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Supporting the Needs of Young Adults With Acquired Brain Injury During Transition From Hospital to Home: The Queensland Service Provider Perspective

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Objective: To explore the availability and perceived adequacy of service support for younger people with ABI and their families in Queensland during the transition phase from the perspective of service providers. **Research Design:** A qualitative research design utilising survey-based open-ended questioning. **Methods and Procedures:** Participants were service provider organisations in Queensland for younger people with acquired brain injury (ABI). A two-part survey was developed for the purpose of the study. The first part of the survey obtained general information regarding client base and service characteristics for each organisation, while the second part was designed to identify gaps in, and barriers and facilitators to service provision. Snowballing recruitment was used with the initial seed point an existing Brain Injury Network. **Results:** A response rate of 20% was obtained with a total of 12 surveys returned representing seven service providers. Services currently available included rehabilitation, consultancy, education and training, and practical and emotional supports. Existing gaps in, and barriers to service provision were clustered under three key themes: service infrastructure, transition support, and transition context. Some of the facilitators to service provision identified included interagency linkages and financial compensation for injury. **Conclusions:** Gaps in, and barriers to service provision during the transition phase were identified that could be utilised to develop models of service delivery to improve short- and long-term outcomes for younger people with ABI.

Keywords: brain injury, transition, service provision

The impact of brain injury on a person's quality of life is significant (Conneeley, 2003) and relates to a diverse range of impairments spanning the physical, cognitive, emotional, perceptual and behavioural domains of life (Cope, 1995). Ultimately, an individual's independence with daily living skills in areas of personal care, work,

and social interaction can be affected to a point where they lose previous life roles (Conneeley, 2003; King, Shade-Zeldow, Carlson, Feldman & Phillip, 2002). The predominant deficits are often within the cognitive and emotional domains, causing changes in personality, self-awareness, memory, problem solving, and social behaviour.

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Consequently, brain injury is often described as an invisible disability (Davis, 2005) and the impact of these changes are not completely understood by individuals or family members until they begin to make the transition from hospital to home (King et al., 2002).

Recovery from, and adjustment to life after brain injury, is incomplete when a person is discharged from in-patient rehabilitation, and the period immediately post-discharge signals the start of a new phase (known as the transition period) in the recovery and adjustment processes (Turner et al., 2007). The transition period, including the time of discharge and up to 6 months after discharge, sees the focus of rehabilitation change from maximising client abilities within a controlled environment to maximising participation within real-life settings (a somewhat less controlled environment; Minnes, Harrick, Carlson & Johnston, 1998). During the in-patient phase of rehabilitation the focus is often on improving physical skills, gaining independence in activities of daily living, restoring basic cognitive functions, and communication skills. While rehabilitation may still be required in each of these areas during the transition phase, the focus of individuals and their families may shift to issues of adjustment, participation in meaningful activities, feelings of affiliation and belonging, as well as recognition and status of the person as an individual (Minnes et al., 1998; Turner et al., 2007). This shift in focus suggests that services available to individuals with brain injury and their families in the transition period should similarly reflect their changing needs.

A retrospective study of individuals with brain injury and their families during the transition using maximum variation sampling revealed a range of perceived needs and wants from support services within the Queensland context (Turner et al., 2007). These included therapy services, case management, support groups, lifestyle support and return to work agencies, respite, and accommodation services. Perceptions regarding the availability and adequacy of such services varied somewhat within the sample; however, in the majority of cases individuals and their families reported difficulty in accessing support services. Similarly, a study from the United States found that 35% of individuals with traumatic brain injury (TBI) had unmet service support needs within the first year following discharge from a rehabilitation facility (Pickelsimer et al., 2007). Turner et al.'s study, in keeping with another US study (Leith et al., 2004), also found that individuals with TBI and their families perceived service provision as poorly coordinated. Specifically, Leith and colleagues found

consumer perception to be that service systems were unorganised and unresponsive. While the opinions of the individuals with brain injury and their families regarding services and support required during the transition phase are extremely important in developing and monitoring service provision, it is equally important that opinions of service providers are obtained.

Previous studies that may help to inform service delivery development for individuals with ABI following hospital discharge include studies that address service utilisation and unmet service needs. A service utilisation study by Hodgkinson, Veerabangsa, Drane and McCluskey (2000) in New South Wales used a cross-sectional design to determine the services accessed by 119 adults with TBI at four time points post-injury (6–18 months; 2–4 years; 6–9 years; and 10–17 years). Results indicated that service utilisation was greatest during the first 4 years post-injury, with the broadest range of different services also accessed within this period. The services most frequently used in order of descending occurrence were medical and allied health, transport, legal, financial, and vocational and education services. This study did not, however, provide information on service utilisation specific to the transition period. A study by Corrigan, Whiteneck and Mellick (2004) did look at service utilisation during the year following hospitalisation for TBI and demonstrated that 59% of individuals required service supports for at least one injury-related need. Specific areas of need related to improving memory or problem-solving skills, managing stress and emotions, and managing finances.

Overall, while these investigations of the perceived service and support needs of individuals with ABI (Leith et al., 2004; Pickelsimer et al., 2007; Turner et al., 2007) provide useful input for development of service delivery models during the transition period, there is a need to supplement this with information from service providers. Currently, little published literature exists that describes the perspectives of health care professionals and support workers concerning the adequacy of the service systems for individuals with ABI returning home. Specifically, future service provision for the ABI population during the transition period needs to be informed by evidence regarding current services, gaps in service provision, and barriers and facilitators to providing services to individuals with ABI and their families during this important phase of post-injury adjustment.

Models of service delivery that seek to assist individuals with brain injury to re-integrate into their community following a period of in-patient rehabilitation are known to differ. Within the

Australian context, a benchmarking study across brain injury rehabilitation services conducted by a hospital-based Brain Injury Service in Queensland (Brain Injury Rehabilitation Service, 2006) demonstrated that service models vary markedly across Australia for people transitioning from hospital with an ABI. The majority of states offer outpatient, community-based, home-based or outreach services. Only two states offer a transitional living service, while a further two states provide limited home-based therapy services. Additionally, access to these services may be limited for some individuals with ABI and their families due to geographical location and funding shortages. This benchmarking process provided insights into different models of service delivery but, again, did not report the service providers' perceptions of the adequacy of current practices for the transition from hospital to home for individuals with ABI and their family. Therefore, the current study aimed to firstly explore the service supports available to individuals with ABI in Queensland during the transition from hospital to home by surveying key service providers for the ABI population. Subsequently, the study sought to explore the perceived adequacy of current services for individuals with ABI and their families during the transition from hospital to home from the perspective of service providers. Specific attention was paid to the identification of gaps in, and barriers and facilitators to service provision.

Method

Design

The study used a qualitative research design utilising survey-based data collection methods.

Participants

Participants were service providers drawn from organisations that provide services to people with ABI within Queensland. Services were identified using a snowballing sampling technique through the Brain Injury Network (BIN) in September 2006. The response rate to this sampling technique was 20%, with 12 respondents drawn from seven service provider organisations who completed the survey within the timeframe of the research. The seven service providers/organisations represented (1) hospital-based in-patient and out-patient rehabilitation services, (2) a state-wide government funded community outreach service, (3) privately funded support services and (4) a private rehabilitation service. All organisations were based in South-East Queensland, although six of the seven

provide services to people from all regions of the state and northern New South Wales. These seven organisations represented the major rehabilitation and support services within Queensland whose core business is service provision for young individuals with ABI across various stages in the continuum of care.

Data Collection

Data collection was completed using a survey developed for the purpose of the study. The survey was divided into two sections. The first part of the survey sought to gain information regarding the range of services provided by each organisation to younger people with ABI (18–60 years), as well as eligibility criteria, referral processes, and when and for how long services are available to people. The second section of the survey was designed to obtain information regarding gaps in service provision, differences in availability of services dependent on cause of injury, barriers and facilitators to service provision during the transition phase, and recommendations for future service development (see Appendix A).

Procedure

Ethical clearance for the project was obtained from the Human Research Ethics Committee at the University of Queensland with gatekeeper approval also obtained from the managers of each service provider prior to commencement of the study. The initial seed point for the snowballing recruitment procedure was the Brain Injury Network (BIN) which is a collective of service providers who work with people with ABI across hospital and community settings within Queensland and meet on a regular basis. Approximately 30 service providers either attend these meetings or participate in the network via email. A presentation about the nature of this study was given to members of BIN at one of their meetings by two members of the research team. At this meeting, the researchers provided a verbal explanation of the project, disseminated copies of the project information sheet, and gained support from members for BIN to serve as the initial point for recruitment. Prior to an organisation completing the survey, gatekeeper approval from the relevant manager or director was obtained by the research group, which was then followed by formal written consent being provided by the team member completing the survey. Organisations were informed that the survey could be completed either individually or by multiple team members within the service, or through one combined response based on group consensus.

Part of the survey included a request for details of other services from which the service provider had made referrals to, or received referrals from. This information was gathered to assist in the snowball sampling recruitment procedure. A 20% response rate ($n = 6$) was obtained for return of the survey despite the use of reminder emails to members of BIN after the initial 1-month return period had lapsed. It should be noted that some members of BIN provide services to children, or are residential facilities for people with ABI and therefore are not involved in the transition process from hospital to home for young adults with ABI. This is likely to have ultimately influenced the response rate. Returned surveys identified service providers outside of the BIN network, which were subsequently contacted and sent the survey for completion. This resulted in one further respondent whose service focus was rehabilitation.

Data Analysis

Written responses to survey questions were collated and transferred directly into a Microsoft word document, with each question representing a separate document. Where there was more than one respondent from each organisation (as in the case of two services), information provided in the first section of the survey regarding range of services, eligibility criteria, referral processes, and timing and duration was compared and summarised to prevent duplication of details. No discrepancies between respondents from the same service were identified in collapsing this data. Responses received from all twelve respondents to the second section of the survey were transferred accurately into a word document for analysis.

Responses to the first section of the survey were compiled to provide an overview of the services currently available to individuals with ABI, based on the seven service providers represented in the current sample. The main purpose of qualitative data analysis within the second component of the study was to explore gaps in service provision for young adults with ABI, as well as barriers and facilitators to providing services to this population. Inductive analysis of the written responses to survey questions was conducted to identify themes, codes, or categories of statements. NVivo 1.2 (Richards, 1999) was utilised to assist in the coding process. Inductive analysis involved seven steps as outlined by Turner et al. (2007), with the exception that the transcripts were based on written responses to survey questions and not participant interviews. Additionally, consensus coding between two researchers was used to ensure that the key issues and themes that arose from the coding process were

unbiased and truly reflective of the respondent's views (Patton, 2002). Member checks were also conducted with all participants who responded to the survey, as well as members attending a subsequent BIN meeting where preliminary results, including main themes, were discussed. Feedback was requested, and member checking revealed a high level of support for the key themes, and no additional themes were identified.

Results

Acquired Brain Injury Services in Queensland

A comprehensive overview of the services available throughout Queensland to younger people with ABI was not possible as only seven services are represented in the study. However, members of the multidisciplinary research team, experienced in the support and management of the ABI population, reflected on the respondents and agreed that this group represented the peak ABI-specific services in Queensland. A summary of the services provided by the seven respondent organisations is contained in Table 1. All respondent organisations provide services to adults with ABI and their families, with six of these organisations indicating that their services are available to people with all ABI diagnoses relevant to young adults. Organisations were based in the South-east corner of Queensland; however, the majority indicated they: (1) accepted referrals from throughout the state, (2) had regional offices throughout the state, or (3) provided outreach visits to regional areas if required. Only two of the respondent organisations required a medical referral to provide services, and in many cases (six out of seven) respondents indicated that the duration of service provision was based on client need. The nature of services provided varied across organisations. Three of the respondent organisations indicated that their major role was in rehabilitation, while the remaining four organisations provided services such as consultancy, education and training, practical support (e.g., accommodation and lifestyle supports), and emotional support (e.g., counselling and support groups/networks).

Adequacy of Services and Support for People With Acquired Brain Injury

The inductive analysis process generated three key themes that encapsulated the perspectives of service provider organisations regarding the range and adequacy of services available to individuals with brain injury and their families/friends.

TABLE 1
Summary of services provided to young people with ABI and their families by Queensland-based respondents

Service	Services provided	Eligibility criteria	Geographical region	Referral process	Timing/Duration of service
A	<p>rehabilitation for outpatients with ABI</p> <p>education and training for patients and family</p> <p>assessment clinics for new patients of the service</p> <p>review clinics for monitoring of known patients</p>	<p>18–60 years olds with ABI</p> <ul style="list-style-type: none"> traumatic brain injury stroke hypoxic brain injury central nervous system tumours other neurology/neurosurgical populations 	<p>located in South-east QLD</p> <p>accepts referrals from anywhere in the State</p>	<p>local acute tertiary hospitals</p> <p>other acute hospitals within QLD and northern NSW, general practitioners, other rehabilitation centres within QLD and northern NSW</p> <p>community-based health services</p>	<p>anytime following discharge from an acute hospital for treatment of an acquired brain injury</p> <p>waiting list can delay start of rehabilitation</p> <p>waiting list for assessment / review clinics (up to 4weeks)</p> <p>1 x 1 hr session / week per therapy, with length of service dependent on patient identified goals (case-by-case basis)</p> <p>during or after treatment</p> <p>assistance not time limited</p>
B	<p>practical support</p> <ul style="list-style-type: none"> accommodation assistance financial transport <p>emotional support</p> <ul style="list-style-type: none"> counselling support groups support network <p>education</p>	<p>any person with brain tumour, their family and friends</p>	<p>head office – Brisbane</p> <p>7 regional offices across the state</p>	<p>drop-in to city or regional office</p> <p>call local office</p> <p>state-wide telephone helpline</p>	

TABLE 1 (continued)
 Summary of services provided to young people with ABI and their families by Queensland-based respondents

Service	Services provided	Eligibility criteria	Geographical region	Referral process	Timing/Duration of service
C	education and training <ul style="list-style-type: none"> information service on ABI, including web-based resources, publications and fact sheets referral to other services, includes web-based referral service carers support group lifestyle support services behavioural consultancy accommodation support	any person throughout QLD with a diagnosis of ABI, or has a family member or friend with ABI information provision to anyone world-wide with an interest in ABI	head office – Brisbane can provide state-wide advice & training	direct referral from individual / family other service providers	any time following diagnosis of ABI assistance not time limited
D	accommodation support community access and lifestyle support day respite rehabilitation emergency and crisis intervention education	people with ABI aged 16–60 years	south-east QLD	direct referral from person / family other service providers	any time following diagnosis of ABI assistance not time limited
E	assessment and treatment of inpatients with ABI counselling, education and support discharge planning to community family education referral to other services	people with ABI and their families <ul style="list-style-type: none"> traumatic brain injury stroke congenital, progressive or other acquired neurological disease aged 16–65 years	located in South-east QLD accepts referrals from anywhere in the state	via referral from acute hospitals throughout QLD and Northern NSW, general practitioners, and other rehabilitation services	when patient is deemed as in need of an inpatient rehabilitation program length of admission negotiated between patient, family, and rehabilitation team <ul style="list-style-type: none"> goal-based case-by-case decision-making

TABLE 1 (continued)
Summary of services provided to young people with ABI and their families by Queensland-based respondents

Service	Services provided	Eligibility criteria	Geographical region	Referral process	Timing/Duration of service
F	<p>community-based and home-based rehabilitation</p> <p>case management with a focus on coordination of rehabilitation and community reintegration</p>	<p>adults have sustained a TBI or ABI</p> <p>teenagers with ABI or TBI diagnosis who are transitioning to adulthood</p>	Brisbane region	<p>general practitioners</p> <p>public rehabilitation services</p> <p>insurance companies</p> <p>direct referral from patient / family</p>	<p>anytime during their recovery</p> <p>minimal time to wait for service to begin once a referral has been received</p> <p>not time limited by service, but duration may be dependent on funding (private or compensation)</p>
G	<p>rehabilitation coordination including:</p> <ul style="list-style-type: none"> • case management • education of services, carers, clients • monitoring • referral to other services <p>education and support programs</p> <p>self-managed support networks for adults with brain injury,</p> <p>consultancy to service providers regarding ABI management in the community</p>	adults of working age with ABI	state-wide service (QLD)	<p>anyone can call to make phone or written referral</p>	<p>not specifically defined, any time post-ABI</p> <p>programs goal oriented, therefore length is related to goal completion</p> <p>no formal time restriction on access to service</p>

Underlying these themes were 24 categories that were organised into a summary coding framework. This framework (see Figure 1) affords a representation of the key factors and issues related to service provision for individuals with ABI during the transition period from the perspective of service providers, with a view to the identification of gaps in, and barriers/facilitators to service provision. A total of 341 statements were coded, and these varied in length from a few words to a few sentences according to how responses related to the objectives of the study and coding descriptions. Respondents provided detailed and comprehensive responses with themes common across the different services. The findings of the study are reported under the three main themes that encapsulate the respondent’s perceptions of service and support needs of individuals with ABI and their families during the transition phase; service infrastructure, transition support, and transition context. Direct quotes from respondents are used to illustrate the findings throughout the results section.

Service Infrastructure

Respondents were able to identify a range of gaps in service infrastructure for younger people with ABI in Queensland during the transition period,

which in turn were related to barriers experienced in providing services.

Funding. The issue of funding — in particular, government-based funding — was mentioned repeatedly in response to questions about gaps in, or barriers to, service provision. Specifically, respondent organisations felt that there was a ‘lack of funding to enable people with severe ABI or limited social support to live in the community’. The amount of *capacity funding* available was thought to limit service delivery options for organisations working with younger people with ABI, as ‘there is no money to assist with anything’. This limits the ability of organisations to respond to and manage the number of clients who require assistance during the transition phase, and to do so in a timely and efficient manner. While many of the comments received were lamenting the lack of funding available, a number of respondents did acknowledge the availability of ‘limited funding for some clients’ through one government organisation.

Staffing. The limited funding available for services working with younger people with ABI in the community was seen to infringe on staffing, which was another category within the service infrastructure theme. Funding levels were seen to restrict organisations’ abilities to attract specialist

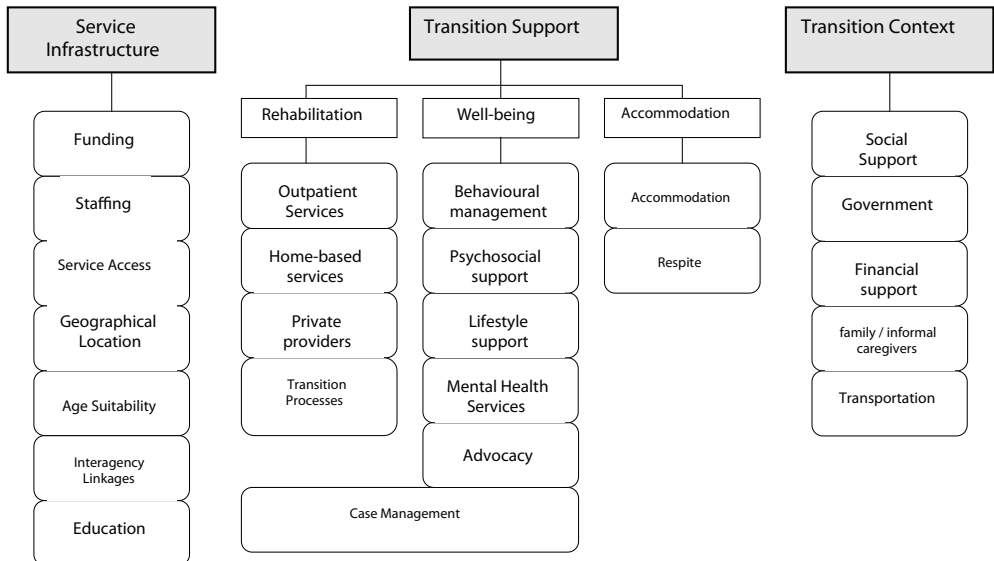


FIGURE 1 Summary framework coding for gaps, barriers and facilitators of service provision.

staff both to rehabilitation services and community-based support staff positions. Additionally limited opportunities for formalised training in managing people with ABI was perceived to preclude skill development in existing staff. The limited skills and qualifications of the workforce was seen to restrict service delivery by influencing the 'frequency and amount of therapy that can be provided' and resulting in therapy services providing intervention 'below the recommended rehabilitation guidelines'. An area specifically identified as being understaffed was psychosocial support services for younger people with ABI and their families during transition, encompassing disciplines such as social work, counselling, clinical psychology and neuropsychology.

Service access. Gaps in service infrastructure related to funding and staffing were reported to lead to problems with service access. Restricted access to postdischarge therapy services was seen to not only reduce the frequency of therapy but also location of intervention, specifically as it was 'not in the home/community environment where therapy can be performed within context'. Where outpatient services do exist it was also reported that there were 'delays in accessing (GO¹) follow up due to waiting lists and waiting times'. Service access in some cases was 'limited either in terms of availability or eligibility of ABI clients', with particular mention of drug and alcohol, mental health, and behavioural management services. Specifically, there was a concern that service access issues existed for individuals with a dual diagnosis, especially those with a combination of ABI and mental health conditions. One respondent suggested the need for ABI/mental health outreach teams that completed 'psychology behaviour management, medication and ABI reviews' for community dwelling individuals. The service access category revealed a difference between younger people with ABI who had a compensable versus noncompensable injury. Respondents indicated that individuals eligible for compensation were able to 'access privately funded services at very short notice with minimal waiting periods', which improves access to services. Furthermore, during the transition phase many compensable individuals are case-managed by insurance providers who 'frequently case-manage the claim long-term, and thus able to arrange services that the individual or their family may not have the capacity or knowledge to do'.

Interagency linkages. The topic of case-management and its facilitation of service access lead to another category identified in the data analysis, namely interagency linkages. The linkages, or lim-

ited linkages, between organisations were seen to be both facilitators and barriers respectively to service delivery for younger people with ABI and their families during transition. Some respondents felt that the networking between organisations was fragmented, resulting in 'poor coordination and inconsistency of eligibility criteria' affecting service provision for individuals with ABI and their families. The responses provided, however, did suggest that contributing to interagency linkage difficulties was 'a lack of existing service providers with whom to link', complex and changing referral procedures, and communication breakdown between service providers. In contrast, some responses reflected the 'development of strong clinical network links with other services', particularly where the core business of organisations was to provide services to people with ABI and their families. Difficulties were reported to occur where organisations had the ABI group as a component of a much larger client base. Collaborative partnerships with other organisations were seen as facilitators to ABI service provision, with a range of linkage patterns discussed, including 'formal referral forms and updated progress reports', the use of technology (e.g., videoconferencing), and 'case conferences with all involved parties'.

Education. Another integral component of the service infrastructure required for people with ABI and their families during transition was seen to be education. Respondents felt that where individuals were aware of resources through either formal or informal education, access to services was greater. Unfortunately, many of the respondents' comments indicated that there was a gap in services related to educational resources, suggesting that educational resources were either not available or not provided. Others suggested that the issue is not just availability, but also the timing of the provision of resources. Specifically, one service provider commented that 'patients and families can be more receptive to ... education in the home environment,' but that 'no more education is able to be provided' once an individual with ABI is discharged to the community.

Geographic location and age suitability. The remaining two categories (geographic location and age suitability) under the service infrastructure theme generally received limited comment from respondents. Respondent organisations did highlight that there was 'very limited support for clients returning to rural areas', which encompassed the domains of therapy, psychosocial, and accommodation services. Additionally, the centralisation of ABI-specific services to major geographic centres was seen as a barrier to effective transition pro-

cesses. It was felt that during the rehabilitation phase 'some families and social supports are geographically away' from the individual with ABI, which makes the 'transition from inpatient to outpatient difficult'. This was reiterated by another respondent, who suggested that 'isolation can impact on clients and support persons and how they cope'. The concept of isolation related to peers and social supports, as well as services able to assist the person with ABI and their family. Services available specifically to support younger people with ABI were also considered restricted in all geographic locations and one respondent mentioned that 'the inappropriateness of using resources in the aged care sector is an issue'.

Transition Support

The transition support theme can be further divided into three subthemes: rehabilitation, well-being, and accommodation, with greatest emphasis on issues surrounding therapy (rehabilitation) and emotional supports during transition.

Rehabilitation. Respondents identified that there was limited availability of rehabilitation services during the transition phase for both outpatient services and home-based services, and no transitional living process (e.g., transitional living unit or transition programs) within Queensland. The availability of limited rehabilitation services has resulted in barriers to the implementation of evidence-based interventions, with responses suggesting that 'patients can only be seen once a week'. Additionally, it was felt that restricted resources for postdischarge rehabilitation meant that rehabilitation could not be performed 'in the home/community environment where therapy can be performed within context'. Respondents also suggested that all appropriate rehabilitation services were not available including neuropsychology and dual diagnosis clinics (e.g., mental health/ABI). The inability to provide therapy in the home context was seen as a barrier to effective rehabilitation with 'patients and families more receptive to therapy in the home environment'. Furthermore, clinic-based outpatient services were sometimes limited by logistic issues surrounding transport (e.g., 'if patient requires ambulance transport they are limited to morning sessions'). It was noted that some of these gaps were diminished somewhat if an individual was receiving compensation for their injury. In particular, they were able 'to access private therapy in home and community contexts', which often increases the amount of therapy received. There are however, still limitations for this patient group with only a small number of private providers who specialise in ABI rehabilitation, and

'difficulty in getting funding approval quickly, which can delay implementation of services'. Injury compensation was seen as a facilitator of service provision for younger people with ABI and their families receiving rehabilitation support during the transition phase. Individuals who receive funding from insurers or Workcover will most likely receive case management, which is seen as a major facilitator of access to rehabilitation in this phase of recovery. Case management as a facilitator of therapy support, however, was not restricted to privately funded clients, and the inception of a government organisation was praised: 'The creation of {GO} had significantly addressed a service need'. Nonetheless, this publicly funded case-management service was acknowledged to be overloaded which resulted in difficulties linking between organisations, 'long waiting lists, and limited service provision'.

Wellbeing. The main areas where transition support was reported to be lacking within the wellbeing theme were for behavioural management and mental health services. Challenging behaviours were identified as sequelae of ABI, which need to be managed within the community, and yet respondents indicated that there is a lack of 'behavioural support, intervention and response training for families'. It was also noted that 'community agencies that can cope with ABI clients due to their challenging behaviours' are lacking within Queensland. The importance of these services during the transition period was highlighted by one respondent who stated that 'behavioural issues stigmatise individuals within their community and prevent reintegration'.

Compounding the issue of access to mental health services for individuals with a dual diagnosis of ABI/mental health condition is a 'lack of knowledge of ABI in the mental health community', with respondents questioning the effectiveness of services that are provided. Respondents also indicated that there are limited psychosocial supports available to individuals with ABI and their family during the transition phase in terms of counselling services (psychology or social work). This 'limited psychological support means reduced support at a critical time of rehabilitation', which was perceived to impact on their ability to adjust to community life with a brain injury. Case management was seen to facilitate access to available mental health, counselling or behavioural management services, while a barrier was the dearth of advocacy services. One respondent indicated that 'there are very limited individual advocacy services' available to younger people with ABI and their families.

Respondents indicated that a gap existed in services that address issues of lifestyle support. This category encapsulated an individual's ability to function within their home and community environments, including activities of daily living, recreation, and community access. It was suggested that where individuals had received compensation for their injury they were more likely to be able to access 'funding for a community support worker who helps patients address goals in the home and community'. As one respondent stated:

If you're on a pension, you are 'existing'.
If you have compensation, you can buy the carer to explore meaningful occupations that create a 'living'.

Although respondents were able to identify that some government funding is available for community support, they did indicate that there was some difficulty with 'access GO lifestyle support packages or family support packages'. Additionally, where appropriate recreation options were available and free, individuals with ABI were still not able to access these lifestyle activities as 'the cost of getting there (transport of the carer support) makes even a free service inaccessible [sic]'.

Accommodation. The final subtheme within transition support was accommodation, with respondents able to identify a number of gaps in service provision that resulted in barriers to finding suitable accommodation for younger people with ABI in the community. In relation to long-term accommodation, respondents indicated that there is a 'lack of appropriate/modified community accommodation options'. They also suggested that there are 'no supported living accommodation trials available' that would assist decision-making by service providers and younger people with ABI about suitable community-based accommodation. It was suggested that 'housing and accommodation options are limited and undignified', with some young people living inappropriately in institutional centres due to the lack of alternatives. In some cases it was suggested that 'compensated people with ABI are able to access accommodation' options as they have 'the financial capacity to access their needed services', but options and choices were still perceived to be limited.

Respite services were also identified as an area where a gap exists in services available to families. It was suggested that there are 'no respite services to cater for young ABI patients', and that available services are 'not geared for cognitive/behavioural disability'. Additionally, an identified barrier to providing respite service to younger people with ABI was 'services not knowing how to work with young people with ABI (e.g. respite services

babysitting young men as though they were grandmas with dementia)'. This again was an area where compensation was thought to make a difference as these individuals 'can pay for support workers/in-home respite' and were able to access more 'appropriate and frequent respite'.

Transition Context

The theme 'transition context' refers to a range of environmental and personal factors that may influence the transition process. The respondent organisations suggested that reduced levels of social support is an area that impacts on younger people with ABI during the transition period. While in many cases social support may occur informally, respondents highlighted that there were no 'social supports or networks looking at leisure and community access' for the young ABI population. The importance of formalised social support networks was often exacerbated for those from non-metropolitan or rural areas where they 'are removed from peers, social supports and family members' during rehabilitation, which may make the transition from hospital to home more difficult. One government-based organisation was identified that had 'the scope to explore meaningful activity in the community (e.g., leisure)'; however, it was also noted that this organisation was stretched to capacity and had waiting lists for all services.

Access to some government services was seen as restricted and in part attributable to government policies and structures. Respondents highlighted the many government departments (health, housing, disability, and so on) that may be involved with a young person with ABI during transition. The need to coordinate service provision across so many government departments was seen to contribute to the 'lack of integrated/collaborative community support services' for younger people with ABI. Although, on a positive note, respondents highlighted that recently government departments had identified the need for 'strategic/policy planning for provision of services for identified ABI need'. Some respondents suggested that one way to overcome the fragmentation of government funded services and facilitate better provision of services to younger people with ABI was 'forming professional referral relationships with inter-disciplinary services'. Another barrier to service provision was identified as a limited understanding within the community and many government organisations of the impact of ABI. In particular, respondents felt that some government policies regarding employment benefits acted as 'disincentives to work for younger people with ABI due to fear of being cut off, reduced income, increased

risk, and paperwork'. Funding policies were also noted to impact on the services available to younger people with ABI within the transition period. It was stated that 'limited funding from GO' was allocated to organisations to 'provide Day Centre services' with the remainder of funding coming from fundraising, community support, and 'clients receiving individual funding packages'. However, where a potential client had not secured government or compensation funding, an organisation was only able to provide a limited service, which highlights issues of equity within the transition phase.

Funding of services was repeatedly mentioned by respondents to this survey. Similarly, financial support received by individuals with ABI to assist them during the period of transition to the community was commented on frequently. Respondent organisations indicated that 'financial barriers' were evident for people in transition, and that a 'lack of funds leads' to poverty, and 'poverty is about limited choice and opportunities'. While responses to the survey highlighted that there are sources of funding available to younger people with ABI, it was also noted that a 'lack of support re application for funding' exists and results in poor access to potential funds. Not surprisingly, respondent organisations identified that financial support was an area where compensated and noncompensated individuals differ. Specifically, individuals who receive compensation have 'the financial capacity to access their needed services'.

Another key category within transition context was the role of family/informal caregivers. The reliance on families 'to care for these patients at home with no support' due to a lack of funding was referred to on a number of occasions. Respondent organisations felt that 'to assist with successful transition, carer support is needed not just for compensable individuals', and this was a major gap in services for the families of individuals with ABI. One of the barriers to accessing support services was the lack of 'consistency of service eligibility, especially for families and carers', and often a 'fragmentation of support available for the long term'. One of the ways respondent organisations felt that they could support families and carers to access required services was through 'informal and formal education and family support programs', but again respondents highlighted that there were only 'a few services to link patients and families — most fend for themselves upon discharge with reviews at the hospital'.

The topic of transportation was a major issue within the context of transition. Accessing the community and available services was seen to be limited by problems with transportation. Many

young individuals with ABI are not permitted to drive on discharge from hospital, and therefore 'patients without medical clearance to drive rely on others to be driven, which presents as a problem'. One respondent organisation indicated that a lack of transport is 'HUGE and have (sic) major implications for people'. It restricts their access to rehabilitation facilities, leisure options, and participation in everyday activities within the community. The cost of discounted taxi travel as a form of transportation was thought to be used only on 'occasional and very short distance trips', with carer support seen as necessary for accessing public transport which again was unaffordable. This was not an area where a difference was noted between individuals who had received compensation for injury and those who had not, with the exception of avoiding public waiting lists to undertake a driving assessment. Ultimately, however, this difference in access may facilitate better community participation for these individuals if they receive medical clearance to drive during the transition period.

Discussion

The present study has found that, within Queensland, there are a number of government and nongovernment organisations who consider their core business to be the provision of services to younger people with ABI and their families. Although the authors acknowledge that the respondent cohort may not represent all organisations that provide services to this population, a comprehensive range of services were reported that encompass rehabilitation, education and training, practical support (e.g., accommodation, respite, funding, and transport), counselling, case management, and behavioural consultancy. This range of available services is somewhat similar to the services known to be utilised in other regions as reported by Hodgkinson et al. (2000), suggesting there is consistency in perspectives across the Australian states as to the nature of support services required by younger people with ABI and their families during the transition period. This summary of services available, however, does not address the issue of adequacy of current services that was investigated in greater detail in the second component of the present study.

Service providers were able to identify gaps in the services currently being provided to younger people with ABI across six areas; psychosocial support, rehabilitation services, case management, accommodation, community-based support and resources, and transitional living programs, which fit within the theme of transition support.

Rehabilitation and wellbeing were most frequently identified by respondents as areas where current services were failing to meet the needs of younger people with ABI. Limited access to rehabilitation services during transition, whether it be hospital- or community-based, was a commonly identified gap in service infrastructure. Specifically, respondents felt that therapy services were typically understaffed and underfunded, thus service access was restricted by long waiting lists and limited rehabilitation outside major geographic centres. The gap in rehabilitation services provided during transition was perceived as the area of greatest need by individuals with ABI and their family caregivers in a parallel study (Turner et al., 2007). Rehabilitation during the transition phase has been highlighted previously as important to decreasing the degree of disability experienced by younger people with ABI living in the community (Barnes, Frank, Montgomery & Nichols, 2005). Case management, either within rehabilitation services or other community-based services has been identified by individuals with ABI as key to facilitating successful transition from hospital to home (Turner et al., 2007). However, the service provider perspective in this study suggested that case management is frequently unavailable which can make accessing support services difficult.

The need for services that address emotional well-being was a prominent theme during the transition to home phase for people with TBI in a study by Rotondi, Sinkule, Balzer Harris and Moldovan (2007), which was expressed in Corrigan and colleagues' study (2004) through high utilisation of services in this domain. The need for emotional and psychological support was identified by service providers, but services able to provide counselling or psychological support was an identified gap. Overlap with the service infrastructure theme can be seen, with poor funding and a consequent lack of staffing leading to restricted access to psychosocial support and counselling services. The limited numbers of services available to support emotional wellbeing is somewhat surprising as studies have shown that post-brain injury adjustment often leads to high levels of stress and strain that require intervention (Anson & Ponsford, 2006; Ponsford, Olver, Ponsford & Nelms, 2003). Furthermore, our respondents suggested that the paucity of community-based support programs to enable younger people with ABI to participate actively in society can place additional strain on families. Interestingly, Turner et al.'s (2007) participants with ABI and their families did not perceive the gap in either psychosocial or lifestyle support ser-

vices that service providers reported. They did, however, identify that return to meaningful activities, social networks, and psychosocial wellbeing were all areas where changes occurred during the transition phase.

Respondents reported a significant gap in services occurred at the point of hospital discharge due to an absence of transitional living programs. These programs typically focus on the complex cognitive, social and behavioural issues associated with brain injury, with the intent to provide appropriate levels of graduated support to individuals during this period of transition back into the community and family life (Harrick, Krefling, Johnston, Carlson, & Minnes 1994). Given that services able to manage the cognitive, social and behavioural aspects of brain injury during transition have been identified as limited within the Queensland context, it is not surprising that the concept of transitional living programs was raised by respondents. In some cases statements referred to 'transitional living centres', while others mentioned 'programs'; however, constituent components of desired programs were not clearly stated, although their intent was perceived as facilitating community integration. The literature would suggest these programs require a degree of flexibility to address each individual's concept of community reintegration (McCull, Carlson, Johnson et al., 1998), while also incorporating certain structural (e.g., degree of supervision), contextual (e.g., independent living) and directional (e.g., therapy and social support) aspects that characterise such programs.

Service providers reported experiencing difficulties in, or barriers to providing services to individuals with ABI and their families, that in many ways relate to gaps in services. Respondents consistently indicated that the lack of rehabilitation options and community-based support services (transition supports) was the biggest barrier to meeting the service and support needs of younger people with ABI and their families. Consequently service needs remain unmet, and this is in keeping with previously reported unmet service provision (Rusconi & Turner Stokes, 2003; Turner et al., 2007; Wade, Crawford, Wenden, King & Moss, 1997). A lack of accommodation options or support services was also identified as a barrier to community reintegration, resulting in unmet long-term community options and reliance on family supports to assist younger people with ABI. Service infrastructure issues contributed to service provision barriers through a lack of funding to support the required services from either developing or expanding, and further compounded by a

shortage in specialist staff to work in rehabilitation and support services.

Key to the provision of community-based services to people with ABI are good communication and inter-agency working relationships (Beecham, Perkins, Snell, & Knapp, 2009); however, respondents in the present study suggested that these areas require further development. Poor inter-agency linkages were identified as a barrier to working effectively, with a lack of coordination between government organisations thought to lead to fragmentation in support services received. Turner et al. (2007) highlighted that this lack of coordination and communication between services was evident to individuals and families, and was perceived to negatively impact their transition from hospital to home. Additionally, government structures and policies were thought to contribute to poor coordination of services and inconsistency of eligibility criteria across services. Notwithstanding this finding, good inter-agency linkages were also seen to be a facilitator of service provision with respondents able to provide examples of effective communication and inter-agency working relationships between some organisations.

Another barrier to service provision and service access involved transportation, particularly in relation to independence with transport and the cost of transport. Many young people with ABI during the transition phase are not able to drive due to medical issues and may also be unable to access other forms of transport. This was perceived by service providers to limit access to services. Reliance on others for transportation (e.g., ambulance shuttles) was seen as restricting attendance at rehabilitation and community-based support services, as was the cost of using either taxis or public transport. This was similar to Turner et al.'s (2007) findings that individuals with ABI identify issues with driving and transport in relation to community participation.

All organisations who completed the survey reported that there were differences in support for compensable and noncompensable individuals with ABI. In general, compensable clients received greater levels of support and were able to access a broader range of services in a timelier manner than individuals without compensation. Areas of specific difference where compensable individuals were thought to receive greater access to services were rehabilitation and in-home support, although it was noted that access to these services at times was restricted.

The current study outlines the views of service providers with regard to the status of transition services available to support younger people with

ABI and their families; however, there are some methodological limitations to the study that must be acknowledged. The snowballing methodology was largely unsuccessful in recruiting a large sample, but service providers who did reply provided rich and in-depth information with a high degree of agreement between respondents. Additionally, the study was restricted to Queensland-based service providers and therefore we were unable to examine similarities and differences in the nature and adequacy of service delivery in other states of Australia. This specific focus on Queensland, however, was deemed necessary due to the state-based nature of funding for Health and Disability services in Australia.

Further research is warranted that examines the needs of younger people with ABI and their families during the transition phase from hospital to home in greater depth. The present study particularly suggests that there is a need to develop and evaluate service models during this phase. These models should encompass the rehabilitation, psychosocial, accommodation and transport needs of people with ABI, as developed within a multi-sector and inter-government environment. This study also highlighted the need for further research to focus on patterns of service use and equity issues for individuals who have a compensable injury as compared to those with a noncompensable injury, with a view to understanding the impact on short- and long-term outcomes.

Conclusion

Services available to younger people with ABI and their families during the transition from hospital to home within Queensland were found to cover a range of identified needs including; rehabilitation, consultancy, education and training, and practical (e.g., accommodation) and emotional (e.g., counselling) supports. However, inductive analysis of qualitative survey responses revealed that there were gaps in, and barriers to service provision. A numbers of these gaps and barriers were described by respondents as relating to service infrastructure issues, namely, a lack of funding and staffing that restricted service access. Interdependence between themes was also evident with gaps in transition support such as rehabilitation, behavioural management, psychosocial, and accommodation services perceived as a major issue in the opinion of our respondents. Other obstacles to successful transition for younger people with ABI were identified such as social support, finances, and transportation. The findings of this study provided useful information concern-

ing the nature of services currently available in Queensland during the transition phase from hospital to home, as well as insight into areas that require service development. Within the rehabilitation continuum, the transition phase is crucial to long-term community integration and from these findings it seems that health and disability organisations have an integral and shared role in supporting the needs of younger people with ABI and their families.

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Endnote

- 1 To maintain the anonymity of service providers referred to within respondents' quotes the names of specific organisations have been replaced with the generic abbreviations GO for government organisations, and NGO for non-government organisations.

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Appendix A

Survey Questions Used in Phase 2 of Study

1. Can you identify any gaps that currently exist in supporting people with ABI and their families during the transition from hospital to community? If yes, please detail these below.
2. Are there differences in supports available to people with ABI who have received compensation for their injury? If yes, please detail below.
3. What difficulties has your organisation experienced in providing services to people with ABI and their families?
4. What has helped your organisation provide services or support to people with ABI and their families?
5. Has your organisation had any difficulties in linking with other service providers for people with ABI and their families? If yes, please detail below.