

# Rural parents' experiences following their child's traumatic brain injury

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# Acknowledgements

My sincere thanks firstly to the parents who so generously shared their experiences.

I also wish to acknowledge and extend my thanks to the following people for their support and guidance:

Assoc. Prof Michael Curtin and Dr Rod Cooper

Dr Emma Webster and David Schmidt

Denise Young, Vicki Hofman and my colleagues in Mid Western Brain Injury Rehabilitation Program

Western NSW Local Health District

My fellow researchers for their great sense of humour and ongoing encouragement

Funding for this project was made available by the Rural Research Capacity Building Program of the NSW Health Education and Training Institute.

## Abbreviations

TBI	Traumatic brain injury
ABI	Acquired Brain Injury
BIRP	Brain Injury Rehabilitation Program
BIRD	Brain Injury Rehabilitation Directorate
NDIS	National Disability Insurance Scheme

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# Abstract

## Background

The voices of rural parents of children who have had a traumatic brain injury (TBI) are virtually absent from the health literature. Furthermore, while models of service delivery are defined for children following TBI, none specifically address the unique needs of rural families.

## Method

This qualitative study used interpretative phenomenological analysis (IPA) to explore the lived experience of rural parents whose school-aged children sustained a TBI. Two separate semi-structured interviews were conducted with four parents recruited via a rural Brain Injury Rehabilitation Program database. Transcripts were analysed according to IPA guidelines.

## Results

Four key themes emerged: 'I just want the reassurance', 'just go with it', 'cause they don't see', and 'the great divide'. These themes collectively reflect the key features of parent experience. The interplay between these features is complex and individual.

## Conclusions

There is support, both in the literature, and in the practice of BIRP clinicians for the use of models of service delivery that contain contextualised rehabilitation, family centred practice and the adoption of long-term approaches for children and their families from both metropolitan and rural locations.

The findings from this study show that while parents benefit from and value many aspects of these approaches there are specific considerations for their successful implementation with rural families. This impacts both metropolitan and rural health services as the key service providers for children following TBI in rural locations.

## **Implications for Practice**

The experience of rural parents could be improved if specialist brain injury services are provided to the child and family where they live; ongoing rehabilitation services are available; the decision for children to receive or not receive ongoing services is determined with families in the form of an individual plan; a model of information exchange with parents is developed; and the development of peer support programs that are accessible to rural families is prioritised.

Keywords: brain injury, children, families, rural, interpretative phenomenological analysis.

# Executive Summary

## Implications

The study results provide key contributions to the current review of the Brain Injury Rehabilitation Program in New South Wales. A number of opportunities for improved client and family experience of the health service as well as improved rehabilitation outcomes are identified. There is potential for improvements within current resource allocation at service design, workforce and individual health provider levels.

## Approach

This qualitative study used interpretative phenomenological analysis (IPA) to explore the lived experience of rural parents whose school-aged children sustained a TBI. Two separate semi-structured interviews were conducted with four parents recruited via a rural Brain Injury Rehabilitation Program database. Transcripts were analysed according to IPA guidelines.

## Findings

Four key themes emerged: 'I just want the reassurance', 'just go with it', 'cause they don't see', and 'the great divide'. These themes collectively reflect the key features of parent experience. The interplay between these features is complex and individual.

## Recommendations

The varied experience of these rural parents points to a number of opportunities for an improved client and family experience of the health service as well as improved rehabilitation outcomes. A key feature of current NSW BIRP service provision to children is the variance in amount and type of service delivery dependent on where you live. The following recommendations are for all children following BI regardless of location. The main recommendations are presented below and divided into service design and future research.

## Service Design

- **Specialist brain injury services to be provided to the child and family where they live.** This would include specialist medical and therapy service

provision as well as rehabilitation coordination or case management. This could be achieved through:

1. Rehabilitation coordination service provided where children live.
2. Provision of specialist brain injury outreach clinics including medical and therapy specialists to rural locations.
- 3 Use of technology to bridge the gap between city, or regionally based specialist services, and parents homes.

Benefits would include:

1. Brain injury specialists providing outreach clinics could develop their understanding of the family in the context of their extended family and community.
  2. The potential to build more collaborative relationships between health service providers in metropolitan and rural areas.
  3. Education for local, generalist health providers could also be provided.
- **Ongoing rehabilitation services** are made available to children and families.
  - **The decision for children to receive or not receive ongoing services is determined with families in the form of an individual plan.** If not indicated **processes for possible follow-up and re-entry to rehabilitation services** as required are clearly defined.
  - The structure and process of how, when and what information is provided to parents is to be revised and an appropriate system developed. It is recommended that **a model of information exchange with parents is developed** that is shared and consistent across metropolitan and rural BIRPs to assist in collaboration and a developing mutual understanding of the two cultures. In NSW the BIRP Paediatric Reference Group would be ideally placed to lead this initiative.
  - **Peer support programs** that are accessible by rural families to be prioritised by Brain Injury Australia and Carers NSW.

## **Future Research**

The following research questions remain to be investigated:

- What are the indicators for children and families to receive planned regular review from specialist Brain Injury Programs versus family initiated follow-up?
- What factors influence the capacity of metropolitan and rural health providers to effectively communicate and work towards common goals with a child following TBI and their family?
- Are online and teleconference forms of peer support acceptable and accessible to rural families?



# Introduction

The provision of rehabilitation to children following a TBI takes many forms. Currently in rural NSW children who have had a severe or moderate injury often receive both metropolitan tertiary health services as well as rural services. These rural services may or may not specialise in brain injury. If specialist services do exist in a specific location they mostly constitute rehabilitation coordination only, or in one local health district specialist therapy services are also available.

Models of service delivery for children following TBI are becoming better informed and defined; however, none have specifically identified if rural families have specific needs and, if so, sought to address them. Researchers have indicated that rural and remote families who have a child with a TBI experienced greater emotional and financial burden, and received limited and fragmented specialist paediatric brain injury services, compared with those located in metropolitan areas in NSW, Australia (NSW Agency for Clinical Innovation, 2011). In order to address this inequity there is a need to understand what rural children and their families experience following a TBI. One way of doing this is to hear from the parents; however, the voices of rural parents of children who have had a TBI are virtually absent from the health literature.

Also, Australia is currently experiencing the staged introduction of the National Disability Insurance Scheme and the National Injury Insurance Scheme. The key objectives of these reforms are to improve care and support for those with a significant and permanent disability (“National Disability Insurance Scheme,” n.d., Welcome). There is an opportunity for good research to inform the current state and national interest in improving services for children who have had a TBI.

This study aims to better understand the experiences of rural parents following their child’s TBI. It is anticipated that this will help inform the development of sensitive and effective models of TBI service delivery in rural and remote locations.

## **The Search Strategy**

A literature search was conducted using the following databases: Ovid Medline, Ovid PsychINFO, Proquest, Informit (Health Collection), Sage Journals Online and PsycBITE. Key terms used included 'brain injury/brain damage/traumatic brain injury/brain concussion/brain haemorrhage', 'children and brain injury', 'family/family characteristics/family relations/single-parent family/parents/siblings', 'parent experiences', 'rehabilitation/treatment/recovery', 'health care utilisation/health care services/health care seeking behaviour/health service needs/health care delivery', 'rural/remote health', 'childrearing practices'. The searches included the following limitations: all child\* (0 to 18 years), English language, human, and published within the last ten years to 2012 when valid for the particular database. Citation chaining, noting references cited in pertinent articles, was then used to further identify and locate other relevant material.

# **Literature review**

## **Background**

Traumatic brain injury (TBI) is one type of acquired brain injury (ABI) and constitutes damage to the brain as a result of an external force. Common causes of TBI include motor vehicle accidents, falls, and blows to the head (Brain Injury Australia, 2008). TBI is a common cause of death and acquired disability in childhood. Approximately 22,300 ABI incidents in 2003 were children aged less than 15 years old (AIHW, 2006).

The sequelae following a TBI range from transient cognitive impairment to lifelong physical, cognitive, and behavioural disabilities. There is a significant burden associated with long-term economic, social, and care costs (O'Callaghan, McAllister, & Wilson, 2009). Several studies have found that the younger a person is at the time of injury the greater the impact. This has resulted in increased attention on the provision of services to children and their families, and the development of models of service delivery that are not simply replications of adult models (Anderson &

Catroppa, 2006; Gillett, 2004; Ylvisaker et al., 2005).

## **Rehabilitation Approaches**

A number of Australian and international acquired brain injury rehabilitation services have described their models of service delivery, demonstrating a variety of significant gains for children when a coordinated combination of specific rehabilitation approaches were utilised. Rehabilitation approaches that were strongly supported across these models included; family and community based context sensitive rehabilitation, family-centred care, and the application of a long-term focus when working with ABI children and their families (Anderson & Catroppa, 2006; Braga, Da Paz, & Ylvisaker, 2005; M. Chevignard, Toure, Brugel, Poirier, & Laurent-Vannier, 2010; McDougall et al., 2006; Savage, DePompei, Tyler, & Lash, 2005; Ylvisaker et al., 2005). No studies were found that focused on the implementation of these approaches for rural families as distinct from families who live in metropolitan areas. These three approaches will now be described and their application for rural families considered. The approaches are presented individually but it is acknowledged that in any one service it is the coordination and integration of a number of approaches that underpins the model of service delivery.

### *Family and community based context sensitive rehabilitation*

Ylvisaker et al. (2005) described context sensitive rehabilitation as intervention that happens within a person's everyday functional routines. It is supported by the everyday people in the life of the person with disability with specialists providing assessment and consultation. Other terms used to describe context sensitive rehabilitation include family and community based, family supported, and indirect rehabilitation. Although few in number, early studies on the efficacy of this approach report improved functional outcomes and wide support from clinicians, suggesting that it may be more effective than clinic based approaches (Anderson & Catroppa, 2006; McDougall et al., 2006).

Braga et al. (2005) conducted a randomised control trial in Brazil that concluded that children following TBI receiving indirect family supported rehabilitation demonstrated statistically significant improvements in cognitive and motor outcome measures compared to children receiving direct clinician-delivered

interventions (Braga et al., 2005). This study provided a significant contribution to the literature on context-sensitive practice; however, it did not consider economic or geographic constraints on participation. While the family delivered the rehabilitation within the child's everyday routines and environment, the family still attended the clinic on a daily basis for the first two weeks, concurrently with home and school visits by professionals, and then returned to the clinic for bi-weekly visits over the course of one year.

With most specialist clinics located in major metropolitan centres the applicability of this study in a rural Australian setting is questionable. Realistically, the capacity of families to access both their everyday environments in combination with regular clinic visits is currently inconceivable in remote areas of Australia and doubtful at best in many rural environments given travel distances. Context sensitive approaches are nevertheless gaining support in Australia. However, knowledge on how best to implement these approaches in rural areas is lacking.

#### *Family centred practice*

Family-centred practice has been considered as both a philosophy and a method of service delivery, which gives priority to the partnership between families and service providers (Law et al., 2005). There is evidence that family-centred practice can improve outcomes for children and families; however, it can also be misunderstood and poorly implemented (Law et al., 2005; Moore, Mah, & Trute, 2009). Definitions in the literature are diverse and range from the family being the focus of care to the family being a partner in care delivery and a key decision maker in plans regarding their child. Pickering and Busse (2010) identified practices that parents most valued as those that contributed to the family feeling supported and being in an equal partnership. Moore et al. (2009) explored the relationship between family-centred care and parent reported Health Related Quality of Life (HRQL) in children from neurosciences clinics in a large acute care hospital in Canada. Family-centred care was described as the interpersonal strategies of demonstrating respect for the family's perspective and expertise, conducting ongoing needs assessments, involving families in decision making, providing information matched to the family's needs and developing flexible services that are responsive to the needs of individual

families. They found support for their hypothesis that family centred care did significantly predict parent reported, children's HRQL, independent of illness severity (Moore et al., 2009).

When rehabilitation professionals partnered with families important benefits were noted, which include gaining invaluable information from the family which is not available from other sources, setting goals which are meaningful for the child and family, and providing interventions within the child's usual environments rather than in a clinic as in context sensitive approaches (Braga et al., 2005; Galvin, Froude, & McAleer, 2010; Sander, Clark, Atchison, & Rueda, 2009; Ylvisaker et al., 2005). The success of this approach is dependent on clinicians being willing to work within the culture, values, and routines of the family, and for families to be meaningfully engaged. Ylvisaker et al. discussed the often unmet challenges of meaningfully engaging the family (Ylvisaker et al., 2005).

When looking beyond the TBI literature, a review of family-centred practice highlighted potential risks in its implementation. In their systematic review of 11 qualitative studies investigating the impact of family-centred practice, Shields, Pratt, and Hunter (2006) identified a drawback of family-centred practice was the risk of overburdening and overwhelming parents. In their investigation into implementation of family-centred principles in service delivery in Western Australia, Dodd et al. (2009) found few instances where there was equal decision making and negotiation between service providers and families. An emphasis on families taking responsibility for implementing interventions was more the norm with subsequent greater risk of families being overburdened and disempowered.

The wellbeing of the family, including both individual family members and the family as a unit, was strongly related to the outcomes of children who have had a TBI (DeMatteo et al., 2008; Spina, Ziviani, & Nixon, 2005). This has been described as a reciprocal or bi-directional relationship in which the health and wellbeing of the family impacts that of the child with TBI, just as the child's wellbeing impacts the health and wellbeing of the family (Spina et al., 2005; Vangel, Rapport & Hanks, 2011; Ylvisaker et al., 2005). When families perceive themselves as well supported this has been shown to have a significant impact on their wellbeing (Vangel et al., 2011). Family

centred practice has the potential to impact whether a family feels supported or not.

The implementation of family-centred practice remains somewhat problematic with confusion regarding best practice and risks to family wellbeing. No studies were found which specifically addressed family centred practice in rural locations and it would appear that the challenge of engaging with families and understanding their culture and values is of ongoing significance.

### *Long term approaches*

The benefits of a long-term focus on brain injury rehabilitation for children have been well discussed in the literature (Anderson & Catroppa, 2006; M. P. Chevignard, Brooks, & Truelle, 2010; Galvin et al., 2010; McDougall et al., 2006). This has been related to the persistent nature of some difficulties; in particular, cognitive and behavioural difficulties, families' changing life stage needs, environmental factors, and the delayed expression of a child's deficits that may not be evident initially post injury. The importance of ongoing available supports and input from professionals, especially at developmental transition points has been consistently reported (Anderson & Catroppa, 2006; M. Chevignard et al., 2010; Savage et al., 2005).

In a review of pertinent issues Savage et al. (2005) found that over the long term the consequences of TBI are frequently ignored or misinterpreted as the child ages. Internationally, the number of children who receive specialised rehabilitation and long-term follow up remains a small proportion of the children injured. Many studies have identified that this results in numerous unmet and or unrecognised needs (Anderson & Catroppa, 2006; M. Chevignard et al., 2010).

In an effort to address this situation attention has recently focused on the development of long-term approaches and methods of service delivery. Savage et al. (2005) suggested a number of methods that may be useful for clinicians, educators, and family members to contribute to the long-term success of children and to help families over time. Chevignard (2010) described the 'Paris model', in which the principles employed included continuity of care, specificity, and consistency of child-centred and family-focused care, and the promotion of education and information to

all persons involved in the child's life (M. Chevignard et al., 2010). This model is one of a number which combines the three approaches of context sensitive, family centred and long term care. However, she did not describe the process of decision making around long-term care, how families re-entered the system when difficulties arose, and how follow-up was managed when families were from a wide variety of socio-demographic and geographic areas.

In 2006 The Department of Human Services in Victoria commissioned a consumer consultation undertaken to inform the development of the Victorian Paediatric Rehabilitation Service (Ipsos Pty Ltd., 2007). The consultations were with families of children with chronic health conditions, including, but not restricted to brain injury. The consultations highlighted a number of valuable findings in relation to long term care, in particular follow-up and re-entry to rehabilitation services. The authors stated that the boundaries between rehabilitation, early intervention, and ongoing maintenance therapy were not well defined or understood, especially amongst families with a child who has a chronic health condition. There was confusion about whether services were ongoing or not and what this meant for the families and their child's outcomes. This was one of a small number of studies in which families were consulted.

While the concept of having access to long-term care is well supported, little is written about how this access is negotiated or experienced by families, and supported within the sparse service provision that is the reality in rural and remote locations.

#### *Rural Health Issues related to models*

No models of service delivery were identified that specifically identified nor addressed the unique needs of rural parents following their child's TBI. A lack of access to rehabilitation services in rural areas, both the amount of services but also the type of services, including specialist brain injury services, has been identified (L. Bourke, 2001; Lisa Bourke, Humphreys, Wakerman, & Taylor, 2010; Harradine et al., 2004; NSW Agency for Clinical Innovation, 2011; Sander et al., 2009; Yantzi, Rosenberg, & McKeever, 2007). While the lack of brain injury rehabilitation services in rural areas is well established little has been written on what actually happens for

rural parents following their child's TBI or the current application of trends and learning from the international models described above and their transferability to the Australian rural context.

## **Parent experiences**

Rural parental experiences following their child's TBI are not well understood. Despite health care systems internationally prioritising the involvement and input of families into the development and evaluation of services there has been little qualitative research exploring the parents' experiences (Rosignano & Swanson, 2011). Of the research that has been completed on rural parents' experiences there is a lack of acknowledgement of the unique qualities of the rural experience, and little focus on rehabilitation stages despite long-term functional implications of TBI in children now being recognised. Increasingly, value is being apportioned to a deeper understanding of parental experiences to inform health service delivery (Clark, Stedmon, & Margison, 2008; Rosignano & Swanson, 2011).

## **Conclusion**

Models of service delivery for children following TBI have been described by a number of acquired brain injury rehabilitation services internationally. These models demonstrated a variety of gains for children when a coordinated combination of specific rehabilitation approaches were utilised (Braga et al., 2005; M. Chevignard et al., 2010; McDougall et al., 2006; Savage et al., 2005; Ylvisaker et al., 2005). However, no models of service delivery were found that specifically addressed the unique needs of rural parents' following their child's TBI even though it was known that rural and remote families who have a child with a TBI experienced greater emotional and financial burden, and received limited and fragmented specialist paediatric brain injury services, compared with those located in metropolitan areas (NSW Agency for Clinical Innovation, 2011). Also, within the limited research the voices of rural parents of children who have had a TBI were virtually unheard. Greater understanding of the experience of rural parents through the use of qualitative research has the potential to sensitively inform clinical practice and service development and is increasingly recognised as a critical source of information. This recognition is further reinforced by the involvement of communities



and families in the development and evaluation of policy and service delivery being highlighted as a priority of governments internationally (Clark et al., 2008; Robson, Ziviani, & Spina, 2005; Roscigno & Swanson, 2011).

This study aims to better understand what rural parents experience following their child's TBI. It is anticipated that this will help inform the development of more sensitive and effective models of TBI service delivery in rural and remote locations. A qualitative methodology was chosen as best suited to the exploration of this experience with a specific phenomenological research approach, interpretative phenomenological analysis (IPA), enabling the in depth exploration of individual parents' lived experiences and how he or she makes sense of his or her experiences within a particular context, the Australian rural environment (Clarke, 2009; Finlay, 2011).

## **Method**

### **Study Design**

Qualitative research methodologies are best placed to address this topic as they are inductive and exploratory, with rich description coming from the participants which then leads to the development of understanding through a subjective relationship between participant and researcher (Finlay, 2011). It is the attention to context that adds to the value of IPA for this study. The influence of the rural context on the experience of individual parents is core to this study and retains its focus within IPA. While IPA does not enable generalisations it is anticipated that the rich personal accounts and the interpretative discussion will provide useful insights and enable meaningful and wider implications for clinical practice and service development.

### **Sampling**

Purposive sampling was used to gather a selection of parents or caregivers who had knowledge about the research question, enabling a detailed and careful examination of similarities and differences, and rich and relevant data to be collected (Smith, Flowers, & Larkin, 2009). The purposive sampling criteria used for participant

selection are summarised in Table 1.

**Table 1:** Purposive Sampling Criteria

- 
- Parent or caregiver whose child has had a traumatic brain injury.
  - The parent or caregiver is the primary caregiver as recorded on the data base of Mid Western Brain Injury Rehabilitation Program (MWBIRP) and confirmed by the individual.
  - Child's injury occurred two or more years ago.
  - Child is of school age and living at home with their parents or caregivers.
  - Parents or caregivers and child live within the geographic boundaries of MWBIRP.
- 

### **Participant Recruitment**

Ten potential participants were identified from a rural Brain Injury Rehabilitation Program database as meeting the criteria described in Table 1. These ten participants were contacted by phone by an administration support officer and invited to participate. Six potential participants volunteered to take part in a series of interviews. One parent declined and three parents did not respond.

### **Data Collection**

Eight semi-structured in-depth interviews were conducted by the principal researcher, two interviews with each of four participants. A decision was made by the researcher and the supervisory team to stop at four participants as the data was very rich due to the length of the interviews and the openness of the participants. This was explained to the extra two potential participants. Data saturation is not a concept supported in the IPA literature; however, experts in this methodology caution against having too much data as this can threaten the depth of analysis (Larkin, 2010).

An interview schedule was used to guide the interviews with the focus on listening and exploring topics and issues raised by the parents (Appendix 1). Interviews lasted between 75 to 130 minutes and took place at either the parents' home or at the local hospital according to the parent's preference. Parent interviews

were digitally audio recorded and then transcribed verbatim by the principal researcher in order to maximise the accuracy of the parents' words and views in data collection (Tong et al. 2007). A written summary of the first interview was provided to the parents for consideration prior to a scheduled second interview. The transcription of each parent's first interview was also made available but all the parents stated they did not want to see this.

The second interview was included to facilitate member checking of the first transcript, enable removal of information or potentially identifying detail that the parent was uncomfortable to leave included, and enable additional information, perceptions and attributed meanings from the participant to be included in the data (Knox & Burkard, 2009). A third interview was offered to participants and all declined as they felt that they had already told their story. Field notes were made after each interview and a reflexive journal was kept by the principal researcher throughout data collection and data analysis.

## **Data Analysis**

Data analysis followed the guidelines provided in the IPA literature (Smith et al., 2009). Interpretative phenomenological analysis is inductive with the knowledge and understandings emerging from the participants' accounts (Reid, Flowers, & Larkin, 2005) and shown through the text of the transcripts. Smith et al. (2009) describe a five-step approach to help guide the researcher through analysis. Interpretative phenomenological analysis advocates analysing the first case in detail and then moving on to the second, third, and so on. The researcher's supervisor and mentor all independently reviewed the data, followed by discussion and agreement on key themes. Pseudonyms were used for parents and their children. No software was used to manage the data.

## **Reflexivity**

The principal researcher is a paediatric rehabilitation coordinator with the Brain Injury Rehabilitation Program in the same geographic area and local health district in which the parents in this study reside. The researcher was known to two of the parents and was the current rehabilitation coordinator for one of the parents. This

was seen as a strength of this study as the researcher was able to bring knowledge of the geographic area and current models of practice. It was also considered that any existing rapport with parents would support rich data collection. This was dependent on the researcher being reflexive and being able to identify her assumptions and the effect this may have on data collection and analysis. This was facilitated through adoption of a reflexive stance before, during and after data collection and analysis, the use of a reflexive journal and regular discussions with her supervisor and mentor.

## Ethics Approval

Ethics approval was granted by the Greater Western Area Health Service Human Research Ethics Committee on the 23<sup>rd</sup> November 2012. Ethics Reference Number: HREC/12/GWAHS/67

# Findings

## Study Participants

A summary of the four participants is given in Table 2.

**Table 2:** Characteristics of Study Participants

Note: pseudonyms are used in place of names

Characteristics	Lorraine	Kate	Jane	Sonia
Age of child at time of interview	15 years	5 years	11 years	15 years
Time since injury	13 years	3 years	6 years	8 years
Severity of injury	Severe	Severe	Severe	Moderate
Gender of children	Male	Male	Male	Male
Relationship of participant to child	Mother	Mother	Mother	Mother
Population of town lived in or nearest to at time of injury	400 people	2000 people	3300 people	36 000 people
Distance to nearest regional centre	50 minutes drive	50 minutes drive	25 minutes drive	10 minutes drive
Distance to tertiary metropolitan hospital	3 ½ hr drive	4 ½ hr drive	3 ½ hr drive	3 hr drive

This report focuses on four themes relating to health service provision. The

themes of 'just go with it', 'I just want the reassurance', 'cause they don't see, and 'the great divide' collectively reflect the key features of parent experience. The interplay between these features is complex and individual.

### ***Theme 1: I just want the reassurance***

This theme relates to the parents' experience of control. It explores the factors that contribute to the varying level of control experienced, as well as parent responses to feeling a lack of control, in particular the need for reassurance and the ways in which this reassurance is sought. How health services and parents interact is shown to be influenced by, as well as to influence the control and confidence that parents report. Living rurally poses particular circumstances that also serve to impact on their experience.

The parents' belief in their own ability to influence and exercise control over their lives was shaken by the trauma of their child sustaining a TBI. The experience of the injury itself and then the following interactions with, an often, unfamiliar health system and multiple professionals working in isolation from each other served to decrease their sense of control.

The unforeseen and abrupt nature of the accident left the parents traumatised with a lack of trust in what they had previously anticipated as a relatively predictable future. When describing how her view of the future changed following her son's TBI Sonia said:

You just don't know. And a lot of it you don't know and you don't have a crystal ball so you can't kind of pre-empt things. You don't know. You've just got to wait for it to happen.

Some parents experienced guilt about the accident and wondered if they could have prevented it from occurring. Some eight years after her son's injury Sonia continued to ask, "Could I have done something?" Having failed at keeping their children safe from harm the parents felt that they could not trust in their instincts, choices, and decision making in relation to their child. Jane describes her uncertainty on leaving hospital and lack of trust in herself:

Oh my god they're just letting me take this child home and you think, how is it going to survive with me not knowing what to do. (Jane)

The way health services were delivered to children and their families made a difference to how parents experienced control and their subsequent response. As the health team took control in the initial stages due to the medical emergency, this combined with the uncertain prognosis of the brain injury, left the parents feeling totally overwhelmed. The parents' initially became immobilised and passive recipients of what was going on around them as they lost faith in their capacity to make a difference. Sonia said that her initial response was, "to go into auto pilot and do nothing and wait." For Jane this feeling of being overwhelmed was continued as the child moved into the subacute and rehabilitation stages.

We were in the hands of the gods there. I wouldn't be able to tell you, now. There wouldn't be one specific. Yeah, I couldn't tell you. No one specific area where I felt like I've got control of the situation, cause as soon as we felt that he was in control in the ICU, they moved him out. And then, as soon as he was able to get up on some sticks, go home.

Two parents whose children were in hospital for much longer periods of time experienced a greater sense of control. Kate was very involved in her son's care. This gave her a sense of satisfaction as she "kinda liked taking control. I knew it was done, I knew that it had been done." Lorraine echoed a similar sentiment when she made the decision to perform the majority of care for her son in hospital stating that, "he's my child. I will look after him." When Kate, Lorraine and Jane took on active roles with their child this contributed to their sense of agency.

In inpatient rehabilitation active roles took the form of parents performing care duties with their children. Once they returned home the parents' were more involved in decision making and working as a team with their health providers.

Yep, like with his physio now and that, we sat down and we went right, you know, what do we think is the best thing for him. What do I want? What do they want? Ted, and she actually asked Ted 'cause he's old enough now, Ted what do you want to do? You know, that type of thing, she said, right, this is what we'll do to achieve those things. [...] So, you know, and that's the difference between the good ones and the not so good ones. (Lorraine)

When health professionals made efforts to engage and support parents in

active roles with their child the parents' confidence grew and they had a greater sense of control. These practices reflect aspects of family centred practice approaches as described in the literature review (Law et al., 2005).

Of interest, was the effect a lack of services had on one parent's sense of control. Sonia commented that in her experience having a child with a moderate severity of injury meant that their child fell through the net, especially when resources were limited in rural areas. While this was difficult it was also ultimately an impetus to moving on. Having to do something because there was no alternative was motivating for Sonia, *"so you think well maybe we've just got to go with what we're doing. [...] what we need to do is implement something."* Being able to 'do' something yourself seemed to have a positive impact and lead to the parent further developing confidence. So for Sonia, a lack of services in the rural location, while difficult, resulted in her developing confidence. The fact that the brain injury specialists from the tertiary metropolitan facility considered that the child did not require intervention or monitoring from them was a powerful message to this family that they were able to return to their usual life. The planned discharge from specialist services was what provided reassurance for this parent.

Jane had a different experience in which she was distressed at her son being discharged and requested that the file be reopened. Jane felt the need to have a safety net in which a clinician is regularly checking her child is well and developing appropriately. Jane reported being unaware that her son's file had been closed. When she heard that his file had been closed she experienced strong feelings of fear and dependency:

They just closed the file and I thought, oh, and it just sort of freaked me out totally thinking, what do we do? How do we get back [...] And I said, you know, please don't close it, you know, because of, um, because we, yeah, felt very lost. (Jane)

The difference in experience emphasises the need for individual approaches and highlights the potential risks for some families associated with long-term approaches. The literature supports models of care in which children following TBI are monitored until reaching adulthood in order to minimise unrecognised and unmet needs (Anderson & Catroppa, 2006; Chevignard et al., 2006). However, this study

shows that while essential for some, maintaining a long-term relationship may contribute to dependency in other families, reducing their capacity to adjust to their situation and achieve acceptance. This raises the question of the impact of long-term monitoring approaches on children and families and invites further research into this area.

Jane's distress may be related to the manner in which she was informed that her child had been discharged. This came as a surprise and did not involve any collaboration, planning or decision-making on the part of the parent or child. Parents in this study stated that opportunities for joint decision making, feeling supported, respected and having information provided in the right way, at the right time were highly valued. Sonia was given information but she would have preferred for it to be more individual:

You get given a lot of, you get overwhelmed with a lot of pamphlets and flyers and information [...] Which we [read], [but] a lot of it's generalised and you're after more of an individual.

The practices of shared decision making, parents feeling supported and respected and effective information provision to families are detailed in the literature as being key features of family centred practice which is known to improve outcomes for children and families (Law, 2005; Moore, Mah & Trute, 2009). While valued when these practices did occur there were many instances in which parents spoke of a health system that was not family centred. When parents were involved in the decision making and planning of interventions and took an active role in the rehabilitation of their child they reported feeling more in control with a greater sense of self efficacy and value. Parents often reported feeling uninformed and undervalued by the health system. Sonia responded passively to this stating that, "if you had questions you'd ask them, whether or not you understood the answers. You know, you'd kinda go, oh, ok then." This was also true of health professionals' willingness to receive information from parents and the value they placed on this. Lorraine felt that some clinicians did not listen to her:

And they don't listen to me anyway. As a Mum they don't listen to me [...] Cause you're Mum and what would you know. Well hello, I'm Mum and I'm with him 24 hours a day. I know better than anybody. It's true.



The parents commented that health professionals often took control and left them out of decision making and planning as reflected by Sonia's comment, "Well you get told to turn up so you turn up."

Dealing with a range of systems including a metropolitan hospital, rural health service and education system with different ways of working, philosophies and agendas was confusing for the parents and placed them in less powerful positions and increased their passivity. They commented on the poor communication between services. Sonia illustrated this point when she said, "the services, that they didn't, you know, talk to one another. I think that's [talking together] really important." When the parents felt that the different health systems and other services were communicating with each other and working towards common goals they experienced a much greater sense of control.

The culmination of these experiences seemed to amplify the parents' need for certainty, which they sought from experts in the city. One example of this was when Jane indicated her need to have her child regularly checked by specialists, even when she was not specifically worried about anything, "just checking him to make sure that he's OK, and I know he's OK but I just want the reassurance."

Accessing health services from one trusted venue such as the city hospital became the best option. Lorraine had difficulties accessing specialist services locally. She became disappointed when she was willing to try local services, which claimed to have expertise with brain injury, but then demonstrated no specialist skills. This reinforced her reliance on city services, "I went, right, I'm just sticking to everything down at the [metro hospital] cause it's a lot easier." This ease related to services being in one place but also extended to the capacity to access shared medical records. Being seen at one service was powerful as opposed to the multitude of services, styles and ways of working parents confronted when needing to work with the full range of services. Sonia perceived the metropolitan service to be superior to the local services, which gave her confidence in their decision to discharge her son:

Yes, he got the big stamp of approval from the huge people in [city] rather than just here in [regional centre].

Health services are shown here to be able to increase the control experienced by parents and provide reassurance to parents when they partner with families in the delivery of care, decision making and rehabilitation planning. Key elements that parents valued included individualised information provision, having a team working together that has specialist knowledge, strong communication processes and a capacity to share information easily, as well as being able to partner together with the child and family in rehabilitation planning and provision. This is shown to be challenging in rural areas when multiple professionals are working across large distances.

### ***Theme 2: Just go with it***

Closely linked with the first theme is the capacity of parents to adjust to their new situation. This theme relates to how parents move from initially being preoccupied with the injury and related symptoms and supports to being able to adjust, take a holistic view of their child and allow their child to lead a more typical life. The parents in this study described the journey they experienced following their child's accident. Their experience and subsequent responses were influenced by their emotional states, their perception of risk, interactions with education and health services, and noticing changes in themselves and their child. Parent's experiences affected their capacity to accept their situation and begin to adjust, to be able to 'go with it'.

The journey begins with a preoccupation with their child's recovery from injury and a change in the parent role. On returning home after the injury and hospitalisation, two parents began to try to understand their children and consider if their behaviour was a result of personality, developmental stage, or the brain injury. The significance of this for these parents was a perception that characteristics of the child that were a result of the brain injury needed fixing. Sonia and Jane expressed their confusion:

We still need to work out whether it is or it isn't but yet some of it was consistent to a brain injury. (Sonia)

And maybe that's just a child thing rather than a brain injury thing [...]

well probably if it was brain injury I would probably look at ways to fix it, and a moody little teenager, well I'll just have to give him deodorant and tell him to shower more or something, I don't know. Um, yeh, that's probably the biggest thing, and I don't know. (Jane)

Parents described being so focused on 'fixing' what they saw as deficits related to the brain injury that they failed to acknowledge their children as an individual.

Initially there was a conflict between a parent who needed to care for and protect their child and a child who wanted to be increasingly independent, included by their peers, and who was desperate to not be different. Some parents discouraged their children's participation in anything that they perceived as risky as they wanted to protect their child from further injury. They saw their child as vulnerable. Jane stated she was, "scared he's not going to cope."

School staff were also overly protective. Jane felt comfortable with this at the time, "but, my state of mind, I actually quite liked that, thinking, good, he won't have any little ratbag kids knocking him or something." However, when Sonia saw her son upset and recognised the effect this was having she identified the need to treat her son as a child:

So, I think, not going out onto the playground [was] a major restriction for him, but that [restriction] was not put on by us, so we had no control over that and we weren't aware of it until he came home and he was quite upset, and then that was really hard to approach the school because their belief was that you're telling us he has a brain injury, but yet you're allowing him out in the school grounds. So ... it was like well, you know, he's gotta be normal, he's gotta be a child.

This state of mind of being overprotective would appear to threaten context sensitive rehabilitation, which is dependent on a child's everyday people such as their family and teachers being able to embed activities suggested by clinicians in the child's daily routines (Ylvisaker et al., 2005).

A shift to seeing the abilities of their children and trusting their children to make decisions and to take risks happened over time. This was described as a circular process. Once parents started to realise that they were being over-protective they noticed the achievements of their children. For Jane, she reported feeling shocked and confused when this realisation came. She then questioned why she acted in this

way: “Oh my God, and I think, oh ah, why are we doing this for him? I don’t know why we’re doing it.” Parents were then more comfortable with their child taking risks and receiving less support. When describing her son climbing an indoor rock wall Jane stated that “he didn’t stop, he didn’t stop, and I thought wow, we were just gobsmacked, we expected him to not have the coordination.” Sonia also shared that there was a time when she started to see a difference “when he was starting to get a little bit better at school we felt he didn’t need the support.” This change in response by the parents seemed to enable the children to accept themselves and get on with their lives. Sonia noticed this in her son:

And then once we got over that he tended to, kind of, step up a bit more. Kinda thought, oh hang on a minute, I can’t get around this, so I may as well just go with it, so... And you could tell when that kicked in, couldn’t you? When he actually started trying, you could tell hugely.

For Sonia this change was also facilitated by the tertiary hospital discharging her son from ongoing care. This seemed to bring with it a freedom to at least in part leave the brain injury behind. However, for Jane the underlying question of whether her son’s behaviours were related to brain injury continues to persist for a long time after the injury. For Jane, in talking about her experience now, some five years following the injury, she continues to interpret her son’s performance through this lens. She states that for her it is “Like a subliminal message saying this is because he’s had a brain injury.”

The two parents whose children had severe TBIs with physical disabilities reported a different experience. These parents were less concerned with minimising risk and more focused on pushing their child to participate in therapy. This was to the exclusion of their own needs and the needs of others within the family. For these parents this was what affected their adjustment and acceptance. Parents described putting their lives on hold. Kate relates this to her son’s life coming first, “So he can still have a life and we can in turn have a life as well.” Some parents changed career plans, life dreams, and in one family the family structure changed, with the parents living separately in order to accommodate the needs of the child; this situation was exacerbated by the struggle parents experienced in accessing therapy locally. They described the distances travelled and the time required to ensure their child received

what they felt was needed:

Because once we got back we used to do therapy at [regional centre]. So we used to travel, in and out, for 40 minutes travel there and 40 minutes travel back every day. And that just wasn't working [...] And that didn't include our trips to [city]. So that was just his weekly therapy. (Lorraine)

When there was not anything available locally, parents felt pressure to find other ways to ensure their child received therapy, such as implementing intensive home programs and undertaking regular trips to specialist services in the city. Lorraine described her therapy routine at home; "and I got stuck in to get Ted to the best he could be. So, you know, just repeating everything, all day, every day, just getting him to that point". This resulted in even less capacity, both physically and emotionally, to attend to their own needs or the needs of other children and spouses. The impact of the TBI on the whole family was too difficult for Kate to face:

Everything always comes back to stopping because of Mark. Which is, I try not to think of it that way. But, if you break it down, everything we can't do, is because of his condition.[...] I don't let myself think of it that way, and I don't usually, verbally say it, because once you say it, out loud, it's kind of, out.

The emotional responses of parents to their new situation impacted on their behaviour and relationships with their child who had the TBI as well as their capacity to look after their own needs and the needs of other children. It is well documented in the literature that a parent's wellbeing affects the wellbeing and outcomes of their child, which then also impacts the wellbeing of the parent in a circular process. This is described as a circular relationship (DeMatteo et al., 2008; Spina, Ziviani, & Nixon, 2005; Ylvisaker et al., 2005).

Despite the initial and the ongoing emotional demands on the parents there was little recognition by clinicians, both rural and metropolitan, of the trauma experienced by the parents.

Nothing about, like the way it could have affected our family or us as a couple or anything like that. Nothing like that at all was discussed. Um [...] it was quite a bizarre surreal thing actually, that sort of side of it. (Jane)

It would therefore seem critical that health professionals support the emotional wellbeing of parents in an assertive, considered and timely manner. However, none

of the parents in this study reported being offered emotional support in a structured way. It is essential that health professionals appreciate and respond to the burden rural parents experience in relation to accessing services for their child and the impact this has on their wellbeing.

### ***Theme 3: Cause they don't see***

Parents in this study valued feeling understood. Having contact with others who knew what they were going through and who offered greater support was seen as important to their wellbeing. This was not always forthcoming from other local community members or friends as time progressed nor was it to be taken for granted from health professionals. Parents saw their family and other parents of children who had had a brain injury as the best sources of understanding. Potential for maximising understanding and support from family members is seen as untapped and access to a local brain injury community is reported by parents to be limited in their rural locations.

Two parents reported that there were good and bad aspects to living in a small town. Being known and supported initially was highly valued and parents talked of financial, practical and emotional support within the rural community. Lorraine experienced this even though she and her family were quite new to their community, "They were all there to support us." However, this was seen to decrease as time went on. Kate felt that this was related to the smaller population in a rural community and people's capacity to understand.

And they want to bend over backwards and do everything for you, but then, in the other respect, cause it is such a small area, people get sick of the situation that you're going through when they can't cope with it themselves [...]

So that initial was, the community rallied behind you, but 3 years on, there isn't that."

Kate responded to community members' reactions and inability to cope by isolating herself and her child when things were difficult.

I kind of, exclude him, so a lot of people just see his good days. And then they kinda go well what are you complaining about? He's just the same as

us. Cause they don't see, cause I don't let them see, when he is having his bad days.

This response by others contributed to Kate's experience of being misunderstood and judged resulting in further isolation. She found that having a smaller community and fewer choices for friends and social groupings amplified this isolation in a small town, "I do like living in a smaller community, but it's harder when, to make the newer friends that don't have judgement." Sonia found that this lack of understanding also extended to schools, "But that was also difficult, getting back into school, cause the teachers just didn't comprehend."

There were mixed experiences of health staff and their level of understanding. All parents in this study had both positive and negative experiences with health professionals. Sonia felt that the nursing staff were, "fantastic, [...] knowing how stressful it was for us." However, Jane's bad experience with one doctor meant that she was more guarded and closed with other health professionals, limiting the possibilities for other professionals to engage with her and identify any struggles the parents were having emotionally or provide supports and information, and suggest appropriate services.

Oh, I don't know, you just sort of, there's your appointment, you know, it's quite, I don't know, it's hard to put into words. You just sort of turn up and you hope that they're on the same wavelength as you, I think. That was the biggest thing. Given that one of the specialists that we saw about the hearing, he was such an awful man. [...] and we were very guarded from then on, thinking I hope we're not gonna strike the same situation, even though we didn't, it was always there, thinking, oh golly I hope they're able to relate to us or, um ... things like that. Yeah.

All parents saw the extended family as being their main support.

Family is everything. You know, if you don't have the family, you really don't have any support. Like you can have close friends, but friends come and go. Families don't. [...] So, you know, while the staff were wonderful [...] .it's just not the same." (Lorraine)

"I just don't think we'd be able to cope without the family's support" (Kate)

When faced with not having access to her family due to their location Sonia had to, "rely upon health and everyone else [...] we didn't have that support network."

Kate and Lorraine believed that the extended family were able to provide the

most support when they understood what was happening for the child and family. However, no parents reported that their extended family were included in health team consultations. The distance to the city and the need to provide practical support to other siblings interfered with their capacity to be involved. This weakened their potential to support the parent.

Yeah, like it's just having that other family member ... You know, well it's not really backup, but it is, because you can only hear and take in so much and you miss things, like when you've got a big conference. (Kate)

It's not about the services, because, yes you can travel to [city] to get the services, it's about having the services closer. It's about having the services closer so they can be near family members. (Lorraine)

This highlights the need for services to be provided within a parent's community. This is more complex than access and reinforces the value that parents place on services being provided in the person's community, a key feature of context sensitive approaches.

Three parents valued the support provided through relationships with other parents who had had a similar experience. They felt that these parents would understand what they were going through, something that they did not experience with anyone else. Sonia wished she had access to someone, "going through the same thing and trying to, you know, impart information to each other about how they handled the situation." Kate and Lorraine had experience of this in the metropolitan hospital but found this difficult to organise in a rural area. A sense of community was important.

It would be good if the brain injury community was as good as the cancer community. With the camp qualities, and the communication between each other and. That would really help, I think, with having a community like that, other than just an online forum, which people do for the first couple of months while there still in hospital and it kind of just loses. (Kate)

Professional and peer support for siblings was also reported to be an unmet need by two parents. Lorraine wished things had been different for her daughter, "I've done everything I can for Ted, but I've failed her big time, [...] I have cried more over her than I have with Ted."

There is potential for health services to contribute to parent's feeling understood by enabling significant family members to be involved in rehabilitation



appointments and planning. This poses significant challenges when a family is from a rural area. Family members often make up the everyday people in children's lives and so their meaningful involvement would also support context sensitive rehabilitation approaches and hence the potential for greater outcomes. Also, all members of the family, including parents, siblings and grandparents were affected by the ongoing demands of their circumstances related to the TBI with many sacrifices made, however, little intervention from health services was provided. Support for families could strengthen a family centred approach to service delivery.

Peer support mechanisms for rural areas would also appear to be failing when not one parent in this study had accessed this type of support since returning from hospital despite three of the four parents identifying that this is something they valued.

#### ***Theme 4: The Great Divide***

The Great Divide refers to the significant degree of separation parents experienced between the two sides of the Great Dividing Range, the city and rural locations. This related to their experience of key differences in health service provision including the number of therapists available, the lack of collegial and professional support available to rural therapists, the differences in work practices between city and rural clinicians and the lack of collaboration and understanding of each other's roles. This lack of understanding also extended to the parents experience of their dealings with metropolitan health services.

Having difficulty accessing therapy and specialist TBI services in rural locations was experienced by all parents. Interestingly, Kate commented on not only what this meant for her, but what she thought it meant for the clinicians:

If you don't like your therapist you're stuck with them. Cause there is only one, you can't get a second opinion, you can't just, and they're the same, like they can't just go well you're too hard of a case for me, I'm kinda out of my league, I'll send you to my colleague, cause there is no colleague to move on to, which is what I think is the biggest struggle out here.

Kate valued therapists being open, honest and willing to collaborate.

One of the speech therapists had said to me, look this is out of my league, I'm

going to need to get help, and, to me, I had so much more confidence in her.

However, parents noted differences in the way that rural and metropolitan clinicians worked, which was seen to contribute to a lack of collaboration, respect and understanding of each other's roles:

The trials of living out here, I suppose. And they don't have, I mean, I know they can call people and, but they, I think, I don't know what it is, but I just get that sense that let's not call anyone over the other side of the mountain. And it's the same with the people in the city, like, you get to the mountains and beyond that don't exist and it's the people out here .. oh don't talk to the people in the city, what would they know? [...] it's really funny to see, like you can see the difference in the two styles when you do two. Like, when you're going to both there's a complete difference with the way that the city people, I mean they're all trained at the same place, but there is major difference. (Kate)

The communication between the two was not great. [...] cause when we said we'd done some similar testing in [regional centre], when we went to [city], well they said we're not looking at that we're looking at this. (Sonia)

Parents also experienced a lack of understanding by metropolitan staff. For some rural parents the city is an uncomfortable place to be and there was no depth of understanding or consideration of what it meant to live in the country and to come to appointments in the city. Jane emphasises how culturally isolated she felt:

We went to one of those clinics down at [metro hospital] where you walked in, and it was like a bloody, dare I say, it was like a train you catch in India. (Jane)

You know, 'cause you've gotta organise for the city. I've gotta organise accommodation [...] and when I get there they always add extra things. Like, last time when we were down there they threw an X-ray in [...] Which could have been an extra day in, you know, oh we need you to go and see this person instead and, like, you know I'm coming, you know, get your shit together. (Kate)

Parents experienced a distinct difference in the provision of health services from metropolitan and rural locations. Partly this reflected workforce capacity, however it also importantly highlights the differences in culture. The success of context sensitive rehabilitation is described by Ylvisaker et al., (2005) as being dependent on specialists being willing and able to work within the culture, values and routines of the family. The parents in this study illustrated their experience of not

always feeling understood by metropolitan health professionals. They related this feeling to being undervalued as parents, their rural context not being understood or considered in any depth, and the lack of collaboration between health professionals as contributing to an inability to engage the family.

### **Study Strengths**

The use of interpretative phenomenological analysis provides a framework that guides access to and interpretation of the individual's experience in this study. Talking to the parents directly about their experiences provided access to understandings and insights, which are rare. Participant checking of their biographies between the first and second interviews added rigour to this study in the form of participants checking that the biographies were a correct representation of their experience.

### **Study Limitations**

This study is limited by the participants being only the significant caregiver rather than both parents' perspectives where they existed. The participants all lived in rural locations and so did not allow for comparison against metropolitan parent experiences. The voice of the extended family, siblings and the child themselves is missing, which would form an important source of data for future studies.

## **Conclusion**

There is support, both in the literature, and in the practice of BIRP clinicians for the use of models of service delivery that contains contextualised rehabilitation, family centred practice and the adoption of long term approaches for children and their families from both metropolitan and rural locations. The findings from this study show that while parents benefit from and value many aspects of these approaches there are specific issues that need to be considered if these approaches are to be successfully implemented with rural families. This impacts both metropolitan and rural health services as the key service providers for children following TBI in rural locations.

# Recommendations

The varied experience of these rural parents points to a number of opportunities for an improved client and family experience of the health service as well as improved rehabilitation outcomes. A key feature of current NSW BIRP service provision to children is the variance in amount and type of service delivery dependent on where you live. The following recommendations are for all children following BI regardless of location. The main recommendations are presented below and divided into service design and future research.

## Service Design

- **Specialist brain injury services to be provided to the child and family where they live.** This would include specialist medical and therapy service provision as well as rehabilitation coordination or case management. This could be achieved through:
  1. Rehabilitation coordination service provided where children live.
  2. Provision of specialist brain injury outreach clinics including medical and therapy specialists to rural locations.
  3. Use of technology to bridge the gap between city or regionally based specialist services and parents homes.

Benefits would include:

1. Brain injury specialists providing outreach clinics would promote their understanding of the family in the context of their extended family and community.
  2. The potential to build more collaborative relationships between health service providers in metropolitan and rural areas.
  3. Education for local, generalist health providers could also be provided which would impact the sustainability of
- **Ongoing rehabilitation services** are made available to children and families.
  - The decision for children to receive or not receive ongoing services is

determined with families in the form of an individual plan. If not indicated **processes for possible follow-up and re-entry to rehabilitation services** as required are clearly defined.

- The structure and process of how, when and what information is provided to parents is to be revised and an appropriate system developed. It is recommended that **a model of information exchange with parents is developed** which is shared and consistent across metropolitan and rural BIRPs to assist in collaboration and a developing mutual understanding of the two cultures. In NSW the BIRP Paediatric Reference Group would be ideally placed to lead this initiative.
- **Peer support programs** that are accessible by rural families to be prioritised by Brain Injury Australia and Carers NSW.

### **Future Research**

The following research questions remain to be investigated:

- What are the indicators for children and families to receive planned regular review from specialist Brain Injury Programs versus family initiated follow-up?
- What factors influence the capacity of metropolitan and rural health providers to effectively communicate and work towards common goals with a child following TBI and their family?
- Are online and teleconference forms of peer support acceptable and accessible to rural families?

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# Appendices

## Appendix 1

### INTERVIEW SCHEDULE

#### Rural parents' experiences following their child's traumatic brain injury

##### Interview schedule for the first interview

Introduction and relax participant	Choice of space On own or with other significant caregiver Informed Explain timing and format of interview
Nature of the child's injury	<b>Can you tell me about 'Jack's' injury?</b>  Prompts: What happened? Where did you go (acute hospital)? What was that like? Where were the rest of the family? PICU – Inpatient rehab? How long was he in hospital for?
Length and experience of hospitalisation	<b>What was it like when 'Jack' was in hospital?</b>  Prompts: Typical day? How were decisions made? Who supported you? How?
Coming home	<b>When did the topic of 'going home' first get raised? How was that for you?</b>  <b>What was involved in planning to go home?</b> Prompts: Family, friends, follow-up arrangements.
Subsequent influences on experiences	<b>Tell me about life when you got home.</b>  Prompts: What was the same/different? What helped? What/who supported you/the family? What/who helped with Jack's rehabilitation? Return to school, play, friends, sport, home?
Longer term	<b>It's been '3' years since the accident, since you came home. Tell me about that time.</b>  Prompts: How have things progressed? Changed? Stayed the same? What has helped/hindered? Family, community, services, changes in you and other members of immediate family.
Views of the future	<b>How do you see the future?</b>  Prompts: What will stay the same? Be different? Supports you may use? Transitions Getting on with life.

Conclusion	Is there anything else you wanted to tell me about? Explain the next step in the research process, the arrangements and purpose of the second interview. THANKYOU
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