow-up and review of people with a brain injury living within a remote community can be overlooked. Support services may not know of the existence of the allied health practitioner, may think that the position is vacant, and may have had limited success in engaging allied health practitioners in the past.

*I think a lot of these rural centres are so used to doing it on their own that they do sometimes forget – being realistic, even if you're in the job for 12 months, they suddenly remember to refer to you, and then people are gone. And that's what always happens, such huge turnover.*

## Summary of findings related to allied health services

- There is limited allied health input to people with an ABI living in remote communities due to vacant or poorly resourced positions.
- Allied health practitioners located remotely mainly focus on assessment of people with ABI rather than providing regular rehabilitation input.
- There is a low priority for providing rehabilitation services from allied health practitioners to people with ABI living in remote communities due to competing priorities and dependence on funding structures.
- Allied health practitioners with limited experiences are reluctant to provide brain injury therapy input. This is particularly so for children with brain injury.
- The Medicare Primary Care Scheme is often the only financial option for allied health input for people with an ABI, but this is limited to five visits only and is only a part-subsidy.

### 4.2.2 Primary health care nurses

Six primary health care centres were consulted for this project, as primary health care nurses in remote communities often coordinate care for people with an ABI. In the towns of Balranald and Dareton, where no input occurs from a NSW rural BIRP, consultation revealed the extent of this coordination. Community nurses have been asked by the local hospital to find permanent accommodation for people with a brain injury, manage behavioural issues and support the person in transitioning to community living. Due to the absence of social work positions, community nurses also assist people to negotiate with such services as Centrelink and emergency housing. As one nurse explained:

*I'm the unofficial social worker, with no training at all.*

It was noted that regular reviews for the management of a brain injury did not occur for people who live remotely, particularly if their injury was a number of years ago. As one community health nurse noted:

*I can think of a guy who had a stroke who had the same brace on his hand, that he wore to bed at night when he came home, and seven years later his wife was still putting this thing on, and he was reviewed by an OT at whatever point it was, and she's going, "What is this?" And the wife said, "I didn't know".*

In the case of alcohol and/or other drugs-related brain injury, primary health care nurses explained that behavioural issues may result in social isolation for a person with ABI within their community and the nurse practitioner may be the only support they have.

Of the six primary health care centres interviewed, three had knowledge of the rural BIRPs. The other health centres were located in areas where input is not available from a rural BIRP.

Notification from the regional or metropolitan hospital to community nurses that a person has had a TBI doesn't always occur before a person is transferred home. Community health staff interviewed discussed a recent experience where a younger person was sent home from a regional hospital after a fall in which he sustained orthopaedic injuries.

The regional hospital did not conduct a brain scan. For two weeks post-injury, this person was experiencing significant ABI sequelae, such as behaviour issues. Community health staff became concerned about the escalating behavioural issues and consulted with a colleague with mental health experience.

They then consulted with a regional brain injury rehabilitation unit, which arranged for a scan to be conducted and a brain injury was identified. It was assumed within the community that this person had a mental health breakdown rather than a brain injury.

### **Summary of findings related to primary health care nurses**

- Primary health care nurses in remote areas are often the only practitioners available to provide care coordination and other services for people with ABI.
- Some primary health care nurses are unaware of the specific brain injury services available in the area they service.
- There are times when regional and metropolitan hospitals do not inform local nurses that a person has had a brain injury. This can have an impact on the coordination of appropriate services, as well as on the person with the brain injury's re-integration back into the community.

## **4.2.3 Remote hospitals**

Rehabilitation following ABI for people under 65 occurs in isolated hospitals, such as Broken Hill and Mildura (for NSW residents on the border). The usual pathway

is that people receive acute medical management and rehabilitation in metropolitan hospitals, returning to Broken Hill or Mildura (see 3.2) for further rehabilitation in preparation for going home or awaiting placement. Consultation occurred with nursing and allied health staff in Broken Hill, Mildura and Bourke hospitals.

Rehabilitation issues identified in remote hospitals included:

- Allied health input to rehabilitation inpatients is limited due to having to service other hospital patients and surrounding areas with limited resources.
- The limited allied health input means it is extremely difficult to provide an intensive rehabilitation program.
- Lack of expertise in neurological rehabilitation and the absence of rehabilitation and/or neurology specialists.
- Patients may be managed by their own GP rather than a rehabilitation physician.
- The provision of services in outlying areas is variable as it is dependent on staffing availability. Even when staff are available, any rehabilitation program that has been recommended can only be monitored and implementation relies on the person/family.
- The acute hospital environment is not ideal for providing rehabilitation.
- People with severe ABI discharged to remote hospitals will be accommodated in long-term aged care beds. In this situation the nursing staff reported needing to do extra tasks so the person continued to receive rehabilitation for improving skills and increasing their independence. Nursing staff were also involved in care coordination and seeking options for discharge.
- Appropriate discharge information from metropolitan hospitals is not always given and discharge occurs before the appropriate home assessment and provision of equipment is completed.
- Obtaining appropriate equipment, especially if specialised, is difficult in a remote area, and quicker outcomes would be achieved if equipment were given on discharge.
- Metropolitan hospitals may not always know about or seek out information on the services available in remote areas, such as allied health and support services.
- Information on how much rehabilitation input a person will receive is not always clearly communicated when planning discharge, resulting in unrealistic expectations from family members as to the intensity of therapy a person will receive within remote hospitals.

## Summary of findings related to remote hospitals

- Rehabilitation within remote hospitals is restricted due to limited numbers of allied health staff and rehabilitation physicians, in addition to a lack of expertise in working with people with ABI.
- If rehabilitation is offered within remote hospitals, it often occurs within the acute setting.
- There is often a lack of brain injury expertise among allied health staff in remote hospitals.
- People with brain injury and their families are often not informed about the limited availability of rehabilitation services provided by remote hospitals prior to discharge from a metropolitan centre.

### 4.2.4 Aboriginal Medical Services (AMS) and Aboriginal Liaison Officers (ALO)

A number of programs and services exist within an AMS which could be utilised by people with brain injury as well as their families. These include wellness programs, exercise physiologist, psychologist, a social-emotional wellbeing officer and medical and allied health services. Accessing allied health services can be difficult as there may be a limited number of practitioners available and those who are available may have limited expertise in working with people who have a brain injury.

Within AMSs, ABI is not identified as a target group and often support is given without the diagnosis of brain injury being recorded. Some AMSs do not have a good knowledge of the rural BIRP available to support them.

One AMS reported that behaviour issues may not be identified, and often could be considered to be mental illness and therefore managed within a mental health agenda. With a number of other issues identified for management within an AMS, such as housing, increase in suicide, domestic violence and drug and alcohol management, the identification of brain injury within a community and management of an individual's brain injury may not be prioritised.

Collaboration with a rural BIRP was identified as important in providing relevant support to the person with the injury and their family. One AMS reported positive collaboration with a rural BIRP. This relationship allowed the AMS to receive specific information on brain injury management and then to support the

client to attend appointments and follow-up on recommendations from the BIRP.

It was identified that due to the absence of social workers in remote communities, ALOs are often utilised in care coordination roles within the hospital. Of concern was the absence of ALOs in rehabilitation wards in regional centres. Inpatient rehabilitation options are available in regional centres, however, due to reasons of community and cultural isolation, Aboriginal people with a brain injury in these areas have been reluctant to complete inpatient rehabilitation. An Aboriginal person in a regional hospital can be very isolated from their community if a link is not provided while they are in hospital. Family may be reluctant to visit due to fears associated with entering a hospital. A dedicated presence of an ALO within these regional rehabilitation hospitals isn't available but would help the person with the injury link up to their people while living away from home.

It was identified that an Aboriginal person's engagement in rehabilitation (both within inpatient regional centres and rural BIRPs) will be influenced by support within the person's community and the identification of the need for rehabilitation. Higher priorities may exist for the person, family and community in terms of housing and social issues.

Developing trust in, and an understanding of, the rehabilitation program offered by the brain injury rehabilitation service can be an issue, especially when the program is not located within their community.

### Summary of findings related to Aboriginal Medical Services and Aboriginal Liaison Officers

- AMSs have many other priorities and as a result have limited resources to focus on people with a brain injury.
- The diagnosis of a brain injury may not be made when an Aboriginal person is serviced within an AMS and behavioural issues may be considered a mental health issue.
- Aboriginal people may be reluctant to complete inpatient rehabilitation in regional centres due to isolation from family and community.
- There is minimal cultural support in regional rehabilitation centre for Aboriginal people with a brain injury due to the absence of ALOs within these rehabilitation centres.



## 4.2.5 Ageing, Disability and Home Care (ADHC) services

The ADHC services consulted for this project included case management services, Aboriginal Home Care and Home Care. The issues raised by these services relating to brain injury rehabilitation and support for people with an ABI living remotely include eligibility, recruitment of staff and providing high needs support.

ADHC offers case management (support, service linkages and care coordination) for children and their families in remote towns. Eligibility for these ADHC services (at time of consultation) was based on intellectual disability, which therefore omits most children with acquired brain injury and their families.

People with an ABI and their families who live in remote areas are eligible for ADHC services such as Home Care, Aboriginal Home Care and ADHC-funded services such as Community Options. In most remote areas these three services are all that exist in terms of services and support.

Service staff reported it is challenging to provide ongoing support for a person with high needs following brain injury. Challenges include the recruitment and training of appropriate support staff within small remote towns, and dealing with issues of confidentiality and familiarity. Accessing allied health practitioners in remote areas to provide the required training to their staff is a continual issue for similar reasons. Rural BIRPs have been used for training, brain injury education and specific management strategies. However there are areas of NSW where BIRPs do not provide programs.

The recruitment of Aboriginal Home Care workers can be difficult in remote areas. Access to a car can be the barrier for many Aboriginal people applying for this work. Aboriginal Home Care predominantly employs Aboriginal people as care workers for their clients. However non-Aboriginal care workers can be employed if preferred by the client. The concept of shame was identified as a reason why a person may choose to have a non-Aboriginal care worker. It may be the person doesn't want an Aboriginal person knowing about their difficulties. The cultural concepts of shame may also prevent a person and their family identifying as having a brain injury and accepting rehabilitation and support.

Those consulted identified that the family unit is important within the Aboriginal community. Support of a person with a brain injury within the family unit and community may be sufficient for that person's desired participation in their community. Returning to live in and be a member of

their community was thought to be of higher importance than mainstream goals of rehabilitation, such as being independent in personal self-care.

### Summary of findings related to ADHC services

- Eligibility criteria for ADHC case management services for children exclude most children with a brain injury.
- It is difficult to recruit appropriate Home Care staff in remote towns to meet the service needs of people with high needs due to their brain injury.
- It is difficult to access allied health practitioners to provide training to Home Care workers in remote areas.
- Recruitment of Aboriginal care support workers within Aboriginal Home Care is difficult in remote areas due to transport issues.
- Cultural concepts of shame may influence an Aboriginal person's acknowledgement of their brain injury and their willingness to seek support.

## 4.2.6 Non-government services

In remote NSW non-government services that provide support, in the areas of accommodation, living skills and employment, to people with a brain injury. These non-government agencies are funded by ADHC or, in the case of employment services, the Federal Government.

The two supported accommodation services identified in consultation are unique in that they provide accommodation and living skills training to clients with ABI and intellectual disability within the same service (see 3.3).

Located remotely, both these services address respite and accommodation needs for people with a severe brain injury living in remote areas. Other than aged care accommodation, options for people under 65 with a brain injury are severely limited in regional, rural and remote areas. Sustainable funding for clients with a brain injury within these supportive accommodation programs has to be negotiated on a case by case basis, and is not always assured.

An employment service located in remote NSW identified positive outcomes when assisting people with disability to obtain employment in the open labour market. Strategies identified included developing and maintaining a local presence within the town and eliminating the stigma associated with disability in that town.



Approaches specific to this client group included a collaborative relationship with a rural BIRP located four hours from the employment service. This relationship included face-to-face meetings to discuss clients, providing education and developing strategies collaboratively to help the person with the brain injury maintain employment.

## 4.3 People with ABI and their families

Personal experiences of having a brain injury and living in remote areas of NSW were sought through interviews with six individuals with ABI, and six family members. For information pertaining to consumer participants see Appendix 13.

Issues raised by these participants included the organisation of care and rehabilitation following discharge from rehabilitation in metropolitan areas, support within remote towns, options for leisure and respite in remote areas, and transport.

### 4.3.1 Organisation of care and rehabilitation

Difficulties were identified in organising care and rehabilitation, including resourcing appropriate rehabilitation, cognitive and emotional support and support care.

A carer described the process of leaving the metropolitan-based specialised BIRP to return to live and care for her son in her home in a small remote town. The initial difficulty she experienced was around organisation and navigation of her own home care support.

Further rehabilitation, such as physiotherapy, did occur for a period of time; this, however, was dependent on staff and resources and, with the loss of a staff member, this intervention ceased. Support is currently being provided by a non-government organisation. However this mother was frustrated that the support received did not include access to the community. No support workers for her son are based in the town; the hours of service provision therefore include travel time for support staff, thus reducing the hours available to her son. No Aboriginal support workers from the town are employed to work with her son. This was explained by the cultural issue of shame:

*Hmm, but they was trying to find someone just to do his showering, but they couldn't find no one here in (name town removed) because black people are ashamed, they would do the work but they wouldn't shower him.*

For another participant, discharge from the metropolitan hospital to a hospital near his home resulted in unmet rehabilitation expectations. Both he and his mother discussed how the rehabilitation they expected, based on their experiences at the metropolitan hospital, did not eventuate in the acute hospital located closer to their home. They explained that daily therapy did occur; however, at times it was in groups with older patients on the wards with more orthopaedic injuries rather than ABI. They expressed concerns that follow-up specialist reviews did not occur within the acute hospital due to the absence of a specialist. The family was expected to travel a distance of six hours to the city for specialist review.

*He was to come back here to have extensive rehab. And he had none ...*

*We just wish we could get him into rehab. He needs extensive rehab at the moment to be able to move forward.*

One parent in a remote town discussed the experience of supporting her son to return to school. The transition back to school became complicated as her child developed behavioural issues, and support and assistance weren't available.

*His main issues were with his anger management, he would get very cranky very quickly.*

Having regular access to psychological support was also an issue consistently raised. Participants stated that they had limited, if any, choice on who to consult and difficulty accessing a psychologist in remote areas. Very few psychological services were available in the public sector, and so, while compensable clients were able to purchase these services, regular psychological intervention for non-compensable clients was limited or not affordable.

*It's just that I feel sorry that if anything happens – if I want to talk about anything – who do I [talk to]? It's my wife. It's always my wife. [Slaps table] It's just not fair. And even if I go to my GP, who's a lovely lady, and really has been no problem at all, she's a GP. She hasn't got an hour.*

Participants mentioned that local health workers, including GPs, lack an understanding of brain injury and did not know how to best respond to families in challenging situations.

*Well, nobody ... to tell you the truth, there is nothing here ... nobody understands a brain injury.*

### **Summary of findings related to organisation of care and rehabilitation**

- Following discharge from a metropolitan hospital to a remote area, people with a brain injury and their families are frequently left to negotiate their own care needs.
- For Aboriginal people living in a remote area of NSW, cultural issues of shame may have an impact on being able to use Aboriginal care support workers.
- A person with a brain injury and their family living in a remote area can have unmet expectations in terms of rehabilitation.
- Input from a rural BIRP to families living remotely is not sufficiently intensive to meet their changing needs, such as school transition.
- In remote areas access to psychology support is limited for people with ABI and their families.
- The understanding of brain injury and its effects among health practitioners can be limited when supporting a person with ABI and their family.

### **4.3.2 Support within remote towns**

People with ABI living within small and remote communities can have differing experiences. Some are appraised in a positive way and some negatively. One participant with a brain injury described his messenger role within his community, which consumes the majority of his day. He is known in his community for this role and he described it as a way to occupy his time.

*I like to go fishing a lot (laughter), but I don't find time to go fishing, I am always walking the streets for people.*

In contrast to this, however, a family member stated that it was difficult residing in a small community when caring for a person with high support needs, especially if that person has behavioural issues. She experienced grief and loss of friends following her son's brain injury when he was 20 years old, and shame when she tried to manage the subsequent behavioural issues.

*I'm talking about friends and stuff; I mean they just all disappear, even our friend disappeared. I suppose they don't know what to say to you. And, really, once you leave the hospital in the first place, you really are on your own. Absolutely on your own, you know?*

*People would walk across the street ... it was just awful. I suppose they don't know. I mean, later on, you'd go home and kick things and say, "What's wrong with these people!" but I guess they don't know what to say. At the time you can't see that.*

### **Summary of findings related to support in remote towns**

- Living within a remote town following a brain injury can be a positive experience for the person and their family, however, they can also feel isolated because of a lack of support and loss of friends.

### **4.3.3 Leisure, respite, transport and emotional costs**

The lack of leisure and respite options and transport restrictions were identified as issues for people with brain injuries who live in remote areas. One participant wanted increased Home Care hours for her son so that he could be taken out into his community for leisure, but there were no leisure programs specific to people with brain injury.

Residents of the supported accommodation services discussed how they were supported to attend leisure activities. This included group activities with other residents and some occasional individual activities, such as a visit to a regional centre.

The majority of the supported leisure activities are group-based. For one participant, this group included older people and he described it as not being supportive of his needs. Another participant described a disability agency for people with developmental disability that her daughter attended for leisure activities. Living in a small remote town, there were no other options for her daughter. Even though her daughter was able to participate in some leisure pursuits, she was not able to go on community outings as she had physical impairments and the group did not cater for this.

*They didn't understand. She couldn't walk, and she couldn't see.*

It was identified that remote towns can offer little in the way of leisure options for a person with brain injury, especially if physical difficulties are present. Leisure and sporting facilities in some remote towns are not wheelchair accessible.

*There's nothing to do here. They closed the sports complex. Sort of closed that off. He used to go there and used to do a lot of gym work, you know?*

People living in remote areas have limited access to respite options. A supported accommodation program in Nyngan was the only program identified for out-of-home respite. Participants spoke of using respite options in Sydney, which involved paying for and arranging transport to and from Sydney.

The restrictive transport options for people accessing services were also identified as an issue. Local transport options within the town for a person with ABI can be very limited if no wheelchair-accessible vehicle is available. Participants explained that if they wanted to access specialist services, specialist doctors and allied health professionals, they would often have to travel a number of hours. Driving to a regional centre such as Dubbo can be daunting and costly, as well as unsafe when fatigue is a problem. Even if a person does access transport to drive to a regional or metropolitan centre, there is the added expense of accommodation. Specialist input and information following the brain injury, especially in relation to medical issues, is often only available in Sydney, which again is problematic in terms of distance and access.

*As one parent noted: Like everyone says, yeah you can get that in Sydney, but Sydney is a long way away!*

Parents highlighted the monetary and emotional costs to a family when the injury first occurs and they have to relocate to a regional or metropolitan centre to be closer to the son or daughter who is receiving rehabilitation. This included one mother who lived away from her home and other children for nearly 15 months to be near her injured son. Sustaining employment can be difficult when a family needs to relocate to be near their loved one, which then affects the financial security and management of a family.

*My husband's lost work; he had to give up work, to go with our son, to go to Bathurst. I had to throw all my work away to just be with our son.*

Travelling to Sydney for regular reviews is another financial and organisational demand on a family. One participant shared how her family needs to plan and save for a number of months to finance a review in Sydney.

*You're looking at about \$1500 down and back, or more. So you sort of make sure there is money put away for that period. Got to make sure that the car's OK and everything here at home is OK because at home here we are not on electricity, we're only on generated power. So I've got to make sure I've got fuel here for the generator, food here and everything in the house. Basically I think that's why my husband stays. It's easier for him to look after things rather than get someone else in to do it.*

### **Summary of findings related to leisure, respite, transport and emotional costs**

- Supported leisure and respite programs are limited in remote areas for people with brain injury and their families.
- Group leisure activities in remote areas may not meet the individual needs of people with a brain injury.
- Specialist review for many people with a brain injury living in remote areas occurs in Sydney or a regional centre. This results in financial strain on families due to transport and accommodation costs.
- Wheelchair-accessible leisure options and local transport are not available in some remote towns.
- There is an extensive emotional and financial cost to families who need to relocate from remote areas to metropolitan or regional centres to support a family member with brain injury who is completing acute rehabilitation.

# CHAPTER 5: THEMES AND PRELIMINARY RECOMMENDATIONS

Five key themes emerged from the issues in Chapter 4:

- 5.1 The unmet needs of people with ABI and their families living in remote areas**
- 5.2 Additional issues faced by Aboriginal people following ABI living in remote areas**
- 5.3 Access and provision of rural brain injury rehabilitation for people following ABI living in remote areas**
- 5.4 Workforce issues**
- 5.5 Community understanding of brain injury.**

This chapter includes for each theme:

- A description of the theme,
- The issues related to the theme,
- Preliminary recommendations.

The material in this chapter was used in the stakeholder meetings in May 2010. The discussion of this material led to further data gathering and shaping of the recommendations into an integrated and detailed plan of action, as described in chapters 6 and 7.

## 5.1 The unmet needs of people with ABI and their families living in remote areas

Living remote from a 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.

- People with ABI and their families may be left to struggle with negotiating 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.
- People with ABI and their families are often not informed before discharge from acute care about the limited availability or type of rehabilitation services provided by remote hospitals. As a result they may not realise that their expectations for rehabilitation, such as follow-up specialist reviews and ongoing therapy, cannot be met when they return to their community.
- Access to psychological support to address adjustment issues and manage cognitive and behavioural changes is limited for people with ABI and their families.
- The lack of local staff with specific knowledge and understanding of ABI is a barrier to clients accessing intensive rehabilitation and case coordination within their own community when they reside remotely.
- Pathways into support services to meet the needs of children following brain injury, including school transition, are often not available when returning 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 by the delays. BIRP teams lack paediatric services to support families locally.
- ABI-specific case workers for children in remote rural areas are not available due to lack of paediatric staff in BIRP services.
- People with ABI can access rural transport subsidies. However, these subsidies only apply to specialist medical services and do not extend to family members. As a result, families can experience financial strain due

to additional costs of transport and accommodation when they support the person with ABI who is attending rehabilitation at their local BIRP, specialist reviews in metropolitan areas, generic rehabilitation and disability services in a regional centre. This is perhaps a more significant issue when a child has a brain injury, as parents (and, at times, siblings) need to be available for support.

- Families are important members of the rehabilitation team and will relocate to metropolitan or regional centres to support a family member with ABI who is completing acute /transitional rehabilitation. This is an extensive emotional and financial cost to families.
- Families need access to respite (in-home, out-of-home and residential) to manage the additional burden of living with an adult or child who is significantly different after an ABI.
- There are limited options for people with ABI who are unable to return to employment and, as a result, are in need of supported non-vocational and leisure options with access to respite programs. Where existing group leisure activities in remote areas are available, they may not meet the individual needs of people with ABI.

### **Preliminary recommendations for theme one (5.1)**

#### **Provide funding for:**

- Development of a network of BIRP community workers located in key rural/remote towns to extend services available from, and linked with, the closest BIRP. These community workers will:
  - Provide a key contact for referrers to improve the handover from acute services to local services for community resettlement.
  - Identify what local services are needed to continue the discharge plans, make referrals and involve service providers.
  - Develop local interagency agreements to maximise services for people with ABI and their families.
  - Have a role in education and information-sharing for families while the person is in acute care and when they return, to improve trust and service engagement.
  - Be located with other health networks, for example spinal, yet still retain specialty focus.
  - Have the capacity to engage the community in individual solutions as well as solutions for people with

similar needs by submissions/grants, accessing generic services where feasible, education of family and friends.

- Be skilled in understanding the issues for both adult and paediatric ABI clients when returning to the community, work and/or school.
- Establish a rural BIRP at Broken Hill as the primary rural centre in the far west of NSW to provide intensive ABI-specific rehabilitation and case management for a distance of 200kms that would include cross-border areas.

### **Enhancements within BIRP**

- Improve access for rural and remote clients to existing BIRP units in GWAHS (based at Bathurst and Dubbo) and GSAHS (based at Albury), and to the range of BIRP services required for intensive ABI-specific rehabilitation and case management.
- Establish paediatric coordinator positions at Dubbo and enhance the position at Bathurst. Include paediatric services in development at Broken Hill and as part of the role of the BIRP community workers.
- Enhance transitional living programs and community services for adults and paediatric clients consistent with services at other rural BIRPs.
- Design/renovate TLUs to have independent accommodation (on the same property) at no/minimal cost to families. This accommodation could also be used at other times to support rehabilitation goals.
- Access to flights for rural BIRP staff.

### **General recommendations**

- Develop key contact lists and resource information with a focus on ABI rehabilitation to facilitate return to community and provide information when re-entering the system:
  - This could be as simple as a map highlighting hospitals where rehabilitation is available and the BIRP services for GWAHS and GSAHS.
  - A system is required to update and circulate the information. This may involve the BIRP or a local agency, such as ADHC, which may already be providing similar information.
  - Effective handover of information from metropolitan acute services is required to utilise assessment and recommendations for identifying goals and developing rehabilitation plans.



- Establish information about transport services and programs available to clients with ABI and their families living in rural and remote NSW:
  - This includes coverage for staff and family travelling with the person, and meeting accommodation costs if the distance requires more than a day's travel.
  - Develop links with agencies that provide brokerage funds when needs do not clearly fit within defined guidelines and client/family has limited or/no spare funds (e.g. transport to access psychological support and psychosocial activities).
- Improve services for children after ABI:
  - Organise access to clinicians to provide teachers with the information they need when a child returns to school and at key development stages.
- Investigate:
  - Inclusion of remote families in the IPTAAS and identify other programs that would reduce the financial burden on families if criteria were extended.
  - Expanding MSOAP to include specialist clinicians.
  - The possibilities for people with ABI to have their rehabilitation managed by local rehabilitation specialists in non-BIRP services, and extend program entry criteria and the locations covered to improve access to health services and support.
  - Access to a brokerage scheme that is flexible enough to bridge the gaps in health rehabilitation and disability care, and to meet support needs of a person with ABI and their family.
  - Rural NSW hospitals and cross-border hospitals and services that can be accessed with modification to provide locally based rehabilitation services within existing resources (e.g. family education and transition at Mildura with a service agreement).

## 5.2 Additional issues faced by Aboriginal people following ABI living in remote areas

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

- The issue of gender has an impact on the acceptance and use of an Aboriginal care support worker by an Aboriginal person following ABI.
- Once an Aboriginal person with a brain injury moves back into the community, the issue of shame (bringing attention to oneself) may affect acceptance of services.
- Trust relationships are required for Aboriginal people to engage with support services.

The development of trust and engagement with an Aboriginal community is difficult when practitioners within the rural BIRP are not based in that town/community.

- Within rehabilitation programs there appears to be a mismatch between an Aboriginal client's goals and the rehabilitation goals of service providers. Meeting an Aboriginal client's priorities may mean focusing on initially meeting needs such as housing and food, before focusing on rehabilitation goals.
- The number of Aboriginal people with ABI within a community may be difficult to establish as the brain injury may not be recognised among competing co-morbidities (e.g. diabetes, drug and alcohol problems and other conditions).
- Intensive ABI rehabilitation within an Aboriginal person's community is difficult due to large distances between rural BIRP workers and a remote community.

### **Preliminary recommendations for theme two (5.2)**

Enhancements within BIRP:

- More flexible arrangements for transitional living programs that support the primary family person to reside in proximity to the TLU in minimal-cost housing. TLU/BIRP staff can establish links with the local Aboriginal community for other family matters, and to provide accommodation and support for additional family members who may want to be involved.
- Design/renovate TLUs to have independent accommodation on the same property for no/minimal cost to the family. This accommodation could also be used at other times to support rehabilitation goals.
- Provide TLP open days for staff and Aboriginal community elders so they come and have a look and know what it is about, so they can pass on a positive image.
- Utilise public relations strategies to develop trust and help the local Aboriginal community to understand the importance of the TLP/BI rehabilitation.

- Target Aboriginal health workers, who have good retention rates and community links, via open days.
- Utilise Aboriginal Liaison Officers (ALOs) in each Area Health Service to maximise contact with families and facilitate positive communication.
- Provide cultural awareness training for BIRP staff that specifically explores the issues relating to perception of brain injury, rehabilitation etc.

### General recommendations

- Develop guidelines to improve how therapists work with Aboriginal people following ABI:
  - Be specific in providing information to the family. Provide a timeframe for how long the stay will be and how it will be managed. Communicate with the extended family so that everyone understands what is happening and so they all feel listened to and supported.
  - Adopt a planned approach by engaging with Aboriginal services (pre-injury for client or family) so the family does not have to admit shameful information and ask for services.
  - Identify family and kinship so that the most appropriate family member/s is/are involved with the person with ABI in the rehabilitation process.
  - Rehabilitation for Aboriginal people after ABI needs to shift from an individual health focus to include the family as part of the rehabilitation team. This can help to maintain participation in rehabilitation. Ancillary support is required to reduce the financial burden and support the family to manage their own commitments and responsibilities.
- Enable therapists to more readily access local flights as this will reduce the time burden of distance and:
  - Enhance therapy services provided to clients in their own home and community.
  - Provide staff with ABI knowledge access to key locations so they can support transition and resettlement in the home and local community.
  - Improve support from the BIRP to local agencies working with people with ABI and their families (BIRP staff and other agency staff travel).
- Build support within the individual's community (everyday people in everyday environments). Note that these recommendations apply to all people following ABI:

- Add local BIRP community workers in key regions as part of the network of BIRP services to develop community supports.
- BIRP staff to provide the community with training on ABI and ABI rehabilitation.
- local BIRP community workers will be able to attend their local BIRP unit to improve knowledge and understanding so they can better engage extended families and involve local services.
- Utilise existing support and develop skills for rehabilitation within these supports.
- Utilise existing support networks and develop local interagency liaison informally and formally with memoranda of understanding.
- Identify local key contacts who can talk to the family while the person with ABI is in acute care and who can support the family during the transition and resettlement phase of returning home.
- ALOs should be available in regional rehabilitation hospitals.
- Provide education on ABI to Aboriginal Medical Services and Aboriginal communities. This includes distinguishing between education that is prevention awareness, and education on specific management of brain injury.

## 5.3 Access and provision of rural brain injury rehabilitation for adults and paediatric clients 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. Some areas in these regions have no rehabilitation service, or the service provided is limited due to distance. However, even where a limited rehabilitation service exists, there are little or no services and support for children who have had a brain injury.

- Within the area of NSW covered by this research, a large area (far-western) is not receiving services from a rural brain injury program.

- When staff numbers are small, a case coordination model is adopted rather than a case management model with clinical input. This essentially means that there may be no access to therapy within a brain injury service or outside.
- Rehabilitation programs and the amount of therapy available is compromised when the person with ABI and their family live more than 2 hours by road from a local BIRP. Establishing rapport, coordination of services and support to family are all difficult when visits are limited due to distance.
- The distance clients need to travel to attend a TLP and/or centred-based service is a barrier to receiving appropriate rehabilitation from a rural BIRP.
- Paediatric support within regional services is absent or fragmented. A paediatric service has been lost in some areas due to the loss of funding or staff. In some cases paediatric support was not developed. Metropolitan paediatric services are unable to effectively support transition of children and adolescents in rural and remote areas due to distance, resulting in the inability to provide face-to-face contact.

### **Preliminary recommendations for theme three (5.3)**

Provide funding for:

- Establishment of a rural BIRP at Broken Hill as the primary rural centre in the far west to provide intensive ABI rehabilitation and case management within a radius of 200kms.
- Development of a network of BIRP community workers located in key rural/remote towns to extend services available from, and linked with, the closest BIRP.

### **Enhancements within the BIRP**

- To achieve equity, minimal standards must be established within rural adult and paediatric BIRPs, including standards for models, programs and staffing mix.
- Guidelines for management of ABI from point of injury to community re-integration.
- TLUs to be available five days a week, with an option for a seven-day-a-week program.
- Establish a paediatric coordinator position at Dubbo, and include in-service development at Broken Hill and as part of the local support role of the BIRP community workers.

- Increase staffing to the unit to build capacity within local services.
- Provide skills, knowledge and mentoring to rural units as and when required to manage skill-base changes and support paediatric services.

### **General recommendations**

- Build capacity within local services to provide local rehabilitation by:
  - Developing partnerships with regional rehabilitation services.
  - Adding local BIRP community workers in key regions as part of the network of BIRP services to develop community supports and awareness.
  - Allowing BIRP staff to provide the community with training.
- Improve transport and funding for transport for:
  - Clients and family members, with availability of brokerage funding for travel.
  - Staff – consider the cost-benefit ratio and integrate into position descriptions.

## **5.4 Workforce issues**

Variation in skills, knowledge and the numbers of staff within rural BIRPs all affect the provision of brain injury rehabilitation in remote areas. This, along with workforce issues within non-brain injury services have an 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 due to the variability of staff resources, skills and knowledge of clinicians within rural brain injury programs. There is no consistency in the provision of therapy by a rural BIRP; it is dependent on the model of delivery as defined by resources.
- Primary health care nurses in remote areas are often the main providers of care coordination and other services for people with ABI, due to limited availability of other allied health resources.
- There is limited allied health input for people with ABI living in remote communities due to often vacant or poorly resourced allied health positions.

- The current structure of allied health affords a low priority to brain injury rehabilitation. Input is often for assessment only.
- It is often difficult to recruit appropriate Home Care staff in remote towns to meet the service needs of people with ABI who have high support needs and require a different approach to other client groups.

### **Preliminary recommendations for theme four (5.4)**

Provide funding for:

- Development of a network of BIRP community workers located in key rural/remote towns to extend services available from, and linked with, the closest BIRP.

### **Enhancements within the BIRP**

- Staff development in rural BIRPs – increasing skills for interdisciplinary/trans-disciplinary delivery services:
  - An organised and continuous program of training within rural BIRPs.
  - Team management requires leadership that promotes the network and responds flexibly and creatively to individual staff needs.
  - Training to facilitate interagency collaboration and secondary consultation.
  - Use of telemedicine to the metropolitan BIRPs to provide education for workers and/or families and support clinical reviews of clients.
- Build capacity with local services by:
  - Developing partnerships with rehabilitation services and private services.
  - Providing training and support, including use of training programs such as STEPS (Skills to Enable People and Communities), [Disability and Research Unit & Acquired Brain Injury Outreach Service, Queensland, 2007].

## **5.5 Community understanding of ABI**

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 family.

- People returning home after an ABI can be isolated from specialist services and be unable to access the care and support they need locally.
- Limited numbers of allied health staff and rehabilitation physicians are generally available, restricting availability and intensity of involvement.
- Clinicians and service providers located remotely can have a lack of expertise and knowledge of working with people with ABI.
- The further the distance from a rural BIRP, the less aware community support services are of specific brain injury services and of access to specific brain injury education.
- Clinicians and service providers can be reluctant to work with people with ABI when they are unsure of what is required and how services should be provided to a client and family.
- Some admission criteria to a support service can provide barriers to receiving the services needed.
- For people living remotely from their nearest local hospital, rehabilitation is usually only available as an inpatient, with non-specialist clinician involvement.
- The numbers of people living remotely requiring rehabilitation intervention at any one time can be limited.
- The understanding of, and expertise in, ABI lessens the more remotely a person lives from a BIRP, making it difficult for remote families to find what is needed for the person with ABI.

### **Preliminary recommendations for theme five (5.5)**

Provide funding for:

- A new service in Broken Hill to provide a team of clinicians and case managers with specialist ABI knowledge that operates in the same way as other BIRP community teams.

- Development of a network of BIRP community workers located in key rural/remote towns to extend services available from and linked with the closest BIRP:
  - A local BIRP community worker would be able to utilise knowledge and understanding of ABI to work with clinicians, service providers and the community to develop local solutions for the person and their family.

### **Enhancements within the BIRP**

Improve access to the expertise of BIRP staff when it is needed and as part of the rehabilitation team approach by:

- Building capacity with local services:
  - Developing partnerships with rehabilitation services and private services.
  - Providing training and support, including use of training programs such as STEPS (Skills to Enable People and Communities), [Disability and Research Unit & Acquired Brain Injury Outreach Service, Queensland, 2007].

### **General recommendations**

- Develop pathways to improve access to disability services provided by ADHC or ADHC- funded agencies for people with ABI living remotely and in need of care and support:
  - Access to disability case management is required to enable individuals and families to receive services locally across the range of their care and support needs.
- Provide information to staff about ABI that is accessible when they need it to best work with people with ABI and their families:
  - Information and learning materials need to be web-based to improve access.
  - Telehealth could be used to do clinical reviews with a local worker and client at the rural centre and clinicians at another centre, which would reduce the need for costly travel and for face-to-face review that do not require hands-on assessment, counselling behaviour management or education.
- Provide access to brokerage funds to bridge gaps and involve private services to manage ABI issues and issues of transport/distance.



# CHAPTER 6: THE PLANNING CONTEXT

This chapter presents essential data for developing a plan of action to address the issue of equity of brain injury rehabilitation in remote areas of NSW when compared with regional and metropolitan services. This includes: population data, ABI prevalence and TBI incidence data, remoteness, existing services, flight services and costing. This data underpins the plan of action in Chapter 7.

## Population data

As noted in Chapter 1, the existing brain injury rehabilitation network comprises 14 services, six of which are located in regional NSW. To highlight gaps in service delivery, population data will refer to BIRPs and geographical areas located within the Greater Western Area Health Service and Greater Southern Area Health Service.

### Greater Western Area Health Service (GWAHS)

GWAHS serves approximately 287,481 people, 4.4% of the NSW population. The population is dispersed across a huge area, representing over 55% of the land mass of NSW (Greater Western Area Health Service, 2008).

The Mid Western BIRP and the Dubbo BIRP operate within the GWAHS. As noted in Table 6.1 below, the Mid Western BIRP services a population of about 192,000, with the areas of Condobolin and Lake Cargelligo (total population about 7,000) experiencing limited service capacity from this BIRP due to remote location and limited resources.

Dubbo BIRP covers approximately 81,000 people (see Table 6.1), this includes the Dubbo area and surrounding areas up to one hour travelling distance from the BIRP location. A number of central-western areas (total population of 19,000) are either not receiving services from the Dubbo BIRP or have limitations in service delivery due to remoteness and limited staff (see Table 6.1).

A rural BIRP service does not operate in the far-western area of NSW. A population of about 38,000, which includes the towns of Cobar, Balranald, Wentworth, Dareton and Broken Hill, and the Central Darling area, does not receive any input from a rural brain injury rehabilitation service (see Table 6.1).

### Greater Southern Area Health Service (GSAHS)

In 2006, GSAHS had an estimated resident population of approximately 474,000 people (GSAHS, 2008). 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 clients under the compensability scheme in north-east Victoria (approximate population of 82,000). SABIS services a population of 198,000. Both SWBIRS and SABIS provide a service to all areas within GSAHS, however there is only a limited service provided to the north-western areas (see table 6.1).

## Prevalence rates according to population data

In 2003 around one in 45 Australians had an ABI resulting in limitations or participation restrictions due to disability; almost three-quarters of these people were aged 65 or less. This information is based on analysis of data from the Australian Bureau of Statistics 2003 Survey of Disability, Ageing and Carers (Australian Institute of Health and Welfare, 2007).

Using this prevalence rate, and comparing to population data (Australian Bureau of Statistics, 2006), Table 6.2 notes possible ABI prevalence for locations of interest in this project. Note that these prevalence numbers includes

all levels of severity and do not identify specific numbers in the moderate to severe injury range.

It is possible that the prevalence rate of ABI in remote areas is less than in regional and metropolitan areas, as, following an ABI, many people choose not to live in, or return to, a rural/remote area due to the lack of services required after an ABI. In addition, populations in rural and remote areas have a transient nature, regardless of their needs.

Table 6.2 notes possible high numbers of ABI even in low populated areas, for example Walgett and Bourke. As discussed in Chapter 4, the provision of support and services to these groups is restricted due to issues of remoteness, service equity and work force.

## TBI incidence data 2007

TBI surveillance data (Tate, Cameron, Mathers, Rosenkoetter & Genders, 2010) inform that in 2007 there were 897 hospital admissions with ICD codes related to head injuries, with a length of stay of seven days or more, suggesting a severe injury. Of these 897, 65 (14%) were located within areas of interest for this project.

Table 6.2 refers to the location of these 65 people and the proportion of the total population. In places like Narrabri, Walgett and Bourke, the percentage of the population who sustained a TBI requiring seven days' hospitalisation or more was greater than in more highly populated areas, such as Bathurst, which receive a consistent and frequent brain injury rehabilitation service.

**Table 6.1 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 IMITATIONS 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)<br>Nyngan (Pop 2,000)       | Bourke (Pop 3,300)<br>Brewarrina (Pop 1,900)<br>Walgett (includes Lightning Ridge: Pop 7,300) | Total=19,000   |
| No rural BIRP In Far-western area               | No service  | No service  | Cobar<br>Balranald<br>Broken Hill<br>Wentworth/Dareton<br>Central Darling (Wilcannia)         | 5,200<br>2,600<br>20,000<br>7,700<br>2,000<br>Total=38,000 |

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

\*\* Includes geographical areas in Victoria

## Remoteness

Areas within an ARIA rating of moderately accessible, remote and very remote are identified in Table 6.2, indicating a range in accessibility to services, from a significant restriction in accessibility of goods, to disadvantaged with very little accessibility of goods, services and opportunities for social interaction (Australian Institute of Health and Welfare, 2008). In Table 6.2 are examples of areas that are very remote, such as Brewarrina, having a higher incidence rate of TBI in 2007 than in areas rated accessible, such as Forbes.

## Aboriginal Medical Services/ Aboriginal Community Controlled Health Service

An Aboriginal Medical Service (AMS) is a health service funded principally to provide services to Aboriginal and Torres Strait Islander individuals (National Aboriginal Community Controlled Health Organisation, 2010). If community controlled, an AMS will be eligible to become a member of the National Aboriginal Community Controlled Health Organisation (NACCHO).

An Aboriginal Community Controlled Health Service (ACCHS) is a primary health service initiated and operated by the local Aboriginal community to provide holistic and culturally appropriate health care to the community that controls it, via a locally elected board of management.

Aboriginal communities operate over 130 ACCHSs/AMSs across Australia. Within NSW over 48 ACCHSs operate throughout the state. The locations of AMSs/ACCHSs for areas of interest in this project were discussed in 3.2 and Table 3.1.

## Hospitals

All locations of interest within the project have access to a hospital/health service, located within the LGA (see Table 6.2). Local hospitals provide opportunities for shared resources, such as access to vehicles, consultation clinics, meeting rooms and staff support.

## Transport

Access to transport is an indication of remoteness. There is a higher cost burden when transport is limited or not available. Table 6.2 summarises transport options for each area. Map 6.2 identifies flight options within GWAHS and GSAHS that, if utilised, will extend the service area of the BIRP and provide access to services for rural and remote communities.

## Costing data

In documenting the cost of ABI, recent data that could be obtained pertained to TBI only, however this data reported estimates of the cost of TBI (both moderate to severe) to Australia. The total cost of TBI in Australia was estimated to be \$8.6 billion, comprising costs attributed to moderate TBI (\$3.7 billion) and severe TBI (\$4.8 billion) [Access Economics Pty Ltd, 2009]. The lifetime costs per case of TBI were estimated to be \$2.5 million and \$4.8 million for moderate TBI and severe TBI respectively across Australia (Access Economics Pty Ltd, 2009).

**Table 6.2 Populations, prevalence, incidence and services summary**

| LOCATION   | TOTAL POPULATION <sup>1</sup> | ABORIGINAL POPULATION <sup>2</sup> | POSSIBLE PREVALENCE <sup>3</sup> | TBI INCIDENCE DATA 2007 <sup>4</sup>        | ARIA RATING <sup>5</sup> | AMS OR ACCHS    | HOSPITAL | TRANSPORT  |
|--|-------------------------------|------------------------------------|----------------------------------|---|--------------------------|-----------------|----------|--|
| Albury   | 46,500                        | 970                                | 880                              | 4 (0.008% of total population) <sup>6</sup> | Highly accessible        | Yes             | Yes      | RPT – rail and coach services from Sydney                              |
| Wagga Wagga  | 57,400                        | 2,400                              | 960                              | 9 (0.01% of total population)               | Highly accessible        | Yes             | Yes      | RPT – rail and coach services from Sydney                              |
| Bathurst   | 35,000                        | 1,200                              | 580                              | 10 (0.02% of total population)              | Highly accessible        | Yes             | Yes      | RPT – rail and coach services from Sydney                              |
| Dubbo  | 38,000                        | 3,900                              | 630                              | 4 (0.008% of total population)              | Accessible               | Yes             | Yes      | RPT – rail and coach services from Sydney                              |
| Mildura  | 50,000                        | 1,500                              | 830                              | Hospital admissions to Victoria             | Accessible               | Yes             | Yes      | RPT from Melbourne and Adelaide. Coach travel from Sydney and Adelaide |
| Blayney (includes Carcoar, Barry and Burnt Yards)  | 6300                          | 151                                | 110                              | 3 (0.04% of total population)               | Accessible               | -               | Yes      | RPT to Bathurst, coach service from Bathurst                           |
| Mid-Western regions (includes Mudgee, Bara, Beryl) | 23,000                        | NA                                 | 380                              | 4 (0.02% of total population)               | Accessible               | -               | Yes      | RPT to Dubbo, CF to Mudgee   |
| Broken Hill  | 20,000                        | 1,200                              | 330                              | 2 (0.01% of total population) <sup>7</sup>  | Accessible               | Yes             | Yes      | RPT, coach services from Sydney/Dubbo                                  |
| Wentworth (Dareton)                                | 7,100                         | 610                                | 120                              | Hospital admissions to Victoria             | Accessible               | Dareton         | Yes      | RPT to Mildura (31km road travel from Mildura)                         |
| Narromine  | 6,400                         | 1,000                              | 110                              | 1(0.01% of total population)                | Accessible               | Yes (committee) | Yes      | Coach travel from Dubbo  |
| Parkes   | 14,300                        | 1,000                              | 240                              | -   | Accessible               | Yes             | Yes      | RPT – rail and coach services from Sydney, coach service from Dubbo    |
| Oberon   | 5,100                         | 100                                | 80                               | 2 (0.04% of total population)               | Accessible               | -               | Yes      | Coach service  |

| LOCATION  | TOTAL POPULATION <sup>1</sup> | ABORIGINAL POPULATION <sup>2</sup> | POSSIBLE PREVALENCE <sup>3</sup> | TBI INCIDENCE DATA 2007 <sup>4</sup>   | ARIA RATING <sup>5</sup> | AMS OR ACCHS | HOSPITAL | TRANSPORT   |
|---|-------------------------------|------------------------------------|----------------------------------|--|--------------------------|--------------|----------|---|
| Forbes  | 9,400                         | 630                                | 160                              | 1 (0.01% of total population)          | Accessible               | Yes          | Yes      | RPT to Parkes (33km road travel from Parkes), rail and coach services from Sydney. Coach service from Dubbo |
| Griffith  | 23,600                        | 900                                | 390                              | 3 (0.01% of total population)          | Accessible               | Yes          | Yes      | RPT – rail and coach services from Sydney   |
| Junee   | 5,800                         | 310                                | 97                               | 4 (0.07% of total population)          | Accessible               | –            | Yes      | RPT to Wagga Wagga (32 km road travel from Wagga). Coach travel from Junee                                  |
| Hay   | 3,500                         | 150                                | 60                               | –                                      | Moderately accessible    | Yes          | Yes      | AHF from Albury, coach travel from Sydney and Adelaide  |
| Bairnald  | 2,600                         | 170                                | 43                               | 2 (0.08% of total population)          | Moderately accessible    | Yes          | Yes      | CF – coach travel from Sydney and Adelaide  |
| Warren  | 2,700                         | 330                                | 45                               | 1 (0.04% of total population)          | Moderately accessible    | –            | Yes      | Bus service from Dubbo (limited service)  |
| Menindee  | 340                           | 150                                | 6                                | Hospital admissions to South Australia | Moderately accessible    | Yes          | Yes      | Community bus from Menindee to Broken Hill (5/7 days)   |
| Coonamble   | 4,400                         | 1,070                              | 74                               | –                                      | Remote                   | Yes          | Yes      | CF – Coach service from Dubbo   |
| Lachlan LGA - (includes Condobolin and Lake Cargelligo) | 7,300                         | 900                                | 121                              | 1 (0.01% of total population)          | Moderately accessible    | Yes          | Yes      | Rail service from Sydney to Parkes, daily buses from Parkes   |
| Narrabri  | 13,000                        | 1,200                              | 216                              | 4 (0.03% of total population)          | Moderately accessible    | –            | Yes      | CF – coach service from Dubbo   |



| LOCATION                                       | TOTAL POPULATION <sup>1</sup> | ABORIGINAL POPULATION <sup>2</sup> | POSSIBLE PREVALENCE <sup>3</sup> | TBI INCIDENCE DATA 2007 <sup>4</sup> | ARIA RATING <sup>5</sup> | AMS OR ACCHS | HOSPITAL | TRANSPORT  |
|--|-------------------------------|------------------------------------|----------------------------------|--------------------------------------|--------------------------|--------------|----------|--|
| Cobar  | 5,200                         | 530                                | 86                               | 1 (0.02% of total population)        | Remote                   | Yes          | Yes      | CF – coach service from Dubbo                          |
| Nyngan   | 2,000                         | 300                                | 33                               | -                                    | Remote                   | -            | Yes      | Coach service from Dubbo                               |
| Walgett (Includes Lightning Ridge)             | 7,300                         | 1,960                              | 122                              | 3 (0.04% of total population)        | Remote                   | Yes          | Yes      | CF – coach service from Dubbo                          |
| Carrathool (Hillston)                          | 2,900                         | 180                                | 48                               | -                                    | Remote                   | -            | Yes      | Coach service from Griffith                            |
| Bourke   | 3,300                         | 910                                | 54                               | 1 (0.03% of total population)        | Very remote              | Yes          | Yes      | CF – coach service from Dubbo                          |
| Brewarrina                                     | 1900                          | 1,160                              | 32                               | 2 (0.1% of total population)         | Very remote              | Yes          | Yes      | Coach service from Dubbo                               |
| Central Darling (includes Wilcannia and Tilpa) | 2,000                         | 780                                | 33                               | 3 (0.15% of total population)        | remote                   | -            | Yes      | Community bus from Broken Hill to Wilcannia (5/7 days) |

1 ABS data 2006 include Local Government Areas (LGAs)

2 ABS data 2006

3 Numbers aged under 65, for total population. Based on prevalence rates of ABI of 1 in 45 Australians (Australian Institute of Health and Welfare, 2007).

4 NSW hospital incidence data for 2007, length of stay over seven days and over (Tate, Cameron, Mathers, Rosenkoetter & Genders, 2010)

5 Accessibility/Remoteness Index of Australia (ARIA) rating

6 Does not include Victorian data where a number of retrievals for severe TBI occurs

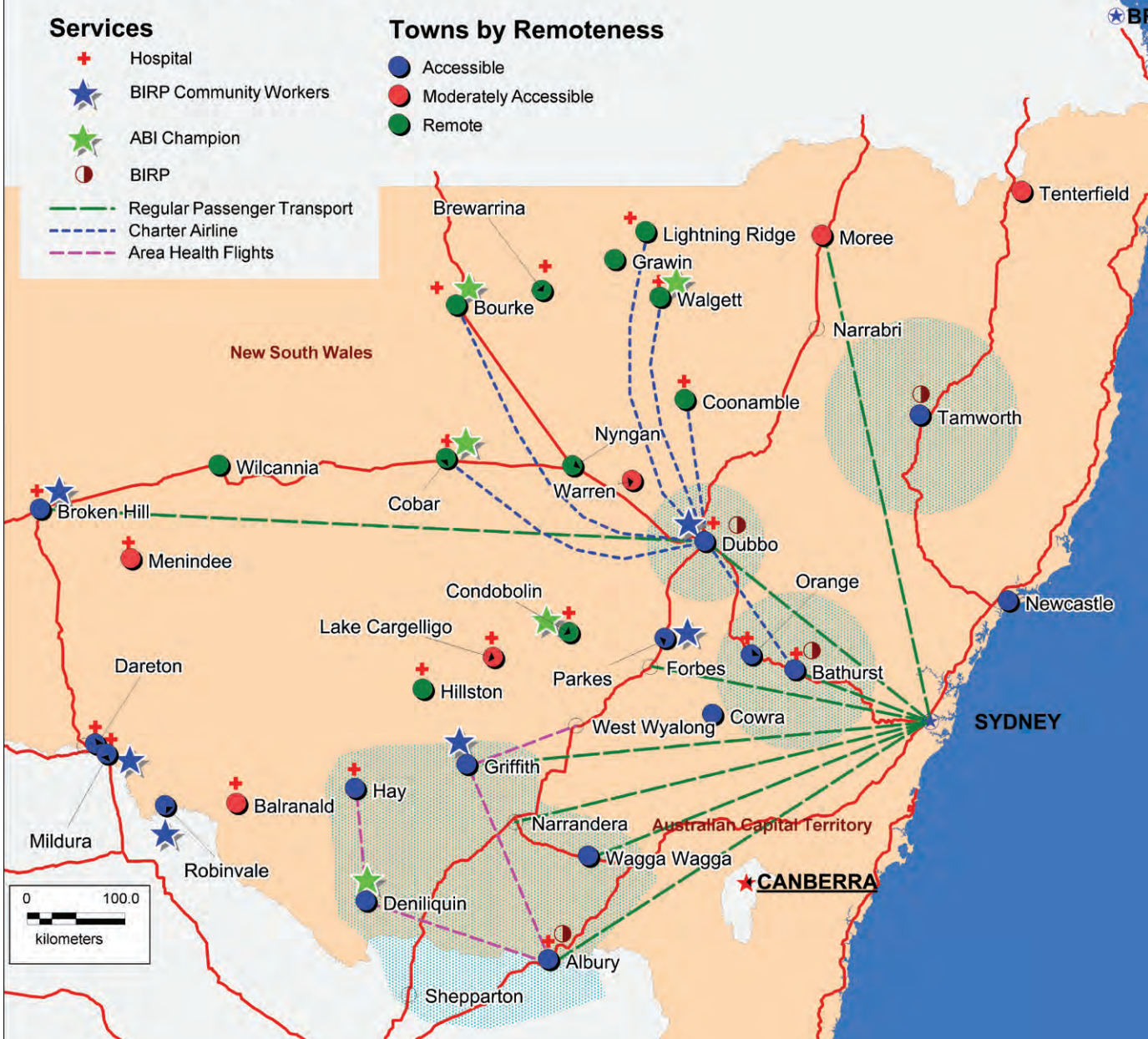
7 Majority hospital admissions for severe TBI to South Australia

RPT – regular passenger travel from Sydney or Melbourne (Mildura)

CF – chartered flights from Dubbo

AHF – area health flights operating within Greater Southern Area Health Service from Albury Airport, operate bi-monthly.

# Map 6.2 Flight pathways



# CHAPTER 7: RECOMMENDATIONS: A PLAN OF ACTION

This chapter is a plan of action to address equity of access to brain injury rehabilitation for people following an ABI living in remote areas of NSW. The plan includes:

## 7.1 The strategic context

## 7.2 The principles

## 7.3 The broad strategy

## 7.4 The specific strategies

## 7.5 The operational details

The following plan of action is an integrated response to the issues and themes that were identified in chapters 4 and 5, taking into account the planning context presented in Chapter 6.

## 7.1 The strategic context

Each of the following points identifies part of the strategic context for addressing equity of access to brain injury rehabilitation for people following an ABI living in remote areas of NSW. These points have been repeatedly identified throughout the consultation process and need to be taken into account in any planning to address the issues:

1. The network of 14 BIRPs endeavors to provide brain injury rehabilitation service delivery across NSW.
2. The strength of the statewide network is lessened when there are gaps between the boundaries of each BIRP location or resources are inadequate for the area included.
3. In north-west NSW, central-western NSW and far-western areas the population centres are smaller, the distances are larger and the proportion of Aboriginal people is higher, especially in more remote areas.
4. People with an ABI do not have equity of access to services across the state. People in more remote areas have less access.

5. Access for Aboriginal people with ABI is made more difficult because of gaps in the cultural appropriateness of services.
6. Availability and employment of appropriate staff is more difficult in remote areas compared with urban or rural areas.
7. The lack of access to services in remote areas and access of Aboriginal people is due to:
  - The small population centres and large distances.
  - Lack of resources in some areas (the total statewide resources are not adequate to effectively cover the state).
  - Existing structures and practices.
8. The context is changing and is open to new strategic responses. This includes responses to the NSW Lifetime Care and Support Scheme, ADHC changing access to the service network available to people following ABI, and the increasing strength of the network of 14 BIRPs.

## 7.2 The principles

The following three principles underpin the action plan:

1. **People with ABI in NSW should be able to access the essential services they need, whether they are living in urban, rural or remote areas.**

An alternative could have been to limit access to services in rural and remote areas, essentially making the statement: 'If you are living in a rural/remote area you do not have a right to access essential services.' This approach was unacceptable to the stakeholders and steering committee members.

**2. The statewide network of 14 BIRPs endeavours to provide brain injury rehabilitation service delivery across NSW, addressing the needs of people with ABI (including Aboriginal people) living in remote areas.**

The implication of this is that the response to addressing issues of access does not just fall to the BIRPs in GWAHS and the GSAHS, but to all BIRPs. For example, metropolitan or other regional BIRPS may be the ones to provide staff for fly-in/fly-out specialist services to rural and remote areas. Metropolitan or other regional BIRPS may be able to provide trainers for the communities in rural and remote areas.

**3. The ability to work in a culturally appropriate way with Aboriginal people should be embedded in all BIRPs.**

An alternative could have been to set up separate Aboriginal services. This was not an approach suggested by any of the consultations. Rather, the principle was unambiguously ensuring that all BIRPs and related services have culturally appropriate services.

Locating BIRP community workers or ABI champions within Aboriginal services, such as Aboriginal Medical Services, is consistent with this principle.

## 7.3 The broad strategy

The broad strategy here is consistent with the issues and themes identified throughout the consultation process. It is broad brush and presents the key ideas that have been used to build the specific strategies and operational details in sections 7.4 and 7.5 below. It includes the following:

1. The statewide network of BIRPs needs to collectively address remote and Aboriginal brain injury rehabilitation service delivery.
2. There needs to be consistency in services available across the network.
3. Smaller population centres and larger distances create inherent difficulties for service delivery, which require an appropriate service model. Service model strategies need to emphasise:
  - Local BIRP community workers or ABI champions, and the building of local networks and connecting these networks with clients and services in the hubs of Dubbo and Broken Hill.

- Improving ABI awareness by up-skilling local staff both within health and generic community services.
  - A specialist fly-in clinical outreach team to extend the geographical borders to include rural and remote towns.
  - Hubs and nodes. This includes the development of brain injury rehabilitation hubs in Dubbo and Broken Hill.
  - Building on the capacity of existing local services and local staff wherever possible.
  - Improving access to communication and other strategies (e.g. telemedicine and video conferencing).
4. Improving coordination and support for local training and capacity building. This includes an education and training position to plan and implement statewide training to build local capacity, by having appropriate learning materials to support BIRP community workers.
  5. Allowing flexibility in BIRP community workers' clients (for example younger people following strokes, and drug- and alcohol-related injuries).
  6. Developing standards and guidelines to provide the necessary framework for action for staff to effectively implement the above.
  7. Further discussions and negotiations to take place with stakeholders including:
    - The NSW Lifetime Care and Support Scheme around the possibility of funding for shared positions within rural and remote areas.
    - Ageing, Disability and Home Care (ADHC), regarding changing criteria or priorities for community programs for people with ABI, including services for children.
    - NSW Health, for identification of sub-acute beds for transitional living programs for people with ABI, and implementation of a funding strategy to support growth and service enhancements within rural BIRPs.
    - Commonwealth Government, regarding Medicare items for ABI.



## 7.4 The specific strategies

This section details the list of strategies embedded in the recommendations.

In the stakeholder meetings, participants found it useful to identify strategies for reshaping and refocusing existing resources (and not necessarily additional funding), as distinct from those that required new resources and probably additional funding.

The following list groups the specific strategies this way. The detail of each of the strategies below is in section 7.5 (the operational details), where they are grouped by location/responsibility. Many of the strategies listed here have an impact on multiple locations.

### The priorities for reshaping and refocusing of existing resources:

1. The development of standards and guidelines within the BIRP network around remote delivery to provide the necessary framework for staff to effectively implement the above.
2. The development of guidelines within the BIRP network for cultural appropriate services for Aboriginal people following ABI.
3. Further discussions and negotiations with:
  - NSW Lifetime Care and Support Scheme.
  - ADHC.
  - NSW Health.
  - Commonwealth Government.
4. Development and implementation of an evaluation strategy for the plan of action to address delivery of brain injury services to remote areas of NSW.

### New resource priorities

1. Strengthen the Dubbo BIRP so it can operate as a hub for central-western and northern areas. This is essential for making the strategies for improving rural and remote ABI rehabilitation feasible and effective.
2. Develop a brain injury program at Broken Hill so it can operate as a hub for the far-western areas of NSW.
3. Develop a network of BIRP community workers and ABI champions within the western area of the state. These positions will provide a resource for ABI rehabilitation in remote communities in addition to developing local capacity for ABI rehabilitation.

4. Appoint paediatric coordinators/clinicians and a paediatric project worker to ensure that essential ABI rehabilitation services exist and are delivered to children, young people and their families in rural and remote areas following ABI.
5. A statewide position to support training and capacity building within rural and remote communities.
6. A project officer employed within BIRD to direct the implementation of the action plan arising from the project.

## 7.5 The operational details

This section includes the operational details of what the recommendations would look like. The operational details are grouped by location/responsibility:

### 7.5.1. Dubbo BIRP

### 7.5.2. Broken Hill BIRP (proposed)

### 7.5.3. Mid Western BIRP Bathurst

### 7.5.4. South West Brain Injury Rehabilitation Service Albury

### 7.5.5 Paediatric Brain Injury Rehabilitation services in remote areas

### 7.5.6. Brain Injury Rehabilitation Directorate (BIRD)

## 7.5.1 Dubbo BIRP-GWAHS

The Dubbo BIRP is operating with 1.6 FTE, resulting in a service capacity that includes Dubbo and a surrounding district of less than a 200km radius. This is a total population of approximately 81,000, leaving a population of 19,000 (approximately) in central-western NSW with limited or no specialist brain injury rehabilitation services. As Dubbo is the key location for services to central-western NSW, enhancements to the Dubbo BIRP are essential to equity of service delivery to these areas and identified as a priority for recommendations within this project.

Dubbo BIRP is central to the success of other key recommendations for models of delivery of brain injury rehabilitation to remote areas within this project, such as fly-in clinical outreach teams, BIRP community workers and ABI champions, due to its locality in central western NSW.



Dubbo BIRP will need to be a service hub to the outlying areas of western NSW. This includes operational support to ABI champions located within the western area, and acting as the base for a flying specialist outreach team.

A funding strategy for the BIRP service additional to the hospital budget is required, so funds generated within the BIRP from compensation schemes can generate income and be used for further enhancement of services to meet the needs of existing clients.

For Dubbo BIRP to operate as an effective BIRP hub the following is required:

### **Transitional living program (TLP)**

A TLP needs to be located at Dubbo, with clinicians attached. The Dubbo TLP will create a discharge pathway for people with moderate to severe brain injury transitioning from metropolitan services to home within western areas of NSW. The TLP will also provide the location for review assessments and further skill enhancement for community participation. Staffing required for this service includes allied health clinicians, residential care staff and a manager.

Infrastructure required for this recommendation includes a large residential house (four or five bedrooms) located on a large block. This house will need to meet accessibility requirements for a spinal cord injury resident, in the case of a dual diagnosis. This includes accessible entries and bathrooms. The residential house will include self-contained family accommodation to meet the recommendations outlined for families in sections 5.1 and 5.2. Funding for capital investment in infrastructure can be sourced outside NSW Health. The existing part-funding of bed day rates and fee for service will reduce health costs once a TLP and enhanced clinical services are operating.

### **Fly-in clinical team**

The fly-in clinical team will provide specialised ABI rehabilitation input, and will work with the BIRP community workers and ABI champions within the community teams of the rural BIRP to provide follow-up clinical input to areas remote from the rural unit. This is an example of a 'hub and spoke' model, where services are rotated through a central hub to target areas/ locations (Wakerman et al., 2006).

The specialist fly-in team will provide education and training to students in a number of key professional vocations, increasing awareness of ABI rehabilitation within rural and remote locations (Thomas, 2010).

Key personnel and resources required for this proposed fly-in service include the following:

- A coordinator/clinician.
- Two further FTE professional positions, such as an occupational therapist or psychologist.
- Provision to hire other professionals on contract for some clinic trips (e.g. rehabilitation physician, psychiatrist). Funding for this medical specialist input could be sourced via the Medical Specialist Outreach Assistance Program (MSOAP) [refer to 4.2].
- Administrative support (e.g. reception duties, organising clinic trips and financial administration).
- A team base office recommended to be located at Dubbo.
- Access to appropriate flying services, including chartered flights and use of any available NSW Health flights and Royal Flying Doctor Service flights.
- The western areas will be divided into three key areas – northern, western and south-west. The team would conduct clinics, with prearranged appointments in several communities within each region, and travel for approximately one week each month to communities in these areas. In this way, the team would visit each community and conduct clinics every three months.

### **Rationale for fly-in clinical team**

Clinical services are required to travel to remote locations as a solution to clients not currently being able to access clinicians with ABI knowledge. A fly-in outreach clinical team within a 'hub and spoke' model is recommended. Specialised outreach services, along with collaboration with local services, has been associated with improved health outcomes, more efficient client care and less use of inpatient services (Greene, Weeramanthri, Knight and Bailie, 2009). The 'hub and spoke' model was recommended as the most feasible model for distribution of rehabilitation services in rural and remote areas at a meeting of the Australasian Faculty of Rehabilitation Medicine in 2006 (Graham & Cameron, 2009). Specialised outreach services include a team of health professionals specialised in brain injury that will provide the following:

- Assessment and consultation with clients, families, BIRP community workers and local service providers across the whole western area of the state. There is extensive evidence that outcomes of ABI rehabilitation are significantly optimised when delivered by expert multidisciplinary teams of rehabilitation professionals,

such as those provided by the NSW BIRP (British Society of Rehabilitation Medicine, 2003).

- Continuity of service to the client, family and local services, commencing prior to discharge from the inpatient setting, through to TLU and community living. Clients, family and local services can get in touch with these staff for consultation between visits.
- Referrals to specialist services, where necessary, and facilitation of these links (e.g. visiting specialist clinics, telehealth).
- Relevant resources to BIRP community workers, ABI champions, local professionals and ABI key workers, and also community development activities, raising awareness of ABI issues and creating opportunities for clients to engage more fully in communities.
- A multidisciplinary clinical placement for student professionals.
- Evaluative research on the therapy approaches utilised and the model of care employed.

Appendix 15 outlines a proposal for fly-in clinical services, highlighting possibilities for delivery.

### **Community team (case managers and BIRP community workers)**

The community team within the Dubbo BIRP will include both clinicians and case managers to promote the principle of continuity of care within transitional and community rehabilitation. Case managers/clinicians will provide community rehabilitation post-discharge from a transitional program. Continuity of rehabilitation within remote areas from Dubbo will be serviced by clinicians/case managers known as BIRP community workers.

#### **BIRP community workers**

##### **BIRP community workers – Dubbo BIRP**

Two positions located in Dubbo (population 36,000), providing clinical input and case management in central-western areas and supporting local ABI champions.

Two positions are recommended within the Dubbo BIRP. These positions will have both clinical and case management responsibilities, providing community rehabilitation input to both children and adults in remote areas within a two to four-hour radius of Dubbo.

It would be ideal if these positions could be located within remote communities such as Bourke. However, due to issues of workforce availability and isolation, a more central position is required.

The BIRP community workers will provide a regular rehabilitation input to these remote areas, maximising rehabilitation recommendations arising from the fly-in clinical outreach team. Included in this is the organisation of the fly-in clinics and the job of linking clients of the rural BIRP and their families to this outreach service.

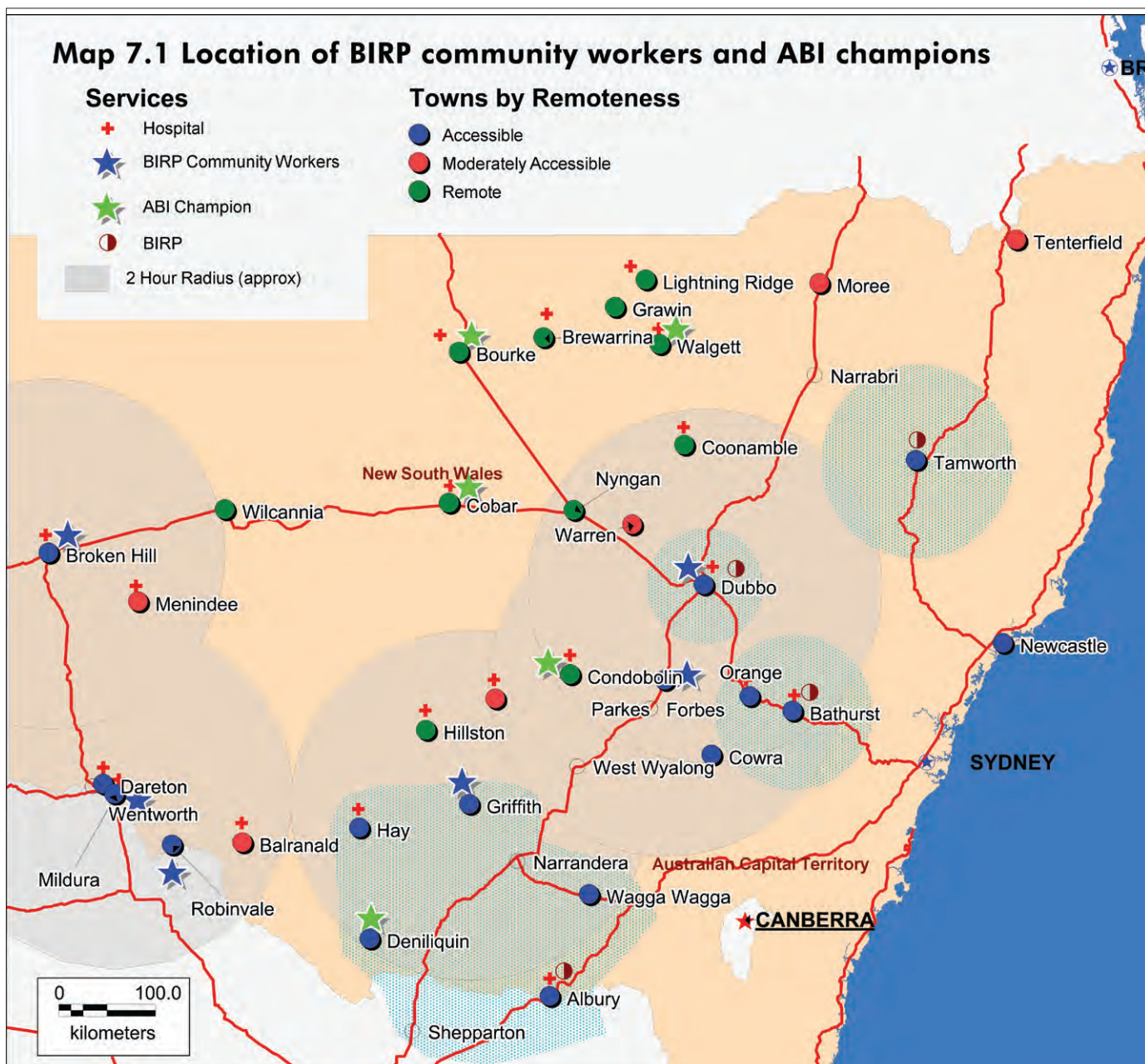
The two community workers for the Dubbo BIRP will be located at Dubbo (see Map 7.1) and will attend regular case review meetings with the whole team, ensuring that regular support and supervision is programmed.

The BIRP community workers will link with ABI champions within remote communities surrounding Dubbo, developing capacity for community ABI rehabilitation through this local collaboration. This will include providing education to the ABI champions and the development of awareness, skills and knowledge within the community, to facilitate community participation following brain injury (see Table 7.1, BIRP community worker role description). This model of service delivery moves beyond the traditional rehabilitation in the community to community-based rehabilitation (CBR), where emphasis is on developing partnerships with the person with ABI and their family, local services and the community to promote community participation (Kuipers et al., 2001, and Kendall, Buys & Larner, 2000).

#### **Rationale for BIRP community workers**

The recommended BIRP community workers and ABI champions are part of the strategy for providing consistent ABI community rehabilitation and capacity building in local resources. The community workers will be employed by the BIRP and located within Dubbo BIRP. This position will involve travel to remote areas (see Table 7.1 for role descriptions) and may have both a paediatric and adult clinical and case management caseload.

Suggestions for location of these key BIRP community workers are based on approximate population figures (Local Government Areas), incidence and prevalence data, and ARIA definition (refer to Table 7.2). Knowledge and experience in rehabilitation and enabling community participation are an expectation of this position (Table 7.1). These positions may be financed by brokerage funds.



Note that the map includes a shaded area from each of the BIRP community worker locations, highlighting areas that can be covered in a two-hour radius

## Paediatric positions

Refer to section 7.5.5.

## ABI champions

### ABI champions, Dubbo BIRP

- Located at Walgett (population 7,000)
- Located at Bourke (population 3,000)
- Located at Cobar (population 5,000)

Working collaboratively with the BIRP community worker, paediatric coordinator, people with ABI and their families, and the local community, the ABI champion will assist in the facilitation of community re-integration following brain injury. This strategy is embedded within the CBR model, where service delivery is integrated within the community structure.

ABI champions are one day per week/fortnight positions attached to other local positions. The additional hours of the ABI champions will be resourced by the Dubbo BIRP and the person employed will be accountable to this BIRP in consultation with their primary employer. Ideally the additional hours will be flexible to be responsive to



local situations as they arise. Additional hours could be provided if the caseload in the local area warranted (see Table 7.3 for role descriptions).

The ABI champion will have a sound knowledge of local services and will receive training and support in ABI issues and specific rehabilitation strategies from both the BIRP community worker and the fly-in clinical service. Telehealth tools, such as videoconferencing, will be used within this broad strategy for provision of support and skill development.

## 7.5.2 Proposal for a Broken Hill BIRP

Currently a rural BIRP service does not operate to the far-western area of NSW. As a result, a population of approx 38,000 including the towns of Cobar, Balranald, Wentworth, Dareton and Broken Hill, and the Central Darling area (including Wilcannia), do not receive any input from a rural brain injury rehabilitation service.

The 2011 health reform changes will see the commencement of the Far West Health Network, incorporating Broken Hill, Ivanhoe, Menindee and Wilcannia (NSW Department of Health, 2010). A BIRP at Broken Hill is recommended to deliver brain injury rehabilitation to this health network. This has been identified as a priority recommendation within this project due to current inequity, and prevalence data support this recommendation (refer to Table 6.2). The development of a rural BIRP at Broken Hill includes the creation of a hub to outreach to areas such as Menindee and the Central Darling area. Discussions with South Australia will take place within this proposed framework.

The towns of Balranald, Wentworth and Dareton will be placed within the new Murrumbidgee Health Network and will be serviced by the enhanced South West Brain Injury Rehabilitation Service (see recommendations in 7.5.4)

The proposed BIRP at Broken Hill needs to be developed in stages.

Recommendations include:

### Stage one (initiating change)

The location of two BIRP community workers at Broken Hill. These positions will be based in the community and will provide transitional and community rehabilitation for people following ABI and their families by providing some clinical input and case coordination, as well as the organisation of fly-in clinical services. Included in this are clinical and case coordination input (refer to Table 7.1).

**Table 7.1 BIRP community workers**

| ROLE DESCRIPTIONS – BIRP  |
|---|
| 1. Knowledge of principles of rehabilitation and ability to implement strategies for enablement of community participation.   |
| 2. Provide clinical and case coordination input within a community rehabilitation framework.  |
| 3. Be skilled in understanding the issues for both adult ABI and paediatric ABI when returning to the community, work and/or school.  |
| 4. Work with clinicians within the rural BIRP teams, including paediatric coordinators, to achieve community rehabilitation goals for people with ABI and their families.   |
| 5. Provide regular and consistent ABI rehabilitation input into communities as required.  |
| 6. Provide culturally appropriate services for Aboriginal people following ABI, their families and community.   |
| 7. Develop and maintain relationships within Aboriginal communities, including Aboriginal-specific services, to assist in the delivery of culturally appropriate rehabilitation.  |
| 8. Provide a key contact for referrers to improve the handover from acute services to local services for community re-integration.  |
| 9. Identify what local services are needed to continue the discharge plans, make referrals and involve service providers.   |
| 10. Develop local interagency agreements to maximise services for people with ABI and their families.   |
| 11. Have a role in education and information sharing for families while the person with ABI is in acute care and when they return, to improve trust and service engagement.   |
| 12. Organise fly-in specialist clinician teams and follow-up on recommendations from the clinician team.  |
| 13. Collaborate with ABI champions in remote communities in the development of a community-based rehabilitation capacity for ABI in remote communities.   |
| 14. Have the capacity to engage the community in individual solutions, as well as solutions for people with similar needs, by submissions/grant applications, accessing generic services where feasible, education of family and friends. |

**Table 7.2 Justification of location of BIRP community workers and ABI champions**

| CLUSTER LOCATIONS                             | PREVALENCE NUMBERS FOR CLUSTER* | TBI INCIDENCE DATA 2007# | TRANSPORT   | HOSPITAL | AMS OR CCHS              | LOCATION OF BIRP COMMUNITY WORKER AND ABI CHAMPION   | SUSTAINABILITY OF POSITION   |
|---|---------------------------------|--------------------------|---|----------|--------------------------|--|--|
| Broken Hill, Menindee and Wilcannia           | 370                             | 5                        | RPT to Broken Hill  | Yes      | Yes                      | Two BIRP community workers – Broken Hill   | Located within accessible area (ARIA)  |
| Dareton, Wentworth, Balranald, Hay            | 110                             | 2                        | Sealed highway from Mildura to Hay via Robinvale  | Yes      | Yes - Dareton, Balranald | BIRP community worker at Robinvale (Victoria) or Dareton   | Existing allied health and community health program at Robinvale servicing NSW. Dareton has existing service agencies and close to Mildura.                            |
| Bourke and Brewarrina                         | 90                              | 3                        | Chartered flight to Bourke. Sealed highway from Dubbo (300km)   | Yes      | Yes                      | Two BIRP community workers at Dubbo to provide regular input, and ABI champion at Bourke                 | Difficulty locating BIRP community worker in Bourke due to remoteness, however due to numbers area requires regular rehabilitation input and fly-in clinical service.  |
| Cobar, Nyngan and Warren                      | 164                             | 2                        | Chartered flight to Cobar. Sealed highway from Dubbo (300km)  | Yes      | Yes                      | Two BIRP community workers at Dubbo to provide regular input, and ABI champion at Cobar                  | Difficulty locating BIRP community worker in Cobar due to remoteness, however due to numbers area requires regular rehabilitation input and fly-in clinical service.   |
| Coonamble and Walgett                         | 196                             | 3                        | Chartered flight to Walgett. Sealed highway from Dubbo (280km)  | Yes      | Yes                      | Two BIRP community workers at Dubbo to provide regular input to Walgett area and ABI champion at Walgett | Difficult to locate BIRP community worker at Walgett due to remoteness, however due to numbers area requires regular rehabilitation input and fly-in clinical service. |
| Parkes/Forbes, Condobolin and Lake Cargelligo | 521                             | 2                        | RPT to Parkes. Parkes to Condobolin (100km good road quality). Condobolin to Lake Cargelligo (90 km on decreased road quality). | Yes      |                          | BIRP community worker at Parkes/Forbes. ABI champion at Condobolin                                       | Located within accessible area (ARIA).   |
| Griffith, Hillston                            | 408                             | 3                        | RPT to Griffith. AHF from Albury. Sealed highway to Hillston (70km).  | Yes      | Yes at Griffith          | BIRP community worker at Griffith  | Located within accessible area (ARIA). BIRP community workers could also service Hay and West Wyalong.   |

\* Based on prevalence rates of ABI of 1 in 45 Australians (Australian Institute of Health and Welfare, 2007).

# NSW hospital incidence data for 2007, length of stay of seven days and over (Tate, Cameron, Mathers, Rosenkoetter & Genders, 2010)

RPT – regular passenger travel from Sydney or Melbourne (Mildura). CF – chartered flights from Dubbo

AHF – Area health flights operating within GSAHS from Albury Airport, operate bi-monthly.



Further roles of the BIRP community worker specific to Broken Hill include liaison with South Australian brain injury services, such as the brain injury unit at Hampstead Centre. The worker will also be expected to link with the person with ABI and their family within the rehabilitation services in Adelaide and assist with transition.

Working in parallel with the BIRP community workers is a project worker for the proposed Broken Hill BIRP. This project worker will complete a scoping project addressing how a BIRP model could best be incorporated within Broken Hill, the need for a paediatric coordinator and how to build capacity of the Broken Hill BIRP. Along with the BIRP community workers, the project worker will develop links with acute and community services to flexibly respond to the further needs of ABI rehabilitation development. Identifying and working with local staff will assist in building capacity for future developments.

Support and supervision for the BIRP community workers and project worker based in Broken Hill will initially come from the Mid Western BIRP at Bathurst. Regular and formalised case reviews via videoconferencing and phone support will take place with both Bathurst and the fly-in clinical service.

#### **BIRP community workers – Broken Hill (Map 7.1)**

Two positions located at Broken Hill, supervised and supported by Mid Western BIRP (Bathurst)

### **Stage two**

The Broken Hill BIRP needs to develop a clinical capacity for ABI rehabilitation within the Broken Hill area. This includes enhanced clinical positions to provide ABI rehabilitation both within the hospital and community.

In addition to the BIRP community workers, two sub-acute beds will need to be allocated to the Broken Hill Hospital to provide some capacity for ABI transitional rehabilitation. Clinical input to these transitional beds will come from existing allied health staff in collaboration with the BIRP community workers. Fly-in specialty clinical outreach services will provide clinical support to the allied health clinicians located within the hospital and the community workers. Regular rehabilitation physician input will come from the fly-in outreach service.

### **Stage three (development of a brain injury hub at Broken Hill)**

This includes both a transitional living program (TLP) and a community team.

The TLP is separate to the sub-acute beds within Broken Hill hospital and includes a residential setting with residential workers, clinical positions and TLP coordinator.

A community team provides the next pathway in the ABI rehabilitation continuum, including clinicians and case managers providing ABI rehabilitation and support within the community. This includes the possible role of a paediatric coordinator.

The BIRP community workers, as per the Dubbo model, will deliver services to areas remote from Broken Hill (Menindee and Central Darling area). Other dedicated clinicians within the community team will deliver services in the Broken Hill area.

Clinical positions within the TLP and community team could be shared positions. Fly-in services support the range of services required to manage clients within a multidisciplinary approach.

## **7.5.3 Mid-western BIRP (Bathurst)**

### **Transitional Living Program**

The following is required for enhancements within the TLP at the mid-western BIRP:

- 1.5 FTE dedicated residential care staff so a consistent program can be offered.
- 0.5 FTE manager/occupational therapist to coordinate the program.
- Enhancement of the current TLP to include self-contained accommodation for families, or to explore alternative accommodation options so families can be part of the rehabilitation program.

The above dedicated positions will ensure that a five-day-a-week (minimal NSW standard) transitional program with a seven-day program option can be offered, responding to the need for consistent transitional rehabilitation within Bathurst and surrounding areas.

### **Paediatric positions**

Refer to 7.5.5.

## **BIRP community worker**

### **BIRP community worker – mid-western BIRP**

Located at Parkes (population 14,000) or Forbes (population 9,000)

This position will be based in Forbes or Parkes within a community location and service the area of Forbes/Parkes and remote towns of Condobolin and Lake Cargelligo (refer to Map 7.1). The BIRP community worker will provide regular rehabilitation input to the areas of Parkes, Forbes, Condobolin and Lake Cargelligo, maximising rehabilitation recommendations arising from the fly-in clinical outreach team and inpatient programs. Included in this role is the organisation of the fly-in clinics and linking clients of the rural BIRP and their families to the outreach service. A dual clinical and case coordination role is included in this position.

This position will be employed under the mid-western BIRP at Bathurst. As a member of the community team, this position will include weekly support and supervision around caseload management. This position will involve travel to remote areas (see Table 7.1 for role descriptions) and may have both a paediatric and adult clinical and case management caseload. Knowledge and experience in rehabilitation and enabling community participation is an expectation of this position (Table 7.1).

Suggestions for location of these key BIRP community workers are based on approximate population figures (Local Government Areas), incidence and prevalence data and ARIA definition to increase retention in these positions (refer to Table 7.2). To further enhance sustainability and support options, this position could be separated into two part-time positions.

## **ABI champion**

One position is recommended within the mid-western BIRP (Map 7.1).

### **ABI champion – mid-western BIRP**

Condobolin – position located in community initially supported by Mid Western BIRP, Bathurst.

Working collaboratively with the BIRP community worker, paediatric coordinator, the person with ABI and their families and the local community, the ABI champion will assist in the facilitation of community re-integration following brain injury. This strategy is embedded within

the CBR model where service delivery is integrated within the community structure.

The ABI champion will be a one-day per week/fortnight position attached to other local positions. The additional hours of the ABI champions will initially be supported by the Bathurst BIRP and the person employed will be accountable to this program in consultation with their primary employer. Ideally the additional hours will be flexible to be responsive to local situations as they arise. Additional hours may be provided if caseloads in the local area warrant (see Table 7.3 for role descriptions).

The ABI champion will bring a sound knowledge of local services and will receive training and support in ABI issues and specific rehabilitation strategies from the BIRP community worker at Parkes/Forbes and clinical fly-in service. Telehealth tools, such as videoconferencing, will be utilised within this broad strategy for provision of support and skill development.

## **7.5.4 South West Brain Injury Rehabilitation Service (SWBIRS) Albury**

### **BIRP community workers**

Two positions recommended (see Map 7.1).

#### **BIRP community workers – SWBIRS, Albury**

Robinvale (population 2,500)\*\* – initially supported by SWBIRS, Albury

OR

- Dareton, located near Mildura (population 50,000) is an alternative option to Robinvale. This position will also be initially supported by SWBIRS, Albury

AND

- Griffith (population 24,000) – initially supported by SWBIRS, Albury

\*\* *Robinvale [Victoria]. Will require negotiations with Victorian agencies.*

A BIRP community worker is recommended to provide brain injury rehabilitation to the far-western areas of Dareton, Wentworth and Balranald, where currently no specialised brain injury rehabilitation service exists.

This position could be located in either Robinvale or Dareton. Robinvale on the Victorian border is centrally

located to Wentworth (near Mildura in Victoria), and Balranald and Hay in south-west NSW.

Hay is approximately two hours' drive from Robinvale. Due to its location, Robinvale Health Service currently provides allied health input to the Dareton and Balranald areas, and has been successful in sustaining allied health positions.

Dareton, located close to the Victorian regional city of Mildura, is also a possible location of a BIRP community worker. Dareton has existing health and community services (for example, Coomealla Health).

**Table 7.3 Role descriptions – ABI champions**

| ROLE DESCRIPTIONS – BIRP  |
|---|
| ABI champions will be employed by, and accountable to, the BIRP, although this will be in consultation with their primary employer. ABI champions will be added to another position in the local community; they are not stand-alone positions. They are one day per week (maximum) and could be one day per fortnight. |
| ABI champions will:   |
| 1. Be knowledgeable in ABI and the impact of ABI on everyday participation.   |
| 2. Enhance knowledge of ABI and skills of existing workers in the community.  |
| 3. Increase the profile of ABI rehabilitation within the community, including prevention of ABI.  |
| 4. Have a role in education and information-sharing for families while the person with ABI is in acute care and when they return, to improve trust and service engagement.  |
| 5. Promote engagement in community participation for people and their families living in remote communities following ABI.  |
| 6. Provide a key contact for referrers to improve the handover from acute services to local services for community resettlement.  |
| 7. Identify what local services are needed to continue the discharge plans, make referrals and involve service providers.   |
| 8. Collaborate with BIRP community workers in the development of a community-based rehabilitation capacity for ABI in remote communities.   |

A BIRP community worker employed under the SWBIRS but located at Robinvale or Dareton is recommended to provide transitional and community rehabilitation to both adults and children in the areas of Dareton, Wentworth, Balranald and Hay. At present all these areas, except Hay, receive no input from SWBIRS.

The recommended BIRP community worker (Dareton/Robinvale) under the structure of SWBIRS is in accord with the recent recommendations under the health reform discussions in NSW. These recommendations place the areas of Dareton, Wentworth and Balranald within the proposed Murrumbidgee Local Health Network (NSW Department of Health, 2010). This will place these areas in the same local health network as the SWBIRS.

The BIRP community worker based at Griffith will provide ABI rehabilitation to Griffith, Hillston and West Wyalong.

As per recommendations for Dubbo BIRP and MWBIRP, the two positions at Robinvale/Dareton and Griffith will have a dual clinical and case coordination role, and will organise regular fly-in specialist clinics and continue with the focus on transitional and community rehabilitation. Knowledge and experience in rehabilitation and enabling community participation is an expectation of this position (Table 7.1).

As members of the community team at the SWBIRS, these positions will include weekly support and supervision around caseload management from this team even though located remotely from the team.

### **ABI champion**

One position recommended.

#### **ABI champion – SWBIRS, Albury**

Located in Deniliquin (population 7, 000)

Located within a community agency in Deniliquin, this position could support people with ABI and their families in the south-western areas of NSW, including Mathoura, Deniliquin and up to Hay. Working collaboratively with the community teams at SWBIRS, BIRP community workers, the person with ABI and their families and the local community, the ABI champion will assist in the facilitation of community re-integration following brain injury. This strategy is embedded within the CBR model where service delivery is integrated within the community structure.

The ABI champion will be a one day per week/ fortnight position attached to other local positions. The additional hours of the ABI champions will initially be supported by SWBIRS and the person employed will be accountable to this BIRP in consultation with their primary employer. Ideally the additional hours will be flexible to be responsive to local situations as they arise. Additional hours can be provided if caseloads in the local area warrant (see Table 7.3 for role descriptions).

The ABI champion will bring a sound knowledge of local services and will receive training and support in ABI issues and specific rehabilitation strategies from the BIRP community worker and fly-in clinical service. The use of telehealth such as videoconferencing will be utilised within this broad strategy for provision of support and skill development.

### **Transitional Living Program**

Enhancement to the current family accommodation to include renovations for self-contained accommodation.

### **Paediatric position**

Refer to 7.5.5

## **7.5.5 Paediatric brain injury rehabilitation services in remote areas**

This report has identified that support and rehabilitation for children and young people with brain injury and their families living in rural and remote areas are absent or fragmented (see 5.1 and 5.3). The paediatric coordinator position within the Dubbo BIRP previously established with MAA funding has been lost (4.1.3). The paediatric position within the Mid Western BIRP has been diminished in role. To address this inequity between adult and paediatric services in rural areas, paediatric coordinators and paediatric-specific clinician input are required in all rural BIRPs. To ensure the implementation of the broad strategy of consistent paediatric rehabilitation across NSW, a paediatric project worker within BIRD is recommended.

Under the umbrella of paediatric brain injury rehabilitation services to rural and remote areas, the following is required:

### **Dubbo BIRP**

- 1.5 paediatric coordinator/paediatric clinician
- Specialist rehabilitation/medical paediatric clinics

The paediatric coordinator (one FTE) within the Dubbo BIRP is essential to reduce the inequities for children and young people and their families following brain injury in the western and central areas of the state. The essential roles of these positions include case coordination and support in transition from metropolitan units to home, key resource and specialty input on brain injury within the education program of the child, coordination of therapy, behavioral support and medical input and coordination with support for families in key transition periods in the child's development. This will include re-engagement with the child or young person and their family in key transition phases as required. Included in this coordination role is collaboration with the BIRP paediatric clinician, BIRP community workers and ABI champions who may be providing specific input and coordination within the child's community. Secondary consultation with providers of child services in the community, such as early intervention, education and mental health services, is also critical in this role.

The recommended designated 0.5 paediatric clinical position for Dubbo BIRP will provide paediatric therapy within the goals of ABI rehabilitation. Identified in section 4.2.1 are the difficulties in accessing therapy for children with ABI in remote areas, and a paediatric clinician position will move towards addressing this important issue. The paediatric clinician's role will include both direct clinical intervention and secondary consultation, and support to BIRP community workers who may be providing therapy.

Establishing specialist medical/rehabilitation paediatric clinics in regional locations will reduce the burden of disruption to family routine and ease travel and accommodation problems for those families who have to travel to Sydney or Newcastle for annual rehabilitation review at Sydney Children's Hospital, Children's Hospital Westmead and John Hunter Children's Hospital. In addition, it will provide the opportunity for enhanced collaborative care planning between local paediatric workers and treating rehabilitation and medical specialists. The staff requirements for these clinics will need to be negotiated depending on the capacity of the primary paediatric BIRP service.



At a minimum this will involve the paediatric rehabilitation/medical specialist but could also involve a psychologist or social worker (Medicare-accredited), physiotherapist, occupational therapist and speech pathologist. Minimum frequency proposed is an annual clinic within each BIRP with specific location to be determined by the greatest number of children. MSOAP funding could be utilised within these clinics.

### **Mid-Western Brain Injury Rehabilitation Program (MWBIRP)**

- 1.5 paediatric coordinator
- 0.5 paediatric clinician
- Specialist rehabilitation/medical paediatric clinics

The current 0.5 paediatric coordinator position needs to be increased to an FTE position, so as to reduce the inequities for children and their families following brain injury in the western and central areas of the state. Essential roles of these positions include case coordination and support with transition from metropolitan units to home, key resource and specialty input on brain injury within the education program of the child, coordination of therapy, behavioral support and medical input and coordination with support for family in key transition periods within the child's development. This will include re-engagement with the child or young person and their family in key transition phases as required. Included in this coordination role is collaboration with the BIRP paediatric clinician, BIRP community workers and ABI champions who may be providing specific input and coordination within the child's community. Secondary consultation with providers of child services in the community, such as early intervention, education and mental health services, is also critical in this role.

Within MWBIRP, an additional 0.5 paediatric clinical position will provide paediatric therapy within the goals of ABI rehabilitation. The paediatric clinician's role will include both direct clinical intervention and secondary consultation, and support to BIRP community workers who may be providing therapy.

### **Specialist rehabilitation/medical paediatric clinics**

Specialist rehabilitation/medical paediatric clinics within regional locations will reduce the burden of disruption to family routine and ease travel and accommodation

problems for those families who have to go to Sydney or Newcastle for annual rehabilitation review at Sydney Children's Hospital, Children's Hospital Westmead and John Hunter Children's Hospital. In addition, it will provide the opportunity for enhanced collaborative care planning between the local paediatric workers and treating paediatric rehabilitation/medical specialists. The staff requirements for these clinics will need to be negotiated depending on the capacity of the primary paediatric BIRP service. At a minimum this will involve the paediatric rehabilitation/medical specialist but could also involve a psychologist or social worker (Medicare-accredited), physiotherapist, occupational therapist and speech pathologist.

Minimum frequency proposed is an annual clinic within each BIRP with the specific location to be determined by the greatest number of children. MYSOAP funding could be utilised within these clinics.

### **South-West Brain Injury Rehabilitation Service (SWBIRS)**

- 0.2 enhancement of current paediatric coordination/clinical positions within the Kids Team SWBIRS

Although SWBIRS has paediatric clinical and coordination capacity within its Kids Team (see 3.1), it is unable to provide a paediatric rehabilitation service to the areas of Balranald, Wentworth and Dareton. A one day a week enhancement is required to increase capacity to respond to clinical and case coordination needs of children and their families within the areas of Balranald, Wentworth and Dareton.

This position will aim to implement the broad strategy of consistent paediatric ABI rehabilitation across the network. This includes the implementation of paediatric coordinators, paediatric clinicians within rural BIRPs and clinical guidelines and standards for paediatric ABI rehabilitation. This role will involve direct collaboration with the paediatric reference group and paediatric services statewide within BIRD to develop a model of care for paediatric rehabilitation services following ABI.

In addition will be the development of interagency policy and practice guidelines with education, early childhood and ADHC-funded services for children to ensure access to required services for children and young people following ABI.



## 7.5.6. Brain Injury Rehabilitation Directorate (BIRD)

- One Implementation Project Officer (one-year position)
- One training and capacity-building position
- 0.5 paediatric project worker

Within the BIRD the following is required:

### **Implementation Project Officer**

To ensure the implementation of the specific strategies discussed in 7.4, an Implementation Project Officer is required. Employed for 12 months in a full-time capacity, the project officer will oversee the implementation of the specific strategies. This includes the development of guidelines within the BIRPs, enhancement at Dubbo BIRP, development of fly-in clinical services, negotiations with communities for BIRP community workers and ABI champions, the lead role in negotiations with stakeholders for funding, and the introduction of evaluation strategies to evaluate the success and utilisation of new programs (for example, BIRP community workers and fly-in clinical teams). Evaluation is required so as to be accountable for funds allocated to, to enhance recurrent funding, and as evidence of the need for further program development, such as within the proposed Broken Hill BIRP. An evaluation strategy will need to:

- Monitor current access to BIRP services by people with ABI from remote areas and compare access following the implementation of the above strategies.
- Assess the cultural appropriateness of services at present and after the implementation of the BIRP Aboriginal cultural appropriateness plans and other strategies outlined above.

### **Statewide training/capacity building position**

Capacity building and development of local resources is a broad strategy within this project. This aims to enhance a community's capacity to support a person with ABI and their family as well as assist the person in skill development for participation within their community. Within this broad strategy is the use of local BIRP community workers and ABI champions, in addition to training and staff development.

To deliver this consistent training and capacity building, a statewide position is recommended with the following role:

1. Coordinate/develop appropriate training and capacity building resources, both in ABI specialist areas and in culturally appropriate services for Aboriginal people following ABI.
2. Support ABI champions and BIRP community workers (and other BIRP staff) in local training and staff development. The local ABI champion or BIRP community workers will identify what training is required specific to their community, and the statewide position could help identify strategies, resources and personnel to address the need.

This position will be located within BIRD with a budget attached to purchase services and resources as required.

The efficient operations of the recommendations discussed above are reliant on the use of effective communication strategies.

Telehealth could be used to do clinic reviews with the BIRP community worker and/or local health worker, the client at the remote centre and clinicians within the fly-in team outside of the scheduled fly-in clinics. This review would not include assessment or complex behaviour management. Telehealth sessions with local ABI champions, local support workers and clinicians can also occur. BIRP community workers will be utilised in the coordination of these reviews via telehealth. Examples include education and training, group work such as adjustment to injury, and review of use of specific cognitive strategies.

The development of information systems to record and monitor local services, contacts, travel and transport relevant to providing services in remote locations will be required. This resource development will be included in the work of the statewide training position.

### **Statewide paediatric project officer position**

This part-time position will aim to implement the broad strategy of consistent paediatric ABI rehabilitation across the network. This includes the implementation of paediatric coordinators, paediatric clinicians within rural BIRPs and clinical guidelines and standards for paediatric ABI rehabilitation. This role will involve direct collaboration with the paediatric reference group and paediatric services statewide within BIRD to develop a model of care for paediatric rehabilitation services following ABI.

In addition will be the development of interagency policy and practice guidelines with education, early childhood and ADHC-funded services for children to ensure access to services required for children and young people following ABI.

## Culturally appropriate services

The operational details discussed within section 7.5 will reduce the inequity of access to brain injury rehabilitation services for people with an ABI and their families living in remote areas of NSW. This includes Aboriginal people with an ABI living in these areas. A priority for all current BIRP and recommended enhanced BIRP services within remote areas, is culturally appropriate services.

A recommendation from this project is that within 12 months each BIRP will develop guidelines and a plan for increasing the cultural appropriateness of its services for Aboriginal people, in consultation and partnership with rural and remote Aboriginal services. Included in this recommendation are guidelines for BIRPs on how clinicians work with Aboriginal people following ABI. The development and implementation of guidelines will be supported by the statewide training and capacity building position.

**Table 7.4 Strategies for culturally appropriate services for Aboriginal people following ABI**

| CULTURALLY APPROPRIATE STRATEGIES |   |
|-----------------------------------|---|
| 1.                                | More flexible arrangements for transitional living programs (TLPs) that support the primary family person to reside in proximity to the TLU in minimal-cost housing. TLP/BIRP staff can establish links with the local Aboriginal community for other family matters and provide accommodation and support for additional family members who may want to be involved.     |
| 2.                                | Provide TLP open days for staff and community elders so they come and have a look and know what it is about so they can provide a positive image.   |
| 3.                                | Utilise public relations strategies to develop trust and engage the local Aboriginal community to understand the importance of TLPs and ABI rehabilitation.   |
| 4.                                | Target Aboriginal Health Workers who have good retention rates and community links to attend open days.   |
| 5.                                | Utilise Aboriginal Liaison Officers (ALOs) in each Area Health Service to maximise contact with families and facilitate positive communication.   |
| 6.                                | Provide cultural awareness training for BIRP staff that specifically explores issues relating to perception of brain injury, rehabilitation etc.  |
| 7.                                | Develop guidelines to improve how therapists work with Aboriginal people following ABI.   |
| 8.                                | Improve access of therapists to local flights to reduce the time burden of distance.  |
| 9.                                | Provide staff with ABI knowledge in key locations via BIRP community workers and ABI champions so they can support transition and resettlement in the home and local community.   |
| 10.                               | Improve support from a BIRP to local Aboriginal Community Controlled Health Services (ACCHSs).  |
| 11.                               | Build support within the individual's community (everyday people in everyday environments), including: <ul style="list-style-type: none"> <li>• BIRP staff to provide the community with training on ABI.</li> <li>• Bring support people to centre-based programs in local BIRPs or to outreach.</li> <li>• Clinics for training and modelling of strategies.</li> </ul> |
| 12.                               | Identify local key contacts who can talk to the family while the person with ABI is in acute care and who can support the family during the transition and resettlement phase of returning home.  |
| 13.                               | ALOs to be available in regional rehabilitation hospitals.  |
| 14.                               | Education on brain injury to Aboriginal Medical Services and Aboriginal communities, distinguishing between awareness-raising and specific management of brain injury.  |

See table 7.4 for some suggested strategies for culturally appropriate services for Aboriginal people with ABI.

### **Policy and guidelines**

Policy and guidelines within the BIRP network are required to direct the operations of the action plans arising from the project and provide a system for evaluation, ensuring best practice. The establishment of a working party within BIRD to develop policy and guidelines for brain injury rehabilitation in rural and remote areas of NSW is required within 12 months of the completion of this project. It is recommended that the working party will include membership from rural and remote Aboriginal services. The working party will be supported in the development and implementation of guidelines by the statewide training and capacity building position.

Policy and guidelines required include:

1. Minimal standards relating to models of delivery, specific programs and staffing mix within the rural adult and paediatric BIRPs.
2. Pathways for management of ABI from point of injury to community re-integration for both adult and paediatric clients of rural NSW BIRPs.
3. Directives around the availability of a seven day a week TLU program.
4. Guidelines to improve how clinicians work with Aboriginal people following ABI.
5. Guidelines for staff to support transition and resettlement of Aboriginal people in their homes and local community.
6. Guidelines for travel of clinical staff and incorporation of some travel into the roles and responsibilities of clinical staff in all BIRPs.

BIRP community workers will be employed by, and accountable to, the BIRP. They are half-time to full-time positions.

The part-time BIRP community worker position could be added to another position in the local community located outside a BIRP.

A BIRP community worker position could be split into a job-share position; this offers internal support to assist with sustainability of the position.

# APPENDICES

|                    |  |
|--------------------|--|
| <b>Appendix 1</b>  | ICD-10 AM codes for 2007 hospital admissions in NSW* |
| <b>Appendix 2</b>  | Information on RRR-BI                                |
| <b>Appendix 3</b>  | Steering committee membership                        |
| <b>Appendix 4</b>  | Information sheet – service providers                |
| <b>Appendix 5</b>  | Consent form – service providers                     |
| <b>Appendix 6</b>  | Information sheet – consumer participants            |
| <b>Appendix 7</b>  | Consent form – consumer participants                 |
| <b>Appendix 8</b>  | Interview format – rural BIRP practitioners          |
| <b>Appendix 9</b>  | Interview format – service practitioners             |
| <b>Appendix 10</b> | Interview format – consumers (family members)        |
| <b>Appendix 11</b> | Interview format – consumers                         |
| <b>Appendix 12</b> | Participant organisations’ key stakeholder workshops |
| <b>Appendix 13</b> | Consumer consultations                               |
| <b>Appendix 14</b> | Service consultations                                |
| <b>Appendix 15</b> | Proposal for fly-in clinical services                |

# APPENDIX 1: ICD-10 AM CODES FOR 2007 HOSPITAL ADMISSIONS IN NSW FOR TBI\*

- |    |  |    |  |
|----|--|----|--|
| 1  | = "S02.0 Fracture of vault of skull"   | 14 | = "S06.21 Diffuse cerebral contusions"                       |
| 2  | = "S02.1 Fracture of base of skull"  | 15 | = "S06.22 Diffuse cerebellar contusions"                     |
| 3  | = "S02.7 Multiple fractures involving skull and facial bones"  | 16 | = "S06.23 Multiple intracerebral and cerebellar haematomas"  |
| 4  | = "S02.8 Fractures of other skull and facial bones"  | 17 | = "S06.28 Other diffuse cerebral and cerebellar injury"      |
| 5  | = "S02.9 Fracture of skull and facial bones, part unspecified"   | 18 | = "S06.30 Focal cerebral and cerebellar injury, unspecified" |
| 6  | = "S06.00 Concussion"  | 19 | = "S06.31 Focal cerebral contusion"                          |
| 7  | = "S06.01 Loss of consciousness of unspecified duration"   | 20 | = "S06.32 Focal cerebellar contusion"                        |
| 8  | = "S06.02 Loss of consciousness of brief duration [less than 30 minutes]"  | 21 | = "S06.33 Focal cerebral haematoma"                          |
| 9  | = "S06.03 Loss of consciousness of moderate duration [30 minutes to 24 hours]"   | 22 | = "S06.34 Focal cerebellar haematoma"                        |
| 10 | = "S06.04 Loss of consciousness of prolonged duration [more than 24 hours] with return to pre-existing conscious level"    | 23 | = "S06.38 Other focal cerebral and cerebellar injury"        |
| 11 | = "S06.05 Loss of consciousness of prolonged duration [more than 24 hours] without return to pre-existing conscious level" | 24 | = "S06.4 Epidural haemorrhage"                               |
| 12 | = "S06.1 Traumatic cerebral oedema"  | 25 | = "S06.5 Traumatic subdural haemorrhage"                     |
| 13 | = "S06.20 Diffuse cerebral and cerebellar brain injury, unspecified"   | 26 | = "S06.6 Traumatic subarachnoid haemorrhage"                 |
|    |  | 27 | = "S06.8 Other intracranial injuries"                        |
|    |  | 28 | = "S06.9 Intracranial injury, unspecified"                   |
|    |  | 29 | = "S07.1 Crushing injury of skull"                           |

\* *Incidence of hospital-treated traumatic brain injury in New South Wales, Australia. (May, 2010). RL Tate, ID Cameron, M Mathers, U Rosenkoetter, and M Genders. Unpublished manuscript, Rehabilitation Studies Unit, University of Sydney.*



# APPENDIX 2: BACKGROUND TO RURAL REHABILITATION RESEARCH ON BRAIN INJURY (RRR-BI)

## Formation of RRR-BI program

The aim of the initiative referred to as RRR-BI (pronounced 'triple R BI') is to facilitate local rural brain injury research and service development. The intent is to focus on clinically relevant research and use research findings to guide teachings and practice.

RRR-BI is a collaboration between SWBIRS and Charles Sturt University, Albury. This partnership between an academic and a clinically based institution benefits both parties. It fosters a spirit of collaboration that enhances the practice-teaching-research feedback loop and facilitates links between professional training and employment.

Seed funding for RRR-BI was obtained through a special CSU grant. The funding of \$64,000 was to be used primarily to employ a part-time project coordinator and award a number of small project grants. RRR-BI formally commenced in April 2004, following the appointment of the project coordinator.

Although the emphasis of RRR-BI is on building rural research capacity, most research projects have direct relevance to other brain injury rehabilitation providers around Australia and overseas.

## RRR-BI vision

That all Australians who have a brain injury and live in regional, rural and remote settings receive best practice brain injury rehabilitation.

## RRR-BI mission

To be active and recognised as a centre of excellence in regional, rural and remote brain injury rehabilitation research and practice.

## Participation Project

A major project within RRR-BI, the Participation Project is the largest study to date investigating the participation of people with traumatic brain injury (TBI) living in rural and regional areas. The three-year collaborative research project was funded by the Federal Government's Australian Research Council and NSW Health, and supported by CSU and the Greater Southern Area Health Service.

### For Further information Contact:

Denis Ginnivan, Director RRR-BI

[denis.ginnivan@gsahs.health.nsw.gov.au](mailto:denis.ginnivan@gsahs.health.nsw.gov.au)

## APPENDIX 3: STEERING COMMITTEE MEMBERSHIP

Members of the steering committee (listed in alphabetical order):

|                                    |  |
|------------------------------------|--|
| <b>Robert Bosi (2007-8)</b>        | Network Manager Brain Injury Rehabilitation Directorate, Greater Metropolitan Clinical Taskforce.  |
| <b>Dr. Michael Curtin</b>          | Charles Sturt University, Course Coordinator (Occupational Therapy). Co-director RRR-BI.   |
| <b>Allan Hall</b>                  | Board member for Dubbo Aboriginal Working Party (DACWP) and Thubbo Aboriginal Medical Co-op.   |
| <b>Elizabeth Keith (2007-2008)</b> | Community Rehabilitation Worker, North Coast Brain Injury Service.   |
| <b>Lacey Healy (2007-2008)</b>     | Manager, Dubbo Brain Injury Rehabilitation Program.  |
| <b>Bonny Foye (2009)</b>           | Manager, Dubbo Brain Injury Rehabilitation Program.  |
| <b>Denis Ginnivan</b>              | Manager South West Brain Injury Rehabilitation Service. Deputy Chair NSW Brain Injury Rehabilitation Directorate and Co-Director RRR-BI. |
| <b>Raylene Gordon (2008)</b>       | Program Manager, NSW Health Aboriginal Chronic Care.   |
| <b>Lyndon Gray</b>                 | CEO Coomealla Health Aboriginal Corp, Vice - Chair Billa Muuji Aboriginal Health Services Inc.   |
| <b>Liz Heta</b>                    | Aboriginal Liaison, Albury City Council.   |
| <b>Dr. Adeline Hodgkinson</b>      | Director, Brain Injury Rehabilitation Directorate, Agency for Clinical Innovation, and Brain Injury Rehabilitation Unit, Liverpool.      |
| <b>Virginia Mitsch</b>             | Project Coordinator, Agency for Clinical Innovation, Brain Injury Rehabilitation Directorate.  |
| <b>Jane Murtagh</b>                | Team Leader/Occupational Therapist, Kids Team South West Brain Injury Rehabilitation Service.  |
| <b>Barbara Strettles (2008-10)</b> | Network Manager, Brain Injury Rehabilitation Directorate, Agency for Clinical Innovation.  |
| <b>Denise Young</b>                | Manager, Mid Western Brain Injury Rehabilitation Program.  |

# APPENDIX 4: SERVICE PROVIDERS' INFORMATION SHEET

## What is this project about?

This project will look at brain injury rehabilitation for people following a severe acquired brain injury (ABI) living in remote areas of NSW. The information from the study will help us in knowing how brain injury rehabilitation happens or doesn't happen in remote areas of NSW. From here we can then develop models on how we can do brain injury rehabilitation better in remote areas, reaching all people who need rehabilitation.

We would like to talk to a number of people involved in ABI rehabilitation in remote areas. This includes people:

- Working within the rural brain injury rehabilitation programs in NSW.
- Who have had an acquired brain injury (ABI) or their family members.
- Working within community and health services in remote areas of NSW.
- Working with Aboriginal people who have had a brain injury in rural and remote areas.

For this project a severe sudden-onset ABI refers to brain injury that has occurred due to a sudden event, either traumatic or non-traumatic. Examples of this include a motor vehicle accident, assault or stroke. It excludes progressive brain injury such as alcohol and other drug use brain injury, progressive tumour, cancers or other progressive illness.

## Who is conducting this project?

This project is a collaboration between the Brain Injury Rehabilitation Directorate (BIRD) and the Rural Rehabilitation Research on Brain Injury.

## If I take part in this project what will it involve?

Your participation in this project will include two individual interviews or focus group interviews discussing your experience with brain injury rehabilitation and service delivery. The interviews will commence in January

/February 2009 and be completed by July 2009. The interviews will usually occur in your place of work or at a location that is mutually convenient. Each interview may be up to an hour in length. The second interview will discuss issues identified across the state from all the interviews that occurred and possible strategies to address best practice for brain injury rehabilitation in remote areas.

## What will happen to the information you provide during the project?

The information you provide through the interviews will be audio-recorded, transcribed and sent to you for verification. Information will be analysed to determine issues and themes around availability and delivery of brain injury rehabilitation in remote areas of NSW. On completion of the project, you will be sent a report of the findings and outcomes of the project.

It is anticipated that the findings from this project will be presented at several conferences and will be published in peer-review journals. This project will commence in December 2008 and will aim to be completed by May 2010.

## Do I have to take part in this project?

You are under no obligation to take part in this project: participation is entirely voluntary. If you do take part you may withdraw from the project at any time without giving any reason for doing so. If you do withdraw, it won't affect your current employment. Please be aware, however, that if you decide to withdraw from the project any information that you contributed to the project within the interviews may still be used.

## How will my privacy, confidentiality and anonymity be maintained?

Only the researchers will have access to the interview data, which will include pseudonyms for anonymity.

The hard copy information from the interviews will be kept in a locked filing cabinet accessed only by the principal researcher. Information in project reports and any publications in journals will not use real names of any of the participants or place of residence and you will not be able to be identified

The ethical aspects of the project have been approved by the Human Research Ethics Committee (HREC) of the Greater Western Area Health Service.

If you have any concerns or complaints please contact the Executive Officer, PO Box 143 Bathurst NSW 2795 or telephone (02) 6339-5601.

## What happens now?

Please ask any questions about any aspects of the project that you are unsure about. We can be contacted by telephone or e-mail. Once you are sure you understand what this project is about and what your involvement would entail you need to decide whether or not you are willing to take part.

- **If you ARE WILLING to take part in this project:**

Please sign the attached consent form and send it back in the self-addressed envelope. We will contact you to make an appointment time in the near future.

- **If you ARE NOT WILLING to take part in this project:**

Please e-mail Virginia Mitsch ([virginia.mitsch@gsahs.health.nsw.gov.au](mailto:virginia.mitsch@gsahs.health.nsw.gov.au)) to state that you have decided to not participate in this research.

If you require any further information you can contact Virginia Mitsch by post, phone or e-mail.

Thank you for your interest. We look forward to hearing from you.

Virginia Mitsch

*RRRBI-Research Coordinator*

*South West Brain Injury Rehabilitation Service*

PO Box 326, Albury, NSW 2640

Ph: 02 60419902

Email: [virginia.mitsch@gsahs.health.nsw.gov.au](mailto:virginia.mitsch@gsahs.health.nsw.gov.au)

## APPENDIX 5: CONSENT FORM – SERVICE PROVIDERS

I, \_\_\_\_\_ agree to participate in the research project (study) described in the attached information sheet.

- I have read an Information Statement which explains why I have been selected and the aims of the study. The statement has been explained to me to my satisfaction.
- I have had the opportunity to ask questions and I am satisfied with the answers I have received.
- I understand I can withdraw from the study at any time without affecting my relationship or contact with any of the brain injury programs in NSW and/or health and community services.
- I agree that the information gathered from the results of the study may be published. I know I will not be identified.
- I understand that if I have any questions relating to my participation in this research, I may contact Virginia Mitsch on ph. 02 6041-9902 or 1800 637 040, who will be happy to answer them.
- I have a copy of this consent form and the Participant Information Sheet.

Participant's Name \_\_\_\_\_ Signature \_\_\_\_\_ Date \_\_\_\_\_

Witness's Name \_\_\_\_\_ Signature \_\_\_\_\_ Date \_\_\_\_\_

## REVOCATION OF CONSENT

I hereby wish to withdraw my consent to participate in the research described above and understand that such withdrawal will not affect our involvement with the SWBIRS.

Participant's Name \_\_\_\_\_ Signature \_\_\_\_\_ Date \_\_\_\_\_

*The section for revocation of consent should be forwarded to Virginia Mitsch, PO Box 326, Albury, 2640*

The ethical aspects of the project have been approved by the Human Research Ethics Committee (HREC) of the Greater Western Area Health Service. If you have any concerns or complaints please contact the Executive Officer, PO Box 143 Bathurst NSW 2795 or telephone (02) 6339-5601.

**Principal Investigator:** Virginia Mitsch  
*RRRBI-Research Coordinator, South West Brain Injury Rehabilitation Service.*



# APPENDIX 6: INFORMATION SHEET – CONSUMER PARTICIPANTS

## What is this project about?

This project will look at brain injury rehabilitation for people following a severe acquired brain injury (ABI) living in remote areas NSW. A severe ABI is a blow to the head from an accident or trauma or a bleed in the brain.

To get this information we would like to talk to a number of people who are involved in brain injury rehabilitation in rural and remote areas. These people may include:

- People working within the rural brain injury rehabilitation programs in NSW.
- People who have had an injury to their brain or their family members.
- People working within community and health services in remote areas of NSW.
- People working with Aboriginal people who have had a brain injury in rural and remote areas.

The information from the study will help us in knowing how brain injury rehabilitation happens or doesn't happen in remote areas of NSW. From here we can then develop models on how we can do brain injury rehabilitation better in remote areas, reaching all people who need rehabilitation.

## Who is conducting this project?

This project is a collaboration between the Brain Injury Rehabilitation Directorate (BIRD) and the Rural Rehabilitation Research on Brain Injury.

## If I take part in this project what will it involve?

Your part of the project includes a single one-hour interview. The interviews will aim to commence in January/February 2009. The interview will be at your closest town and help will be given with transport if needed. If you wish you may have someone with you while you are being interviewed. The interview will include questions about your experience of having a brain injury and living in remote areas and the services you have received. Information given in the interview will be taped and later typed up.

## What will happen to the information you provide during the project?

The information you provide through the interview will be audio-recorded, transcribed and sent to you for verification. Information will be analysed to determine issues and themes around availability and delivery of brain injury rehabilitation in remote areas of NSW. On completion of the project, you will be sent a report of the findings and outcomes of the project. It is anticipated that the findings from this project will be presented at several conferences and will be published in peer-review journals. This project will commence in October 2008 and will aim to be completed by May 2010.

## Do I have to take part in this project?

You are under no obligation to take part in this project: participation is entirely voluntary. If you do take part you may withdraw from the project at any time without giving any reason for doing so. If you do withdraw, it won't affect your relationship with any services you currently use. Please be aware, however, that if you decide to withdraw from the project any information that you contributed to the project within the interviews may still be used.

## How will my privacy, confidentiality and anonymity be maintained?

Only the researchers will have access to the interview data, which will not include your real names or name of where you live.

The hard copy information from the interviews will be kept in a locked filing cabinet accessed only by the principal researcher. Information in project reports and any publications in journals will not use real names of any of the participants or place of residence and you will not be able to be identified.

## What happens now?

Please ask any questions about any aspects of the project that you are unsure about. We can be contacted by telephone or email. Once you are sure you understand what this project is about and what your involvement would entail you need to decide whether or not you are willing to take part.

- **If you ARE WILLING to take part in this project:**

Please sign the attached consent form and send it back in the self-addressed envelope. We will contact you to make an appointment time in the near future.

- **If you ARE NOT WILLING to take part in this project you don't need to do anything or respond.**

If you require any further information you can contact Virginia Mitsch by post, phone or email.

Thank you for your interest. We look forward to hearing from you.

Virginia Mitsch

*Research Coordinator*

*South West Brain Injury Rehabilitation Service*

PO Box 326, Albury NSW 2641

Ph: 02 6041 9902, or 1800 637040

email: [virginia.mitsch@gsahs.health.nsw.gov.au](mailto:virginia.mitsch@gsahs.health.nsw.gov.au)

# APPENDIX 7: CONSENT FORM – CONSUMER PARTICIPANTS

I, \_\_\_\_\_ agree to participate in the research project (study) described in the attached information sheet.

- I have read an Information Statement which explains why I have been selected and the aims of the study. The statement has been explained to me to my satisfaction.
- I have had the opportunity to ask questions and I am satisfied with the answers I have received.
- I understand I can withdraw from the study at any time without affecting my relationship or contact with any of the brain injury programs in NSW and/or health and community services.
- I agree that the information gathered from the results of the study may be published. I know I will not be identified.
- I understand that if I have any questions relating to my participation in this research, I may contact Virginia Mitsch on ph. 02 6041-9902 or 1800 637 040, who will be happy to answer them.
- I have a copy of this consent form and the Participant Information Sheet.

Participant's Name \_\_\_\_\_ Signature \_\_\_\_\_ Date \_\_\_\_\_

Witness's Name \_\_\_\_\_ Signature \_\_\_\_\_ Date \_\_\_\_\_

## REVOCATION OF CONSENT

I hereby wish to withdraw my consent to participate in the research described above and understand that such withdrawal will not affect our involvement with the SWBIRS.

Participant's Name \_\_\_\_\_ Signature \_\_\_\_\_ Date \_\_\_\_\_

*The section for revocation of consent should be forwarded to Virginia Mitsch, PO Box 326, Albury, 2640*

The ethical aspects of the project have been approved by the Human Research Ethics Committee (HREC) of the Greater Western Area Health Service. If you have any concerns or complaints please contact the Executive Officer, PO Box 143 Bathurst NSW 2795 or telephone (02) 6339-5601.

**Principal Investigator:** Virginia Mitsch  
*RRRBI-Research Coordinator, South West Brain Injury Rehabilitation Service.*

# APPENDIX 8: INTERVIEW FORMAT – RURAL BIRP CLINICIANS

**Note – this is for the purpose of a guideline rather than a checklist.**

The interview is divided into sections, however the interview discussion may jump between these sections. The aim is to achieve as much descriptive and reflective data as possible, therefore prompts may be needed for examples or to further explore the topic.

## 1. Introduction:

- Aims of the study.
- Target population of the study.
- Overview of what will be covered.
- Explanation of remote.

## 2. Background information:

- Describe the population and the geographical area your BIRP services.
- Job title and responsibilities.
- Prevalence numbers including people who are Aboriginal.

## 3. Model of service delivery:

- How do you provide a service to a person with a severe ABI living in remote areas?
- In-reach versus outreach.
- Contact frequency.
- Transport for people with an ABI in accessing your service.
- What resources or strategies do you utilise to provide rehabilitation for people with a severe ABI?
- Difficulties you have in providing this service.
- What supports are currently available to Aboriginal people with an ABI?
- What barriers exist for Aboriginal people to accessing available services?
- What do you see are the needs of Aboriginal people recovering from brain injury?
- What is your understanding of culturally sensitive care? How do you provide it?
- Describe or discuss areas that are not serviced or people who don't receive a service.

- What could be been done better in providing services to people with an ABI in remote areas?
- What resources would be required to provide a more comprehensive service to people residing in remote areas?
- What would make a difference to you being able to provide a better service to people in more remote areas?
- Do you know of any other resources/services/ supports in your health service and geographical area for a person with a severe ABI?
- How is the health/community service provided?

## 4. Summary and explanation of next step in project.

# APPENDIX 9: INTERVIEW FORMAT – SERVICE PROVIDERS

**Note – this is for the purpose of a guideline rather than a checklist.**

The interview is divided into sections, however the interview discussion may jump between these sections. The aim is to achieve as much descriptive and reflective data as possible, therefore prompts may be needed for examples or to further explore the topic.

## 1. Introduction:

- Aims of the study.
- Target population of the study.
- Overview of what will be covered.

## 2. Background information:

- Describe the population/community you service and the geographical area.
- Job title and responsibilities.
- How do you provide a service in your community?
- How are health and community services provided in your service?
- What is your understanding of acquired brain injury?
- Do you think you provide a service to the target population (severe ABI) in this project?
- If so, describe this service:
- Does it provide rehabilitation?
- Number of people within the target population you have seen in last two years.
- How long are you able to see people with a severe ABI?
- Did you refer them elsewhere?

## 3. Model of service delivery:

- What supports are currently available for a person with an ABI and their families?
- Are they being utilised?
- How do you provide a service to a person with a severe ABI living in a remote area?
  - I. In-reach versus outreach
  - II. Contact frequency
  - III. Transport for people with an ABI to access your service.
- What resources or strategies do you utilise to provide rehabilitation for people with a severe ABI?

- Difficulties you have in providing this service.
- What supports are currently available to Aboriginal people with an ABI?
- What barriers exist to Aboriginal people accessing available services?
- What do you see are the needs of Aboriginal people recovering from brain injury?
- What is your understanding of culturally sensitive care? How do you provide it?
- What is your understanding of the unique impairments and difficulties experienced by someone with a severe ABI (for example, cognitive and behavioural impairments).
- Understanding of what is cognitive and behavioural intervention.
- How effective do you think you or your service is in addressing these impairments and needs?
- Difficulties you have in providing this service.
- What could have been done better in providing services to people with an ABI in more remote areas?
- For Aboriginal people with an ABI what could have been done better in providing services?
- What may have been the impact of expertise input on ABI rehabilitation, especially in regard to cognition?
- What resources/supports/services do you utilise when working with a person with a severe ABI?
- Do you know of any other resources for a person with a severe ABI?
- Understanding of a rural BIRP.
- Did anyone else assist the person with an ABI as well as your contact?

## 4. Summary and explanation of next step in project.



# APPENDIX 10: INTERVIEW FORMAT – FAMILY MEMBERS

**Note – this is for the purpose of a guideline rather than a checklist.**

The interview is divided into sections, however the interview discussion may jump between these sections. The aim is to achieve as much descriptive and reflective data as possible, therefore prompts may be needed for examples or to further explore the topic.

## 1. Introduction:

- Aims of the study.
- Phases of the study.
- Overview of what will be covered.

## 2. Injury details and acute hospital experience:

- Where did you go when you relative or significant other had their injury?

## 3. Rehabilitation:

- Did your relative or significant other have rehabilitation?
- Where was it?
- If they didn't have rehabilitation what happened?

## 4. Going home:

- When was your relative/significant other able to go home?
- Who do you think helped you when they went home?
- What services were you offered?
- Did you accept them?
- How did they find out about you?
- Where did the service come from?
- How long did you receive that service for?
- Are you still receiving services?

## 5. What did you think of the help you received?

- Were you happy with the services you received?
- Was it the right sort of help?
- What else could have helped your family?

## 6. Summary and explanation of next step in project.

# APPENDIX 11: INTERVIEW FORMAT – CONSUMERS

**Note – this is for the purpose of a guideline rather than a checklist.**

The interview is divided into sections, however the interview discussion may jump between these sections. The aim is to achieve as much descriptive and reflective data as possible, therefore prompts may be needed for examples or to further explore the topic.

## 1. Introduction:

- Aims of the study.
- Overview of what will be covered.

## 2. Injury details and acute hospital experience:

- Where did the ABI occur?
- Where did you go when it first happened?  
What hospital?

## 3. Rehabilitation:

- Did you have rehabilitation?
- Where was it?
- If you didn't have rehabilitation what happened?

## 4. Going home:

- When were you able to go home?
- What did you remember of that time when you first come back?
- Who do you think helped you when you went home?
- What services were you offered?
- Did you accept them?
- How did they find out about you?
- Where did the service come from?
- How long did you receive that service for?
- Are you still receiving services?

## 5. What did you think of the help you received?

- Were you happy with the services you received?
- Was it the right sort of help?
- What else could have helped you and your family?

## 6. Summary up and explanation of next step in project.

# APPENDIX 12: PARTICIPANT ORGANISATIONS' KEY STAKEHOLDER WORKSHOPS

## 12 May 2010

- Motor Accidents Authority (MAA)
- NSW Agency for Clinical Innovation
- Brain Injury Rehabilitation Directorate
- South West Brain Injury Rehabilitation Service
- NSW Health, Aboriginal Chronic Care
- Mid Western Brain Injury Rehabilitation Program
- NSW Health – Centre for Aboriginal Health
- NSW Health – Primary Health and Community Partnerships
- ADHC – Attendant Care and Physical Disability Branch
- Life Time Care Authority
- Greater Western Area Health Service
- Southern Area Brain Injury Service
- NSW Institute of Rural Clinical Services & Teaching, (IRCST)
- Brain Injury Association (BIA) NSW
- NSW Health – Clinical advisor to drug and alcohol division

## 14 May 2010

- Brain Injury Association (BIA) NSW
- BIRD Network Manager and Director
- NSW BIRP Directors and Managers from the following 12 of 14 units

### Metropolitan

- Children's Hospital Westmead BI Service
- BIR Unit Liverpool
- BIRP Westmead
- RRCS BIRP
- Hunter BIRS Newcastle
- Illawarra BIS
- Sydney Children's Hospital BIRP
- Kaleidoscope Paediatric BIRP, Newcastle.

### Rural

- Southern Area Brain Injury Service
- South West Brain Injury Rehabilitation Service
- Mid Western Brain Injury Rehabilitation Program
- New England BIRS

## APPENDIX 13: CONSUMER PARTICIPANTS

| NAME<br>NB: all names are pseudonyms        | INJURY TYPE | LOCATION         | ACCOMMODATION TYPE   | SUPPORT RECEIVED                   | BIRP INVOLVEMENT |
|---|-------------|------------------|--|------------------------------------|------------------|
| Anthony                                     | ABI         | Far-west NSW     | Lives with Mum & Dad   | Home care                          | No               |
| Paul  | ABI         | Far-west NSW     | On own, in rented accommodation  | In-house services (ADHC)           | No               |
| Stan  | ABI         | Far-west NSW     | Lives with Wife  | No services                        | No               |
| Murray                                      | TBI         | Central-west NSW | Supported accommodation  | Accommodation and living skills    | Yes              |
| Doug  | TBI         | Central-west NSW | Supported accommodation  | Accommodation and living skills    | Yes              |
| Rob   | TBI         | Far-west NSW     | Lives with Mum & Dad   | Home care and others (ADHC)        | No               |
| Sharon – Mother of Rob                      | N/A         | Far-west NSW     | Cares for Rob in own home  | Home care and others (ADHC)        | No               |
| Louise – Mother of Anthony                  | N/A         | Western NSW      | Cares for Anthony in own home  | Home care                          | No               |
| Mary – Mother of adult son with TBI         | N/A         | Central-west NSW | Cares for son in own home  | Home care and others (ADHC)        | Yes              |
| Alison – Mother of Murray                   | N/A         | North-west NSW   | Previously cared for son in own home                                   | N/A                                | Yes              |
| Jill – Mother of an adult daughter with TBI | N/A         | Central-west NSW | Lives in own home (provides support for daughter who lives on her own) | Daughter receives in-house support | Yes              |
| Michelle – Mother of a son with TBI         | N/A         | North West NSW   | Lives in own home with son with TBI                                    | School support                     | Yes              |
| Esther – Grandmother                        | N/A         | Central-west NSW | Lives in own home, cares for grandson with TBI                         | ADHC funded support service        | Yes              |

## APPENDIX 14: SERVICE CONSULTATIONS

| SERVICE   | NSW LOCATION   | CORE SERVICE DELIVERY   | ELIGIBILITY   | FUNDING  |
|---|--|---|---|--|
| Mid Western Brain Injury Rehabilitation Program                               | Bathurst Base Hospital                                     | Community transitional rehabilitation and case management. Transitional living program (TLP) as required. Currently only 0.5 paediatric coordinator | 5-65 following ABI. Priority afforded to TBI  | Greater Western Area Health Service NSW Health       |
| South West Brain Injury Rehabilitation Service (SWBIRS)                       | Albury – within the community                              | Community transitional rehabilitation and case management. Five day a week TLP program  | 5-65 following ABI. Priority afforded to TBI  | Greater Southern Area Health Service- NSW Health     |
| Dubbo Brain Injury Rehabilitation Program                                     | Dubbo – Lourdes Hospital                                   | Outreach case management service following ABI  | Adults working age  | Auspiced under Mercy Health Service, NSW Health      |
| New England Brain Injury Rehabilitation Service (NEBIRS) – Children’s Program | Co-located with adult team at Tamworth Hospital            | Case management service   | 0-16, ABI   | Hunter New England Health Service- NSW Health        |
| Brain Injury Rehabilitation Program, Sydney Children’s Hospital               | Sydney Children’s Hospital, Sydney                         | Inpatient, outpatient and outreach services   | Brain injury up to school age   | NSW Health   |
| Brain Injury Rehabilitation Program, Children’s Hospital at Westmead          | Rehabilitation ward of the Children’s Hospital at Westmead | Inpatient and outpatient case management and clinical service   | –   | NSW Health   |
| Kaleidoscope Paediatric Brain Injury Rehabilitation Team (PBIRT)              | Newcastle  | Rehabilitation service  | Brain Injury, birth to adolescents  | NSW Health   |
| Home Care   | A number of rural areas                                    | Domestic, personal and respite support within the home  | Young people with a disability and frail older people and their carers                | Ageing and Disability and Home care (ADHC) provided. |
| Aboriginal Home Care  | A number of rural areas                                    | Part of the Home Care Service of NSW. Domestic, personal and respite support within the home  | Younger Aboriginal people with a disability, older Aboriginal people and their carers | Ageing and Disability and Home care (ADHC) provided. |
| Children’s services provided by ADHC  | A number of rural areas                                    | Local support coordination offered in specified rural and regional communities and disability services  | Developmental delay (under 6) or intellectual disability (over 6)                     | –  |
| Broken Hill Base Hospital and Health Service                                  | Broken Hill  | Acute and ambulatory service  | All ages  | Greater Western Area health Service (GWAHS)          |



| SERVICE  | NSW LOCATION  | CORE SERVICE DELIVERY   | ELIGIBILITY                                      | FUNDING  |
|--|---|---|--|--|
| Mildura Base Hospital                              | Mildura (Victoria)  | Acute and ambulatory service  | All ages   | Ramsey Health and Victoria Health  |
| Robinvale District Health Services                 | Robinvale (Victoria/NSW border)   | Acute, aged residential, primary health care and community based services                                   | All ages   | Victoria Health and Commonwealth   |
| Primary Health Care Centres                        | Majority rural and remote areas   | Generalised primary health care to residents of a shire   | All ages   | NSW Health   |
| Aboriginal Liaison Officers (ALO)                  | A number of rural areas   | Advocate and provide support  | Aboriginal people of all ages                    | NSW Health   |
| Dubbo Plains Division General Practice             | Dubbo and surrounding rural and remote areas  | Primary health care, wellness and prevention and chronic care programs                                      | All ages   | Receive funding from Department of Health and Ageing   |
| NSW Outback Division of General Practice Ltd.      | Shires of Bourke, Brewarrina, Cobar and Walgett                                       | General practice, allied health, early intervention and prevention, nursing and medical specialist services | All ages   | Receive funding from Department of Health and Ageing   |
| Aboriginal Medical Services (AMS)                  | Balranald, Bourke, Brewarrina, Coonamble, Dareton, Dubbo, Orange, Walgett, Wellington | Operated by local community to deliver primary health care  | All ages   | Receive funding from Department of Health and Ageing   |
| Community Options                                  | Coordination of services and domestic and personal assistance                         | Eligible under HACC scheme and have complex and fluctuating needs.  | Younger people with disability and older people. | Auspiced by Home Care Service of NSW and supported by ADHC   |
| Yarrabin Services                                  | Western NSW   | Accommodation and support.  | Younger people with intellectual disability.     | Supported by ADHC  |
| Mackillop Rural Community Services                 | Balranald, Brewarrina, Coonamble and Walgett  | Promote and develop wellbeing on rural communities includes living programs                                 | All ages   | Supported by ADHC  |
| Uniting Care Ageing Community Care Far West Miraga | Broken Hill   | Domestic, personal assistance, case management, and respite care.   | Aged Care  | Supported by ADHC  |
| Employment Works                                   | Kerang and Hay  | Support unemployed people with a disability.  | Working age                                      | Supported by Commonwealth Government   |
| Private Practice                                   | Select areas  | Allied health services  | All ages   | Utilise the Medicare Primary Care Scheme where consumers can receive up to five funded allied health services. |

# APPENDIX 15: PROPOSAL TO ESTABLISH A TEAM OF BRAIN INJURY REHABILITATION PROFESSIONALS TO PROVIDE CLINICAL SERVICES IN RURAL AND REMOTE COMMUNITIES IN NSW

The model of service delivery proposed here seeks to support and extend the recommendations of the ACI-BIRD by providing regular clinics in remote communities conducted by a discrete team of ABI rehabilitation professionals.

## Overview of the proposed model of service delivery

The team would work to support the model proposed by the ACI-BIRD, in a manner consistent with established approaches to Community Based Rehabilitation (Bonner et al. 2009; RRRBI), by providing:

### **1. Best practice assessment and coordination of community-based rehabilitation with individual patients/clients and families.**

This service would engage individuals with ABI, their families/carers and local support workers in best practice assessment, rehabilitation planning and coordination. A multidisciplinary assessment conducted by ABI professionals would determine the functioning and care needs of the client. The team could facilitate development of a rehabilitation plan in collaboration with the client/family and local service providers. The team would then support local stakeholders in their work with such a plan. This approach would likely be effective with clients who are living in TLUs and also with those living in the communities.

### **2. Training and ongoing support for patients/clients, families and local service providers in remote communities.**

In undertaking the clinical services outlined above, the team would have a role in training and supporting local service providers in the remote communities to develop appropriate ABI rehabilitation knowledge and skills. There is likely to be a need for clients, families and local service providers in the remote communities to contact the team for ongoing support with rehabilitation and this could be conducted by phone, (telehealth/Skype). By undertaking a training and support role, the team

would increase the awareness of ABI issues and enhance the prospects of clients' engagement in psychosocial activity (e.g. work, relationships, and leisure activities) in communities as well as developing the competence of local service providers.

### **3. Community development to support injury prevention and opportunities for people with injury.**

There are significant advantages for clients, families and service providers in raising general awareness of ABI issues in these communities. It is highly desirable that the team would assist communities to develop their capacities on a range of strategies, including injury prevention work as well as vocational and leisure opportunities for people with an ABI. As such, the team could conduct a range of education sessions from general awareness of ABI in the community (e.g. to school students and local service groups) to more technical ABI-related topics, such as memory and behaviour management strategies.

### **4. Multidisciplinary placements for professionals-in-training.**

Multidisciplinary workplace training is a favoured approach for professional training and an excellent strategy to promote clinicians' interest in working in rural and remote communities. Additionally, students can make valuable contributions to service delivery and other aspects of the operation in a multidisciplinary rehabilitation team.

There may be some opportunities for cost recovery via new professional training funds.

## Key operational issues

The area to be serviced by the proposed professional team is very large and would most efficiently be conducted by air travel. This could be undertaken by dividing the area into three and spending a week each month in communities in each region.

Three areas might be as follows:

- Northern area: Moree, Lightning Ridge, Walgett, Bourke.
- Western area: Cobar, Broken Hill, Wilcannia, Ivanhoe.
- South-west area: Condobolin, Balranald, Wentworth.

The team would conduct clinics, with prearranged appointments in several communities within each region, and travel for approximately one week each month to communities in these areas. In this way, the team would visit each community and conduct clinics every three months. Clients, families and local service workers could consult with team members between visits. The team would also have a role in helping clients transition from acute care to communities.

It is envisaged that key team members would be employed in their professional roles in this travelling team full-time and others could be sourced from a pool of suitable staff from the Brain Injury Rehabilitation Program (BIRP). They would be selected according to the needs of clients in communities to be visited on each trip.

Practical considerations of this proposed operation would include:

- **Key personnel** – coordinator/clinician, two further FTE professional positions, provision to hire other professionals on contract for some clinic trips (e.g. rehabilitation physician, psychiatrist). Administrative support (e.g. reception duties, organising clinic trips and financial administration).
- **Office space at a team base office (e.g. Bathurst or Dubbo) and also in the communities for consultations** – office space rental, NSW Health may provide space.
- **Access to appropriate flying services** – the most cost-effective and flexible means would utilise clinicians on the team with appropriate flying qualifications, and operating hired aircraft in association with an approved flying services body (see attached example). Other options would include NSW Health flights, RFDS flights, charter services and other services (e.g. Angel flight).

- **Transport while in communities** – options could include use of NSW Health vehicles or hired vehicles.
- **Accommodation and meal allowance for the visiting team in the communities** – options could include hotels, NSW Health staff accommodation. This typical trip from Dubbo to Broken Hill would be difficult to undertake by road in a single day. It would likely require two days and nights of road travel before the team would be in position to begin consulting in Broken Hill. In comparison, the team would be able to cover this distance by air in about 2.5 hours, placing them in a position to commence clinical work near the beginning of the first day of travel. The table below shows flying can provide a significant travel time saving of up to 75% over these distances, allowing the team to travel with flexibility and as necessary between communities to conduct consultations.

In addition, when daily expenses are compared (see table), flying provides a significant travel cost saving of up to 60%. It is also noted that the flexibility and efficiency of flying would enable a relatively small team to undertake clinical work that would effectively cover the communities across the vast area of remote NSW. It seems unlikely a small team such as that proposed here could sustainably service the remote communities across such an extensive area of NSW by road.

The example presented is for the most cost-effective flying option. It would be undertaken in a hired aircraft operated by a member of the clinical team who also holds appropriate flying qualifications (e.g. commercial pilot licence). It may be necessary for the team to charter an aircraft and pilot for a week-long trip. This can cost approximately \$500 to \$1500 per flying hour, depending on the aircraft, and also some provision for daily expenses for the pilot. As such, the most cost-effective means of travel for the team is by aircraft on hire, operated by a qualified member of the clinical team, rather than by private charter.

*Thomas, M. (2010).*

### Driving vs flying time and cost example

| JOURNEY              | DRIVING |            |              |                      |            | FLYING    |             |           |
|----------------------|---------|------------|--------------|----------------------|------------|-----------|-------------|-----------|
|                      | ROAD KM | DRIVE TIME | VEHICLE COST | STAFF DAILY EXPENSES | TOTAL COST | FLIGHT KM | FLIGHT TIME | COST EST. |
| Dubbo to Cobar       | 495     | 6.25hrs    | \$230        | \$900                | \$1130     | 275       | 1.0hr       | \$350     |
| Cobar to Broken Hill | 457     | 5.2hrs     | \$208        | \$900                | \$1108     | 420       | 1.5hrs      | \$525     |
| Totals               | 952km   | 11.45hrs   | \$438        | \$1800               | \$2238     | 695       | 2.5hrs      | \$825     |

*Note. Driving comparison is for a vehicle travelling at 100 km/h and at a cost of \$40 per operating hour. Road distances and times were estimated by Mapmaker (online). Staff daily expenses were based on a team of six (three professional staff and three students) at \$150 per person. Flying comparisons are based on a Cessna 210 aircraft, a single engine, six seat (including pilot) cruising at 285 km/h, aircraft hire is approximately \$350 per operating hour.*

# ACRONYMS LIST

|       |   |        |  |
|-------|---|--------|--|
| ABI   | Acquired brain injury                           | ICD    | International Classification of Diseases                     |
| ACCHS | Aboriginal Community Controlled Health Service  | IPTAAS | Isolated Patients Travel & Accommodation Assistance Scheme   |
| ACI   | Agency for Clinical Innovation                  | MAA    | Motor Accidents Authority                                    |
| ADHC  | Ageing, Disability and Home Care Services       | MSOAP  | Medical Specialist Outreach Assistance Program               |
| ALO   | Aboriginal Liaison Officer                      | MWBIRP | Mid Western Brain Injury Rehabilitation Program              |
| AMS   | Aboriginal Medical Services                     | NACCHO | National Aboriginal Community Controlled Health Organisation |
| ARIA  | Accessibility/Remoteness Index of Australia     | NCBIS  | North Coast Brain Injury Service                             |
| BIRD  | Brain Injury Rehabilitation Directorate         | NEBIRS | New England Brain Injury Rehabilitation Service              |
| BIRP  | Brain Injury Rehabilitation Program             | PTA    | Post Traumatic Amnesia                                       |
| CBR   | Community-based rehabilitation                  | RFDS   | Royal Flying Doctor Service                                  |
| FTE   | Full-time equivalent                            | RRR-BI | Rural Rehabilitation Research on Brain Injury                |
| GIO   | Government Insurance Office                     | SABIS  | Southern Area Brain Injury Service                           |
| GSAHS | Greater Southern Area Health Service            | SWBIRS | South West Brain Injury Rehabilitation Service               |
| GWAHS | Greater Western Area Health Service             | TBI    | Traumatic Brain Injury                                       |
| HACC  | Home and Community Care                         | TLP    | Transitional Living Program                                  |
| HREOC | Human Rights and Equal Opportunities Commission |        |  |

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