How can metropolitan rehabilitation services support remote area people with an ABI best?

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Aims

There were two main aims of this research project

- To investigate how a specialised multidisciplinary brain injury rehabilitation service in Perth can improve the process for referrals, treatment and support for people with an ABI and their care givers in remote areas.
- To engage with remote area service providers to understand how best to support them and caregivers of people with ABI.

Methods

Three methods of data collection were utilised.

Part A: Education sessions on ABI including causes of brain injury, common presentations and cognitive rehabilitation techniques were provided in three towns across the West and East Kimberley. Information on an ABI rehabilitation service in Perth was also discussed. These were held with various service providers including disability service providers, allied health, nursing staff, teachers, legal aid lawyers and aged and disability support workers. Following the education session, participants were invited to complete a survey investigating needs and suggestions for service provision and considerations for supporting people with ABI in the area in which they work.

Part B: To further review the survey findings, a small focus group was conducted. Individuals representing a remote area service provider for people with disabilities, including ABI, were invited to participate in a focus group. This was then transcribed and thematically analysed.

Part C: Brightwater Care Group, provides rehabilitation, residential, respite and transition care to adults aged 18 – 65 with a neurological condition at nine locations across the Perth metropolitan region. Many clients relocate from rural and remote locations to receive services, or transfer from Perth metropolitan hospitals before discharging home to rural and remote areas.

318 Brightwater staff members who work directly with neurological clients were invited to participate in a survey regarding working with Aboriginal and/or rural and remote clients and caregivers. This was conducted via anonymous survey attached to payslips.

Relevance

High rates of brain injury, resulting from stroke or trauma, are evident in rural and remote communities; however, there is currently limited access to specialised ABI services in these areas.

People from remote areas are underrepresented in metropolitan services due to the geographical distance involved, wanting to return home, a lack of understanding of cultural needs and resource limitations. In order to provide effective rehabilitation services, support of remote area living environments is needed.

Aboriginal people with an ABI are significantly under-represented in rehabilitation programs, despite the apparent high rates of brain injury, as the assessment of ABI in Aboriginal and Torres Strait Islander Australians (June 2013) states:

> Whilst there is little data or research on brain injury in Aboriginal and Torres Strait Islander Australians, statistics suggest that risk factors for brain injury, including head injury, substance use and stroke are more common in this group than in the mainstream population. For instance, head trauma accounts for 30% of injuries requiring hospitalisation in Aboriginal and Torres Strait Islander Australians (Helps & Harrison, 2006) compared to 18% in the general population (Tovell, McKenna,Bradley, & Pointer, 2012). Between 2005-2008, Aboriginal and Torres Strait Islander Australians were 21 times more likely to suffer a head injury due to assault than their mainstream counterparts (Jamieson et al., 2008).
>
> (Stephens et al, 2013 p.14)

It is also recognised that there are limited appropriate rehabilitation services for Aboriginal people.

> "Despite the high rates of risk factors for brain injury, the use of relevant health, rehabilitation and advocacy services is **extremely low** among Aboriginal and Torres Strait Islander Australians"
>
> "Further, a lack of ABI specific services and trained service providers may contribute to ABI going undetected or misdiagnosed"
>
> (First Peoples Disability Network, 2010; Gauld et al., 2011).

It is integral that in order for ABI services for Aboriginal people to be effective they need to be '*culturally competent'.*

> " Aboriginal and Torres Strait Islander people are far less likely to engage with non-Indigenous services if they perceive or experience the service as lacking cultural competency." (Stephens et al, 2013 p.15)

Programs which are not culturally competent may not only be ineffective, but also harmful according to the *Assessment of ABI in Aboriginal and Torres Strait Islander Australians* (28th June 2013).

The provision of targeted services for Aboriginal people needs to consider the extent to which people live in rural and remote areas and the environmental difficulties in access to services.

> "In 2006, 24% of Aboriginal and Torres Strait Islander Australians lived in remote or very remote areas, compared to around one per cent of the general population (Australian Government Productivity Commission, 2011). Remoteness can be a significant barrier for service access for Aboriginal and Torres Strait Islander Australians with an ABI, there are often no or very limited disability support services and workers in remote communities" (First Peoples Disability Network, 2010).
>
> "In addition, living remotely limits an individuals' access to specialised ABI rehabilitation programmes and experienced specialised staff and services. There are limited allied health services available to people with an ABI in remote communities, and a lack of adequate transport and support for travel create additional barriers" (NSW Agency for Clinical Innovation, 2011).
>
> "Cultural competence can be defined as a distinct, but cumulative relationship between cultural awareness (knowing), cultural competence (practicing, demonstrating) and cultural proficiency (embedding as organisational practice)" (Westerman, 2012)

It is also acknowledged that a targeted, specialised, approach for Aboriginal people with a disability is required.

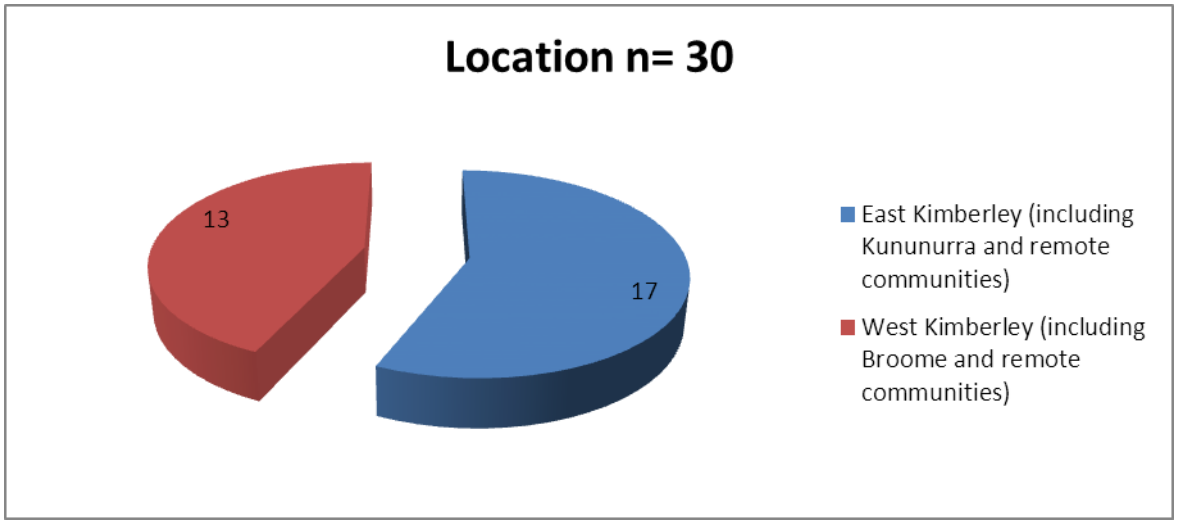
> "Aboriginal and Torres Strait Islander Australians with a disability, equitable benefit can only be achieved if additional and specialised measures are devised and implemented to overcome the pre-existing disadvantage to which Aboriginal and Torres Strait Islanders with disability are subject relative to other Australians with disability". (First Peoples Disability Network, 2010).

Results

Part A: Summary of remote area survey results

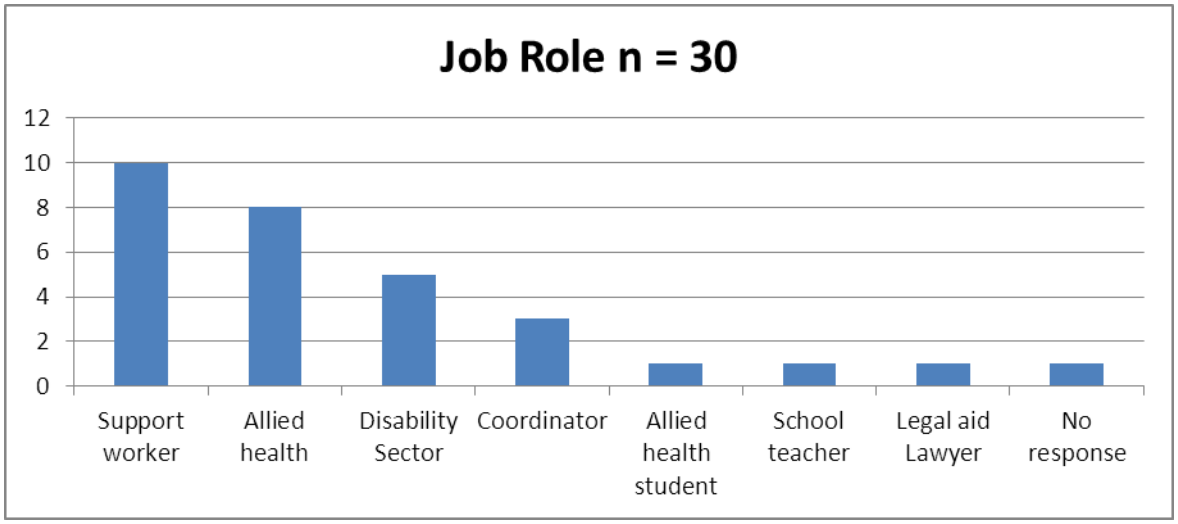
30 service providers to people with an ABI in the Kimberley region of Western Australia completed surveys regarding the needs of individuals with ABI in the communities they were working in. 17 respondents worked in the East Kimberley, including Kununurra and remote communities and 13 respondents worked in the West Kimberley, including Broome and remote communities (See Figure 1).

Figure 1



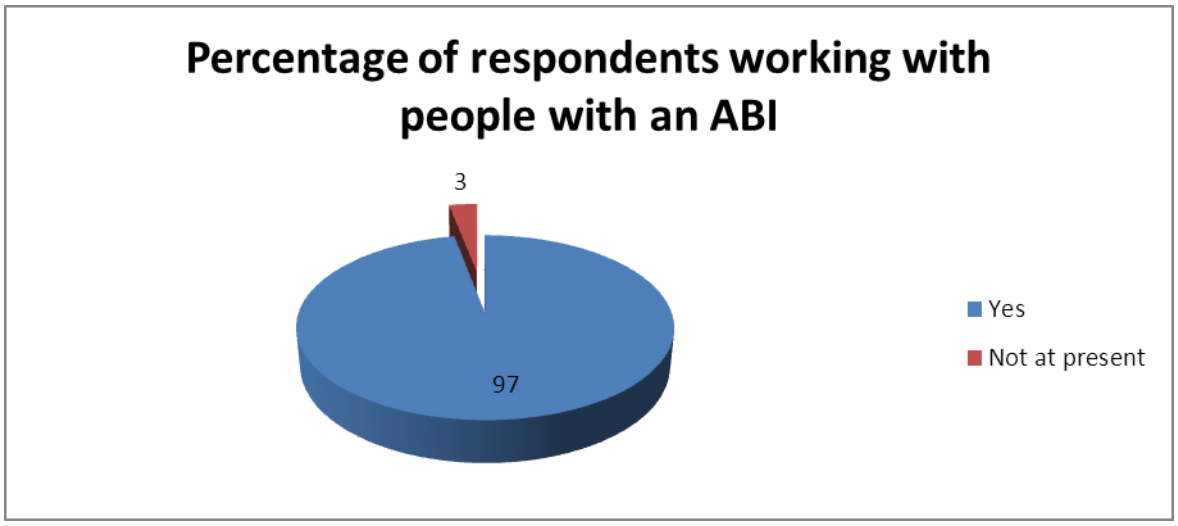
Of the respondents, most were support workers, followed by allied health workers and then workers in the disability sector. Respondents covered a large range of professions including a school teacher and legal aid lawyer (see Figure 2).

Figure 2



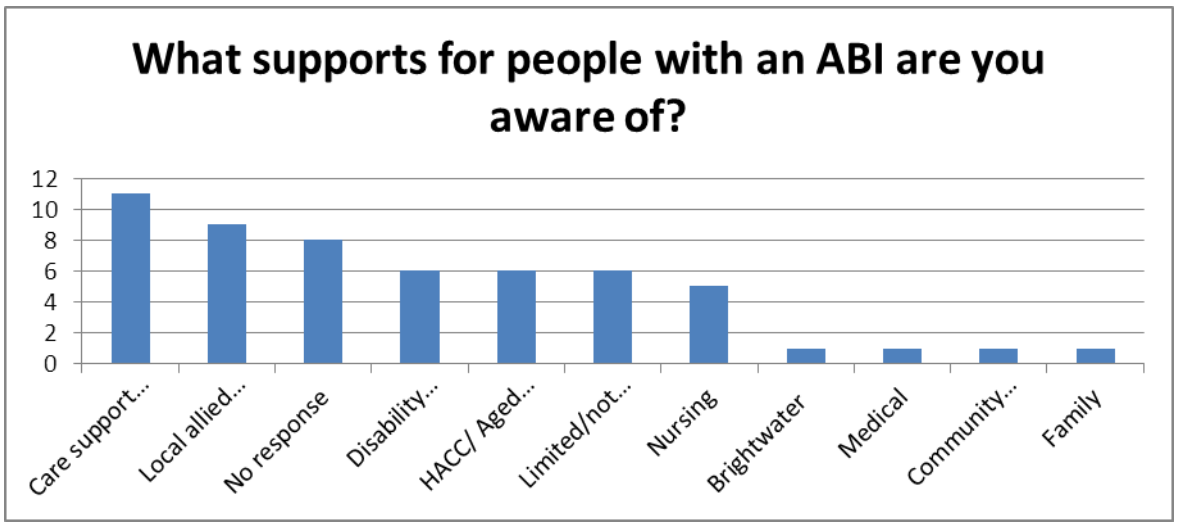
97% of respondents were currently working with people with an ABI. Only one respondent reported that they were not currently working with any clients with an ABI.

Figure 3



Respondents were asked to discuss what supports for people with an ABI they were aware of. A range of responses were provided, including care support providers, disability services, allied health, Home and Community Care (HACC) and aged care. Forty-seven percent of respondents reported that supports were limited, that they were not aware of services or they did not respond to this question (see Figure 4).

Figure 4



Respondents were then asked *'what do you think works well?'.* Responses were varied due to the diverse roles of respondents. The most common themes (ranging from most popular to least) were:

- effective communication
- supporting carers and family
- patience
- understanding client need
- a positive approach
- a consistent approach
- interagency collaboration.

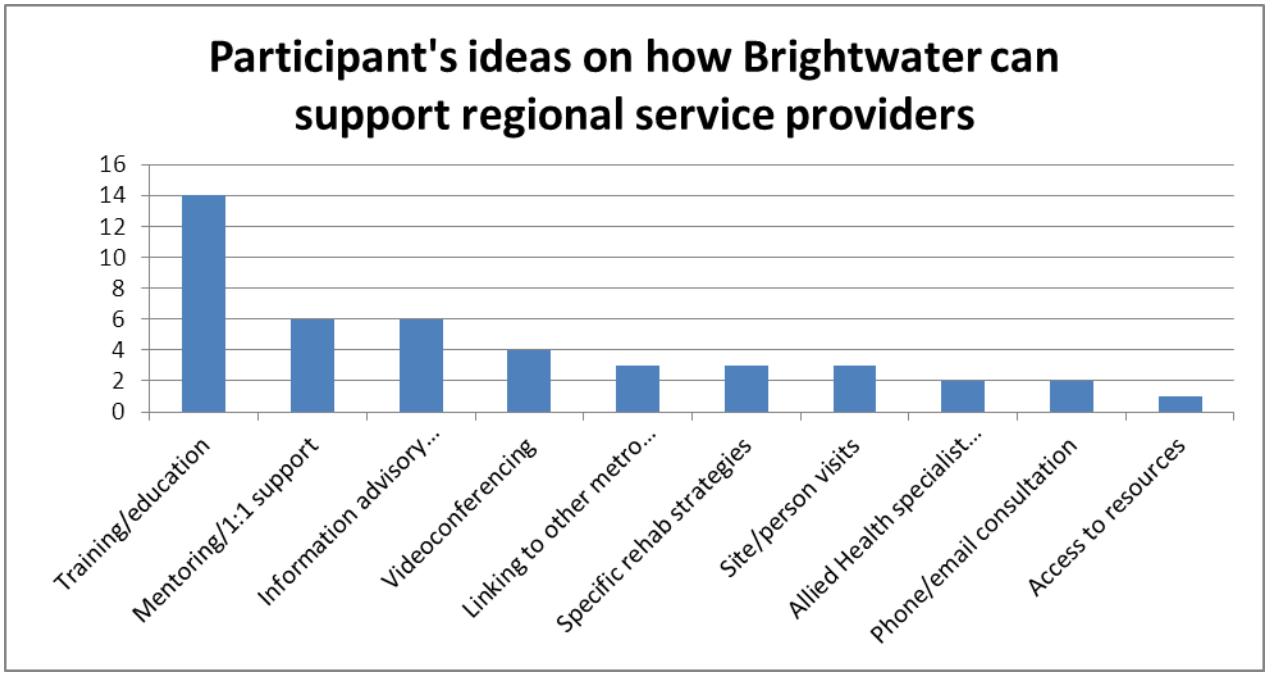
Respondents were asked for their perspectives on what is important to consider when working with people with an ABI. The themes of their most common responses (ranging from most popular to least) were:

- empathy, encouragement and inclusiveness
- function and abilities
- language and culture
- understanding service and resource possibilities and limitations
- family
- communication skills.

Participants were asked how Brightwater Care Group could support regional services providers in working with people with an ABI. The most frequent response was ***'training and education'*** which was reported by **47%** of respondents (see Figure 5). Other responses included:

- information advisory service
- mentoring/1:1 support
- videoconferencing
- specific rehabilitation strategies
- site/person visits
- phone/email consultation
- allied health specialist support
- access to resources.

Figure 5



Part B: Focus Group completed with Service Provider in Kununurra

A summary of results from a focus group with service providers to remote areas of the Kimberley is as follows.

Most service providers are external and visit remote communities for short periods.

Some providers are based in the remote communities, such as disability coordinators.. There is variability in the frequency of visits from different health and disability providers some fly in and out in a day, others stay one or two nights.

Joint collaboration between service providers is integral.

> "We rely on them, but they also rely on us for information."

> "We often take out commodes, or wheelchairs, or equipment, sticks, whatever, frames for people because the allied health can't get there."

In some cases external service providers to the remote communities provide funding to the community to employ local workers.

> "We give the money to the communities. The communities employ local people, local Aboriginal people to fill that role and they are the ones who undertake the work."

Alternative, flexible, culturally relevant respite options are able to meet people's needs more effectively.

It was discussed how one remote community has a women's center which women can go to for respite if it is acceptable based on cultural reasons related to family relationships. Many clients don't want to leave their land, so they do not want to travel into a town for respite. There are not many options for respite beds available in the Kimberley, particularly within an area accessible to individuals in remote communities (the distance between Kununurra and Broome is over 1000kms and many places require air access or long car journeys to access). When trying to access respite one participant reported:

> "it's not a matter of just picking up the phone and saying you can have this person, it is a matter of trying to find a place in the first place you know. "

Community care centers based in communities can provide a flexible approach to respite which works well through providing a 'drop in' system for providing support for breakfasts showers picking people up for appointments, shopping, hair cuts, foot baths and so forth.

> "…You do see good things, … when you go there and you see smiles on people's faces and people leaving their houses to go and visit the centers, sitting down, getting away from the humbug of general life, …watching a DVD and sitting in the air con for a while and having their feet up, its what people like and it's what people need".

> "It's very different from a metro setting where you would say okay on Wednesday you are going to be picked up and we will take you to the HACC center and then we'll take you to go and do your shopping. With this,... people walk up whenever they want, whenever they feel like it, so if they don't want to go on a particular day, they won't, but if they feel like they haven't had a very good night's sleep, they might go and lie on a couch for an hour or two and sit there and relax and take off again".

Mobile respite is positively demonstrating meeting the needs of remote area families in need of respite.

> "Mobile respite officers …they go out and they get to know people, they offer to take them fishing or back to country…"

> "They can take them back to country, they can take them to the gorges or waterholes, then can take them camping out. It's a very popular option, rather than respite coming into town."

Allied health was identified as a high priority for remote area clients.

> "The supports that my clients, … in my case load …need is mostly Allied Health."

> "…Wheelchairs, mobility aids, bathroom rails, commodes, those sorts of bits and pieces. …the best supports are allied health, and although they can't actually provide sort of physiotherapy on a regular basis because they are only out there 3 or 4 time a year, their provision of equipment and mobility aids is kind of what supports it all."

A variety of ways in which metropolitan based ABI service providers could support clients and services was discussed. Key outcomes were:

- Advice and assistance

> "Advice and assistance, especially at that initial point, when they come back to town, it's really good to have a bit of information and insight on the best way to go with people."

- Resource development

  Developing resources that are easy for both remote area service providers and clients to read and understand with simple language, with translations to Aboriginal language and visual aids (similar to the 'looking out for dementia' flip chart which is translated into three indigenous language for people living in remote areas of the Northern Territory).

> "We're not specialists in ABI… good resources for us to at least be able to share information and pass that on especially in a culturally specific way..because that means a lot to people when it's more specific to them and their home environments"

> "They are very good resources because at the same time what we're doing is we're learning as well. We can be able to relay information to people"

- Training that is culturally sensitive and appropriate

  It is important that presenters are culturally knowledgeable and preferably with experience working in remote areas. In regards to past training it was discussed:

> "Often they have no idea of Aboriginal people, Aboriginal communities and it is a waste of time."

> "We had an all day (training) here and I counted of over 64 visual images that they showed of clients there was not one Aboriginal picture, or picture of an Aboriginal person."

- Promotional material regarding what metropolitan services can provide to be given to remote area services

> "Have a bunch of pamphlets, this is what [service provider] does, this is what [service provider] can offer. We can have a bundle and start handing them out at interagency meetings. …because it is quite hard for communication lines sometimes with so many different services and so many different people."

> "If there's a way of contacting you or a way of people knowing about you, of course you don't have to be running in and out of the community when providing information will be enough."

- Advisory service

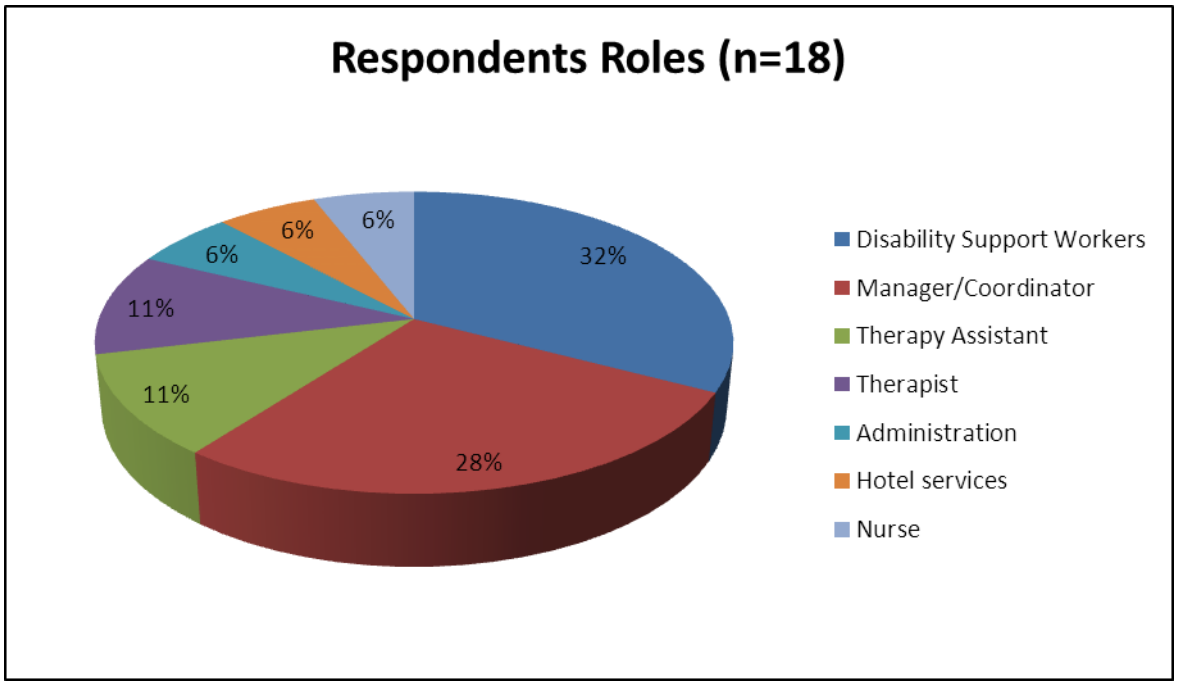
  Advisory service with regular visits to remote areas, once or twice a year, to provide training and support to regional service providers, clients and caregivers.

Part C: Surveys completed by Brightwater Care Group staff

Of the 318 surveys, 18 were returned (a response rate of 5.67%). There was a broad range staff roles represented by those who completed the survey.

The graph below indicates the percentage of responses from each staff group (Figure 6).

Figure 6



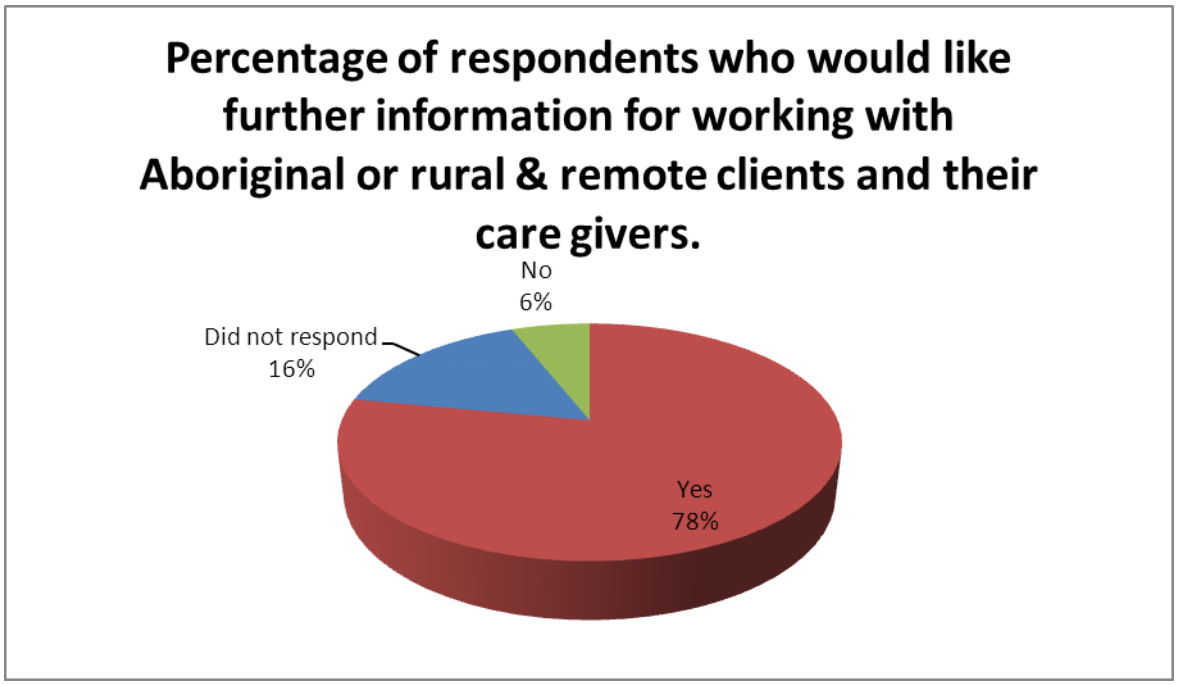
Respondents were asked to discuss the strategies and approaches they found effective for working with Aboriginal and/or rural and remote clients. A number of themes emerged, most frequent responses were:

- awareness of cultural needs and values
- adaption of communication style (including body language, listening, visual and auditory prompts)
- showing respect
- speaking some Aboriginal language
- understanding regional resources
- developing rapport.

Respondents identified awareness of cultural needs and values as well as adaptation of communication styles as key factors for working effectively with Aboriginal and rural and remote clients.

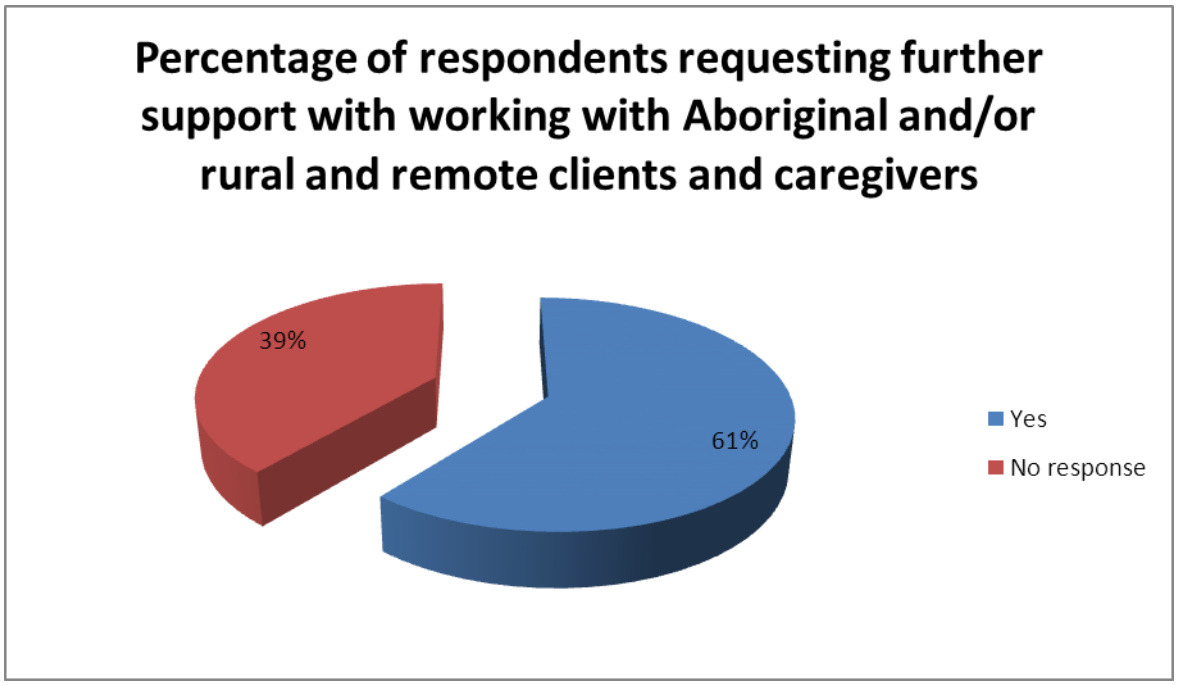
Respondents were asked if they would like further information for working Aboriginal clients and their care givers. There was a positive response with 78% of respondents indicating that they would like more information (See Figure 7).

Figure 7



Respondents were asked if they felt that they needed more support with working with Aboriginal and/or rural and remote clients and care givers. Sixty-one percent of respondents reported that they would like further support (see Figure 8).

Figure 8



Staff were asked to discuss the ways in which they would like to be supported with working with Aboriginal and/or rural remote clients and their care givers. The most frequent response was **cultural awareness training.**

Followed by:

- communication skills
- employing Aboriginal staff
- Aboriginal guest speakers
- attending Aboriginal community events

Two of the respondents reflected on the difference in service provision to people in New Zealand compared to Australian Aboriginal people.

> "As a New Zealander I have been previously confronted by the way Aboriginal people are delivered and receive services. If a training package is developed around Aboriginal Cultural Awareness I [would be] very motivated to attend." (Respondent 1)

> "In New Zealand cultural understanding, cultural etiquette and sensitivity is built into this industry's core training. I've noticed this is not a focus in Australia. This is a shame." (Respondent 2)

A third respondent commented on the effects of a brain injury being exacerbated for Aboriginal clients due to a lack of cultural understanding by service providers.

> "As a generalisation more Aboriginals come to [Brightwater Care Group] with an ABI [and] its effects seems to be exacerbated by lack of understanding of culture … a thorough pre-morbid history would be excellent." (Respondent 3)

Conclusion

There are large numbers of service providers visiting communities who have existing relationships with clients and families and thus effective service models must support these service providers. Specialised ABI services must demonstrate cultural understanding of the people and region to enable effective service provision. There are large numbers of unidentified people with ABI in remote areas and further research is required to identify and support these people.

To provide effective support to people with an ABI in remote areas, service models must recognise cultural and geographical differences. Support can be provided via various methods of communication, education and resource development. Metropolitan services providing state-wide rehabilitation services need to consider appropriate alternatives to overcome barriers.

Recommendations

- Development of policies and procedures to support Aboriginal people and their care givers residing in metropolitan rehabilitation services and promote service delivery to rural and remote areas
- Development of culturally and language appropriate resources on ABI using visual aids for support
- Implementation of identified culturally appropriate resources (such as the Strong Living Scale[1])
- Liaison and strengthening of relationships between metropolitan and remote agencies providing services to people with an ABI
- Promote greater community understanding and awareness of ABI in rural and remote regions

[1] Bohanna I (2013). Manual for the Strong Living Scale. Unpublished, James Cook University

- Develop streamlined processes for referral, admission, discharge and transition to remote areas from metropolitan services that includes support for family members whilst clients are residing in metropolitan area
- Development of mentorship processes for rural and remote health providers with ABI specialist therapists and nurses (through phone, video or email consultations)
- Further develop training programs for rural and remote health providers through utilising videoconferencing
- Accessible training and education (via various media including videoconferencing and face-to-face)
- Education packages to be delivered to remote areas and translated into local languages
- Advocacy services
- Scheduled remote community visits by ABI specialists to support local families, health providers and community members.

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References

Bohanna I (2013). Manual for the Strong Living Scale. Unpublished, James Cook University

First Peoples Disability Network. (2010). First submission to the productivity commission inquiry into disability care and support. In D. Griffis (Ed.): First Peoples Disability Network (Australia).

Gauld, S., Smith, S., & Kendall, M. B. (2011). Using participatory action research in community-based rehabilitation for people with acquired brain injury: from service provision to partnership with Aboriginal communities. Disability and Rehabilitation, 33(19 - 20), 1901 - 1911. doi:10.3109/09638288.2010.550382

NSW Agency for Clinical Innovation. (2011). Acquired brain injury rehabilitation service delivery project developing a model of care for rural and remote NSW: Brain Injury Rehabilitation Directorate.

Stephens, A., Bohanna, I., Wargent, R., Catherall, J., Timms, C., Graham, D. & Coulgh, A (June 2013) Assessment of Acquired Brain Injury in Aboriginal and Torres Strait Islander Australians: Guidance for Disability Care Australia.

Westerman, T. (2012)Indigenous Psychological Services 'General Competency Program – Supervising and supporting Aboriginal people in the workplace'.

Presenter

Kristylee Sharp is the Training and Evaluation Coordinator for Services for Younger People; Brightwater Care Group. Since graduating as an Occupational Therapist in 2002 she has worked in various fields specialising in rural and remote services, Aboriginal health and brain injury rehabilitation. Kristylee has received a number of scholarships for research and service development and has presented at conferences including the Australian Society for the Study of Brain Injury (ASSBI) and Occupational Therapy Australia on topics including developing culturally competent services for rural and remote clients; utilising contemporary technology in rehabilitation and implementing outcome measures for service evaluation. She has been on the scientific committee and chaired sessions for ASSBI and was a co-convenor of the WA Occupational Therapy Neuroscience interest group. She is passionate about providing equitable health care to all.