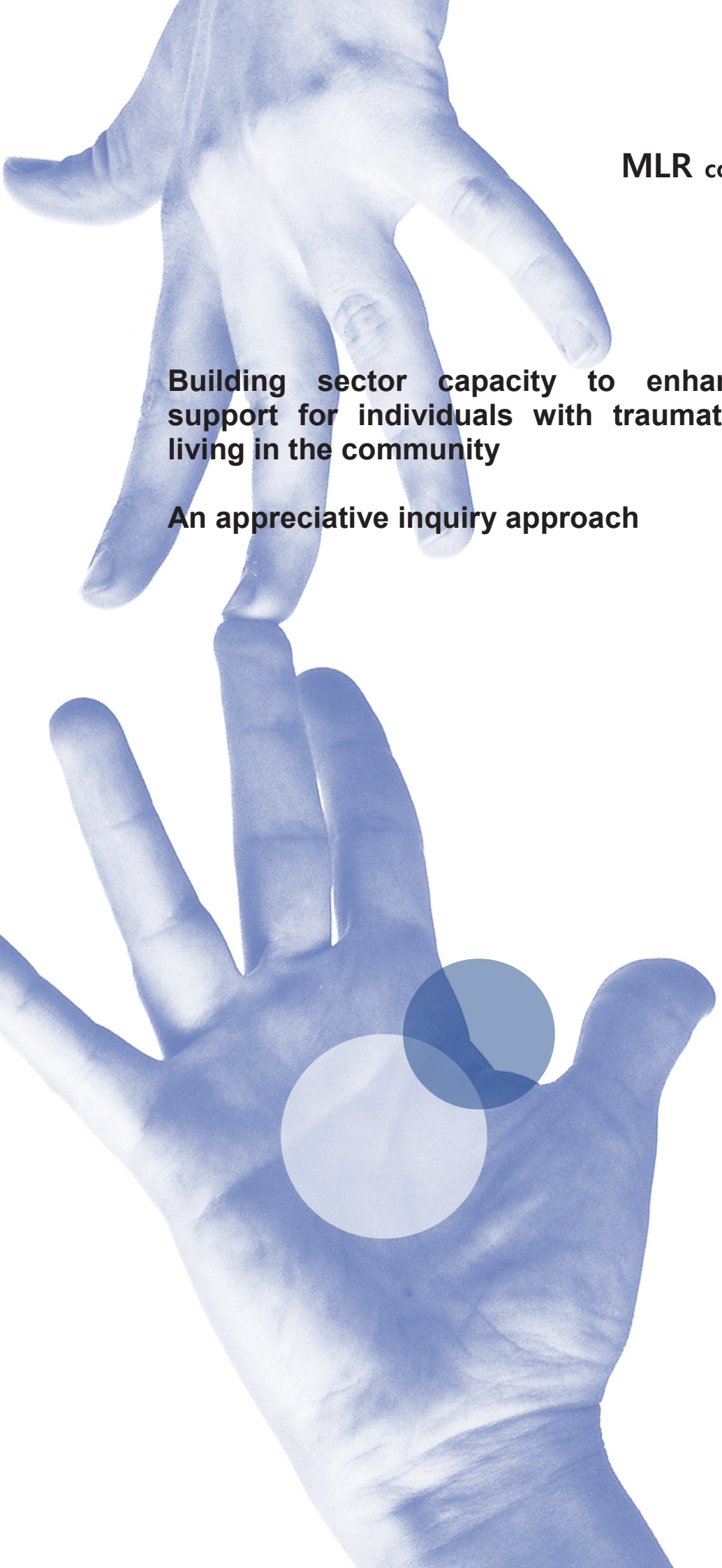

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Building sector capacity to enhance behaviour support for individuals with traumatic brain injury living in the community

An appreciative inquiry approach

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PROJECT LEADER

Report Building sector capacity to enhance behaviour support for individuals with traumatic brain injury living in the community

An appreciative inquiry approach

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Definitions

Attendant care worker: An attendant care worker is a paid support worker with, or without, formal qualifications providing support to a person with a brain injury.

Behaviour support: Behaviour support is a psychosocial service or services co-ordinated to reduce behaviour(s) that impede community inclusion and participation, and that reduce the likelihood of consumers achieving their desired outcomes.

Behaviour support practitioner: A behaviour support practitioner is a professional person providing behaviour support services.

Carer: A carer is an individual who provides ongoing personal care, support and assistance to the person with a brain injury. Although not always, this person is often a partner or family member.

Challenging behaviour: Challenging behaviour is defined as behaviour that jeopardises the safety of the person exhibiting it, or the safety of others, and/or that limits the person's access to services.

Circles of support: People who provide formal or informal support to the person with a brain injury.

Funder: Those bodies that approve the funding of services.

Traumatic brain injury: An induced disruption of brain function that is the result of an external force leading to impairment in cognitive, physical and/or psychosocial functions.

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1. BACKGROUND

1.1 The New South Wales Lifetime Care & Support Authority (LCSA) funds treatment, rehabilitation and attendant care services to people severely injured in motor accidents in New South Wales (NSW), regardless of who was at fault in the accident. Included in the scheme are people who have sustained a traumatic brain injury (TBI). TBI is the major cause of disability in people aged under 40 and the annual incidence is estimated to be 100 per 100,000 population each year (World Health Organisation 2006).

1.2 In May 2012 the NSW Agency for Clinical Innovation published a review of prevalence of challenging behaviour in participants of the NSW brain injury rehabilitation programme (Sabaz 2012). Established in 2010 and reporting to the NSW Health Minister, the Agency engages clinicians and consumers in designing, improving and implementing models of care. The report noted challenging behaviour in 53% of the 659 people with TBI surveyed. Inappropriate social behaviour, aggression and adynamia were the three most common individual behaviours. Over a third displayed more than one challenging behaviour.

1.3 The cognitive, emotional and behavioural sequalae of moderate and severe TBI affect all areas of an individual's life and can necessitate co-ordinated support over lengthy periods of time, sometimes over the lifespan. It is changes in these aspects of neuropsychological functioning that impact most upon the person's ability to achieve desired goals and restrict most his or her participation and inclusion in the community. Recent Australian research has also shown that reduced participation further contributes to psychological disruption and adversely affects family functioning (Winstanley, Simpson, Tate and Myles 2006). This is consistent with earlier research showing it is behaviour change rather than physical change following TBI that contributes most to family distress long term. Although family members often provide the majority of support, they are often anxious about this role, receive little support from other services and experience significant levels of psychological distress (Rietjidk, Togher and Power 2012).

1.4 Engaging people with brain injury and their families in community behaviour support is often critical to improving outcomes. The goal of behaviour support and community rehabilitation is to reduce the effect of ongoing impairment and to support the person to achieve his or her maximal degree of functional recovery, participation and quality of life (Khan, Baguley, and Cameron 2003).

This project

1.5 LCSA recognises that there are many examples of excellent practice in behaviour support being carried out everyday in the NSW community by dedicated practitioners and significant others, including family carers and paid attendant care workers. Even so, the number of professionals currently providing this service to LCSA clients and their wider circles of support is relatively small. There remains a need to enhance capacity in this area.

1.6 In December 2013 LCSA approved funding for a project to help produce a strategic action plan to build sector capacity to support individuals with traumatic brain injury who exhibit challenging behaviour and who are living in the community. It was expected a particular emphasis of the project would be on individuals living in rural and remote areas.

1.7 David Manchester, a clinical psychologist with extensive experience in traumatic brain injury rehabilitation was appointed by LCSA as the project leader.

1.8 A steering group of interested stakeholders was formed in early 2014 to advise the project leader and to feedback on the project's findings. The steering group members are set out in Appendix 1.

1.9 After consultation with the steering group it was agreed the project would adopt an appreciative inquiry framework. Appreciative inquiry (AI) is a collaborative search to identify and understand a system's strengths, its greatest opportunities and also its peoples' aspirations and hopes for the future. It is an approach to complex behaviour change that has been found to be helpful in multiple organisations and service systems throughout the world. For a recent overview of AI theory and practice see Cooperrider, Whitney and Stavros (2008).

1.10 AI does not approach problem solving with a focus on what is not working. Instead its focus is on appreciating what is working and why it is working (the positive core) and how this can be enhanced. A tenet of the AI approach is that answers to these questions reside in a distributed network that exists amongst the practice community. Thus, in order to find out what works well in behaviour support post TBI in the NSW community and how can this be strengthened, it is necessary to consult widely with the people providing good practice, those contributing more broadly to its knowledge base, as well as consumers receiving good behaviour support.

1.11 With this in mind, LCSA committed to pursuing a broad consultation process with key stakeholders including practitioners, case managers, researchers, educationalists, and consumers covering both carers and attendant care workers. By bringing members of the practice community together in this way it is expected that recommendations made will be relevant to the community, will be feasible, will be useful, and will be supported. LCSA was, and is, committed to funding or co-funding future joint ventures where these are recommended and where they can be managed within available resources.

1.12 Over the first three months the project leader completed a generative literature review. This was added to over the ensuing months based on steering group members' feedback for the duration of the project. An annotated literature review is attached at Appendix 2.

1.13 The project leader also carried out AI interviews with the majority of steering group members and four additional interviews with three psychologists and an LCSA case co-ordinator. Nine steering group members conducted further interviews with consumers of behaviour support services. Each of these nine group members interviewed one consumer. The primary AI interview questions are set out in Appendix 3.

1.14 A review and analysis of interview data led to the initial identification of 15 themes. These are set out in Appendix 4.

1.15 On 26 August 2014 steering group members, senior LCSA management and other invited stakeholders from brain injury services, advocacy groups, research bodies and the department of education attended a whole day meeting in Sydney, the AI summit day. The purpose of the meeting was to discuss the findings to date and to outline future goals and designs that might guide capacity development in this area. A list of summit day participants is provided in Appendix 5. This led to a refined set of five key themes and related goals. These are set out in Appendix 6.

1.16 This report reviews the key findings from the literature review, the AI interviews and the summit day. Finally, it sets out a series of recommendations based on these findings for LCSA to consider to enhance sector capacity and to address the project's intended outcomes.

Project limitations

1.17 Several clarifications establish the limits of this project. The project does not aim to identify all areas in which practice may be improved. Rather, it seeks to help establish sustainable change in a small number of areas that the practice community identifies as relevant, needed and sustainable.

1.18 It is accepted that there will always be a small number of individuals with TBI who will not be able to be supported successfully in the community for particular periods of time because of very severe cognitive and behavioural difficulties. In the USA and the United Kingdom this group is often supported in specialised residential brain injury services run on the principles of neurobehavioural rehabilitation (e.g. Alderman 2004, Giles and Manchester 2006). At present no such service exists in NSW although a case has been made for this previously (Manchester, Hodgkinson and Casey 1993). The need for such services in other areas has been recognised recently by the NSW government intellectual disability services. A report by NSW Ageing, Disability and Home Care (Ponzio and Williamson 2013) includes a proposal for a more structured and secure residential setting for those individuals who exhibit severe challenging behaviour and who have cognitive impairment due to intellectual disability. That report is being considered for further progress by the NSW Department of Health.

1.19 Aggression after TBI is most often due to irritability, angry arousal and poor impulse control. A further factor is spontaneous electrical brain disturbance usually implicating the temperolimbic system that leads to episodic dyscontrol (Wood and Thomas 2013). These are the types of aggression considered in this report. Violence and sexual violence that is premeditated, planned or predatory is more usual in forensic and criminal justice settings. There are standardised forensic risk assessments for this type of violence risk. Forensic violence risk assessment is a highly specialised area and is not the focus of this project. For a review of forensic violence risk assessment issues and measurement see Otto and Douglas (2010).

1.20 This report recognises the thorough earlier work of the Agency for Clinical Innovation's Challenging Behaviour Project (Sabaz 2012), in particular its recommendation for the establishment of a community behaviour support and development service. It also acknowledges the 2013 initiative of the National Trauma Research Institute in Victoria on behaviours of concern (i.e. challenging behaviour) that calls for more rigorous research to further the evidence base for behaviour support. This report is

not intended to repeat or replace these initiatives. Rather, its recommendations ought to sit alongside and contribute to service outcomes that emerge from these earlier works.

Declaration of interest

1.21 David Manchester is in private practice and provides consultation, seminars and courses in motivational interviewing and other psychological approaches to assist with behaviour support.

2. PROJECT PURPOSE

2.1 To enhance sector capacity to provide behaviour support to LCSA clients living in the community after TBI. A particular emphasis is on enhancing support in rural and remote areas.

2.2 The anticipated outcomes of this project include:

- Recommended early indicators for when behaviour support is required.
- Recommended measurable minimum standards of good behaviour support practice with this client group.
- A decisional framework that specifies when it may be reasonable for LCSA staff to suspend or cease behaviour support services.
- A recommended knowledge translation programme that helps to increase and sustain practitioners' confidence and ability in delivering behaviour support services to this client group.
- A recommended programme, or series of innovative approaches to increase behaviour support capacity across the State. A particular focus is on rural sectors of NSW where there is a disproportionate need for behaviour support for individuals with TBI.

3 KEY FINDINGS

3.1 Not surprisingly, findings in the literature review and advice provided by both the steering group and stakeholders at the AI summit day converged on several issues. Below is an overview of key findings from all three sources.

The literature review

Early indicators of the need for behaviour support

3.2 **General factors:** Identifying early indicators is perhaps best framed as risk assessment. Risk assessment is concerned with identifying those factors that when present or absent increase the likelihood that challenging behaviour will occur.

3.3 There is no standardised approach to risk assessment and early identification of the need for behaviour support after TBI. There are recommendations in the general clinical literature regarding factors to consider in violence risk assessment that will have relevance in brain injury for example younger age, lower socioeconomic status, poor social functioning, low mood and alcohol or substance abuse.

3.4 In the Agency for Clinical Innovation's Challenging Behaviour Project (Sabaz 2012) the following six criteria discriminated clients with challenging behaviour from those without challenging behaviour.

- Pre-injury alcohol problems
- Current drug and alcohol problems
- Level of cognitive impairment
- Severity of depressive symptoms
- Severity of other mental health problems, and
- Level of disability

3.5 **Depression:** After TBI, depression is a key factor in challenging behaviour in adult presentations. It is often associated with a gradual increase in awareness of residual difficulties caused by the brain injury (Baguley, Cooper and Felmingham 2006). It has also been associated with higher levels of expressed emotion in families (Alway, McKay, Ponsford and Schonberger 2012). Expressed emotion refers to the level of criticism, hostility and emotional overinvolvement directed towards the person with TBI by significant others.

3.6 **Carer stress and burden:** Carer stress and burden is an important target for assessment and support in cognitive disability more generally (Oyebode 2003). Carer stress can be

overlooked or poorly responded to when identified (Rietdijk, Togher and Power 2012). In a NSW study relatives' distress was mediated by the degree of community participation the person with TBI achieved, more so than the extent of his or her neurobehavioural impairment (Winstanley, Simpson, Tate and Miles 2006).

3.6.2 An emphasis on carer needs is consistent with emergent legislation for example the NSW Carers (Recognition) Act 2010. LCSA is obligated under the Act (Section 8.1) to reflect its principles in the work that it does. These principles are set out in the NSW Carers Charter (Schedule 1 of the Act) and are provided in Appendix 7 of this report.

3.7 **Communication:** Ylvisaker, Turkstra, Coelho et al. (2007) in their review of evidence based behavioural interventions for adults and children noted a large number of negative behaviours appeared to have a communication function. Eleven of the studies discussed training given to everyday communication partners, e.g. family members, teachers, and nursing assistants to deliver the interventions. Given that frustration is a precursor to angry aggression it may be that disturbed communication contributes to frustration and is a particular risk factor for challenging behaviour in this group.

3.8 **Attributions for challenging behaviour made by significant others:** A further factor that can be usefully considered in terms of risk is the nature of the support that is available. Rather than locate all risk within the individual with TBI, it can help to recognise that behavioural difficulties occur in a context and very often that context is an interpersonal one. How significant others interpret and respond to difficult behaviour has implications for behaviour support.

3.9 Attribution theory suggests that our beliefs about the causes of behaviour mediate how we feel about it and how we respond to it (Weiner 1995). These causal attributions are especially important in behaviour support as they influence subsequent helping behaviour by significant others. For example, in intellectual disability services staff who consider challenging behaviour to be controllable by the person experience more anger towards that person and are more likely to withhold help. Those who see the cause as less controllable conversely feel more sympathy and offer more help. In intellectual disability, staff sympathy was found to be the single best predictor of helping intentions (Dagnan and Cairns 2005).

3.10 In TBI, Manchester (2002) found community support staff who attributed a person with TBI's aggression to the person's personality were significantly more likely to endorse aversive responses such as time out and punishment. Attributions also influence staff optimism that support will be helpful. Staff in a forensic setting exhibited less optimism when they perceived behaviours as being under the person's control. Helping behaviour was more likely to occur when staff were optimistic (Sharrock, Day, Qazi and Brewin 1990).

3.11 Attributions and response styles of significant others can be considered potential risk factors for challenging behaviour. In particular, attributions of blame and support for aversive responses are likely to increase risk. This is because they are potentially provocative and are likely to engender frustration and anger in the person with TBI. Improving significant others understanding of neuropsychological causes for challenging behaviour, for example poor impulse control due to orbitofrontal brain injury, or reduced drive and initiation due to ventromedial frontal brain injury may reduce blame attributions and enhance helping behaviour. Elsewhere, interventions that aim to alter parent attributions have been shown to be helpful in parent management training when combined with anger management to assist supporting children with disruptive behaviour (Sanders, Pidgeon, Gravestock et al., 2004).

Recommended measurable minimum standards of good behaviour support practice

3.12 **Effective behaviour support:** There is evidence of effective behaviour support for both adults and children with TBI residing in the community (e.g. Willis and LaVigna 2003, Feeney and Ylvisaker 2006, Laatsch, Harrington, Hotz et al., 2007, Ylvisaker, Turkstra, Coelho et al., 2007). The strongest evidence is for positive behaviour supports and contingency management programmes provided in the context the behaviour occurs (i.e. contextual rehabilitation) that are also sensitive to the person's neuropsychological profile. In particular, addressing changes in learning and memory and executive functions for example impulsivity, poor initiation, poor planning, impaired self monitoring and impaired self awareness is helpful (Laatsch, Harrington, Hotz et al., 2007). Positive behaviour support also has favourable outcomes for challenging behaviour in intellectual disability (e.g. LaVigna and Willis 2012).

3.13 A critical factor appears to be ensuring key people in the person's life are included in supporting and maintaining behaviour change.

3.14 There is evidence that cognitive behaviour therapy (CBT) leads to reductions in self reported anger in community dwelling adults with TBI (e.g. Aboulafia-Brahka, Bushbeck, et al., 2013, Medd and Tate 2000, Walker, Nott, Doyle et al., 2010, Hart, Vaccaro, Hays and Maiuro, 2012). Group therapy for anger is particularly advocated in a review of CBT derived approaches for anger management post TBI (Demark and Gemeinhardt 2002). Studies are however often quite selective in their inclusion criteria. Also, self report does not always correlate highly with actual behaviour change observed by others.

3.15 A review of CBT for depression and anxiety in adults with acquired brain injury concludes that those receiving treatment do improve compared to controls. However, there is only a partial reduction in symptoms (Waldron, Casserly and O'Sullivan 2013).

3.16 A telephone intervention for depression with community dwelling TBI adults reduced depression in comparison to a control group. The telephone intervention included behavioural activation and motivational interviewing (Bombardier, Bell, Temkin et al., 2009).

3.17 Carer stress and burden is amenable to psychosocial interventions. In pediatric brain injury rehabilitation, family functioning and child recovery are closely linked. Improvements in family functioning contribute to improvements in child adjustment and behaviour. Improvements in family functioning have been achieved using family problem solving interventions (e.g. Wade, Michaud and Brown 2006).

3.18 Stepping Stones Triple P is a version of Triple P adapted for parents of children aged 2 – 12 years with intellectual disabilities. Triple P (Positive Parenting Program) is an evidence-based parenting program that gives parents practical positive strategies to assist them to manage their children's behaviour and prevent problems developing. In Australia it has been effective at improving child behaviour problems after brain injury and improving parental responses when combined with acceptance and commitment therapy (Brown, Whittingham, Boyd et al., 2014).

3.19 Internet family problem solving interventions with ongoing remote therapist support are able to reduce parental distress after child TBI (Wade, Carey and Wolfe 2006a). The same intervention also leads to improvements in the behaviour of children with moderate and severe TBI. Older children and those from lower socioeconomic status show greatest gains in self management and behaviour problems (Wade, Carey and Wolfe 2006b). As these authors note, "Evidence of the feasibility and

efficacy of an online approach with this population holds the promise of providing access to needed treatment for children who might not otherwise be able to attain it because of distance or unavailability of experienced providers."

3.20 A systematic review of tele-health approaches in TBI rehabilitation (including internet, telephone and videoconferencing) concluded that such approaches could be used to access families in rural areas and to train family members in skills required to facilitate recovery after TBI (Rietdijk, Togher and Powell 2012).

3.21 Self help internet CBT therapy has also been found to reduce depression in TBI clients when additional telephone weekly support is provided (for a review see Simblett, Ring and Bateman 2011).

3.22 Therapist provided support is likely to be a critical factor in internet treatment success. In the Wade, Carey and Wolfe (2006) study parental distress did not improve with only access to internet resources. More generally, therapist support is likely to enhance satisfaction and reduce drop out in internet provided therapy. Without it drop out can be very high. For example, in general mental health services drop out from self-help internet CBT amongst males can be over 80% and over 50% in females. (Twomey, O'Reilly, Burn et al., 2014).

3.23 In TBI rehabilitation it is possible to improve paid care workers communication skills in structured conversations after relatively brief training. These skills are maintained at six months follow up, (Behn, Togher, Power and Heard 2012). Training partners of a person with TBI to improve everyday conversations is also possible. Training partners is more helpful than only training the person with TBI (Togher, McDonald, Tate et al., 2013).

3.24 There are examples of outcome measures in the literature specific to TBI for example the Health of the Nation Outcome Scales for Acquired Brain Injury. However, there is no 'gold standard' for outcome measurement. Goal attainment scaling is one approach that is able to include multiple measures. It is conducive to collaborative goal setting and has been advocated in brain injury rehabilitation (Malec 1999). Also, the Agency for Clinical Innovation's Goal Training Project (2013) developed a structured approach to goal setting that was built in part on previous work of the State-wide Goal Group of the Agency for Clinical Innovation Brain Injury Rehabilitation Directorate. This work has already been widely disseminated to practitioners in brief training courses. Its aim is to enhance communication between clinical services and funders by providing a common

approach to the formulation and communication of goals.

3.25 **Core standards and evidence based training:** Whilst there are examples of suggested curriculum in the literature for those working in community brain injury rehabilitation (e.g. Ylvisaker and Feeney 1998, Jackson and Manchester 2001, Brake and Gunn 2006) there is no commonly agreed set of core standards for behaviour support. Initiatives to agree core standards across a practice community have been seen recently in Australian mental health services with work undertaken by Health Workforce Australia (2013). This is also seen in NSW government disability services with the development of the Core Standards for Practitioners Who Support People With a Disability led by Family and Community Services, Ageing, Disability and Home Care (2014).

3.26 Even when core standards are agreed there remains the issue of such standards being translated into practitioner behaviour change on the ground. Providing information or brief education courses alone is unlikely to be sufficient to lead to skills enhancement in behaviour support practitioners. A robust and consistent finding in the literature is that single exposure training models, or the simple provision of information in manual or guideline form are ineffective methods for producing practitioner behaviour change (e.g. Brooker and Brabban 2006, Berry and Haddock 2008, Lyon, Stirman, Kerns and Bruns 2011, Tarrier, Haddock and Barrowclough 1998).

3.27 Effective approaches to training practitioners in psychosocial interventions include expert instruction, ongoing supervision, coaching and feedback on work practice (e.g. Corrigan and Steiner 2001, Sholomska and Syracuse-Siewart 2005, Miller, Yahne, Moyers et al., 2004) and organizational support (Repper and Brooker 2002). Coaching skills demonstrated to improve practice include working towards agreement on learning goals, strategies that support autonomy, giving feedback and remaining on task (Lyon, Stirman, Kerns and Bruns 2011).

3.28 **Consumer engagement:** TBI has the same difficulties with securing consumer engagement and retention in treatment as other clinical areas including general psychotherapy and family interventions. Motivational interviewing is an evidence based approach to improving treatment engagement and adherence with both consumers (Miller and Rose 2009) and significant others (Nock and Kazdin 2005). It has been advocated as one approach to help improve parent engagement rates in parent management training (Scott and Dadds 2009). It has been used successfully in the TBI population to help with anxiety (Hsieh, Ponsford et al., 2012), and with depression (Bombardier, Bell et

al., 2009). It has also been demonstrated to improve emotional functioning in a large randomised controlled trial with individuals post stroke (Watkins, Auton, Deans, et al., 2007). Its use is recommended following the NSW Agency for Clinical Innovation's Challenging Behaviour Project to enhance engagement in treatment post TBI (Sabaz, Simpson, Walker et al., 2013).

3.28.2 Motivational interviewing is also an evidence based approach for substance use disorder in particular alcohol (Miller and Rose 2009). However, with regards to substance use after TBI additional work is likely to be required to translate motivation into action given common neuro-cognitive problems with planning, initiation and self monitoring (Graham and Cardon 2008).

3.28.3 The core skills in motivational interviewing, including how to establish a therapeutic relationship with clients, can be taught relatively quickly to practitioners in a two day workshop with brief telephone coaching sessions provided afterwards (Miller, Yahne, Moyers et al., 2004).

3.29 **Transdiagnostic research with implications for this project:** In psychiatry, good practice in dual diagnosis i.e. drug and alcohol problems and also mental illness is for the provision of integrated treatment (Corrigan, Mueser, Bond et al., 2008). Integrated treatment refers to the same clinician or clinical team providing appropriate interventions for both substance abuse and mental health issues in a co-ordinated fashion. The behaviour support practitioner or clinical team take responsibility for blending treatment (e.g. Barrowclough, Tarrier, Lewis et al., 2001, Barrowclough, Haddock, Wykes, Beardmore, Conrod et al., 2010). Treatment manuals have been published outlining how the same service/provider may provide such integrated support (e.g. Graham, Copello, Birchwood et al., 2004).

3.30 An Australian training initiative taught alcohol and other drug workers in the assessment and management of additional mental health problems. Practitioners, managers and supervisors were included in the training. Extensive evaluation showed positive outcomes in practitioner knowledge, skills and confidence. Effective supervision was a key factor in implementation (Cameron, Lee and Harney 2007). This is an approach that may be helpful in brain injury rehabilitation as most drug and alcohol treatment services will not have skills in dealing with moderate and severe TBI.

Consultation with stakeholders: The appreciative inquiry interviews

3.31 Several factors underpinning effective behaviour support practice were evident across nearly all interviews. Effective behaviour support is grounded in a positive philosophy that places the wishes of the person receiving the service at the centre of that service. Goals are person directed. There is an emphasis on strengthening adaptive behaviour and emotional adjustment that enhances inclusion and community participation.

3.32 The work is grounded in positive behaviour support and is informed by functional behavioural analysis.

3.33 There was a particularly strong emphasis on the importance of communication between the behaviour support practitioner, the person with TBI and his or her wider circle of support. This was especially so for family members and other carers.

3.34 Effective behaviour support practitioners were able to communicate genuine respect for the contribution of all involved in behaviour support including family members, case managers and attendant care workers. They listened well to significant others and included their ideas into behaviour support plans. They were truly 'team players.' The most tangible method of identifying this was regular meetings by the behaviour support practitioner with key stakeholders to review progress and to discuss changes in behaviour support needs. This communication was repeatedly cited as critical in the interviews.

3.35 Effective behaviour support was often overseen by one person who was responsible for co-ordinating assessment, team communication, and completion of agreed tasks.

3.36 Several psychologists talked about the importance of being able to address emergent depression and its links with challenging behaviour. Psychologists and case managers emphasised the benefits of being able to fund activities that engaged the person with TBI to relieve boredom, enhance participation and subsequently reduce the risk of depression.

3.37 Psychologists identified their knowledge of brain behaviour relationships as critical to informing support networks of neuropsychological factors contributing to challenging behaviour. This was seen as essential for changing mis-attributions (i.e. incorrect beliefs about the causes of behaviour) amongst attendant carers and the person's wider circle of

support. This knowledge was believed to improve attitudes and positively influenced subsequent responses. The importance of correcting mis-attributions was also made by advocacy group members.

3.38 Psychologists providing behaviour support understood how to adapt supports to take account of neuropsychological difficulties. They also integrated cognitive behaviour therapy approaches into their work.

3.39 There was broad support amongst the practice community for a checklist identifying key factors that underpin good behaviour support. It was felt this would be most helpful if used as a guideline only and if it was not too prescriptive.

3.40 There was no generally agreed framework for terminating or postponing behaviour support services. There was a clear focus by psychologists that decisions regarding termination of support ought to be made on the basis of reliable data measuring the person's progress towards his or her goals.

3.41 Psychologists were clear that behaviour support ought to cease or be postponed when it was evident that gains had plateaued or that no gains were accruing after several weeks of sustained effort and when alternative approaches were unsuccessful.

3.42 Psychologists spoke clearly about what enhanced their enthusiasm in, and confidence to do, their work in this area. Knowledge of brain behaviour relationships was frequently cited as important. Several identified their training in cognitive behaviour therapy as also important when working with the person with brain injury.

3.43 Many psychologists, both inpatient and community based, talked about initially coming to brain injury feeling unprepared via their training to provide behaviour support. Factors they identified as helping to increase their confidence were exposure to the client group (their confidence developed as their experience grew) and mentoring or supervision from more expert practitioners. Working in the large urban brain injury rehabilitation units was also seen as very helpful by those who had come through this system. This allowed many psychologists to gain confidence and to learn from multidisciplinary colleagues. Further, once they saw behaviour support was helpful their confidence developed and this reinforced their desire to continue to work in this area. A medical practitioner similarly talked about her enthusiasm at the beginning of her career being strengthened when she saw that change was possible and was not always difficult to achieve.

3.44 At a systems level it was identified that only a very small number of private behaviour support practitioners with widely recognised expertise were providing behaviour support regularly in the NSW community to LCSA clients. Infact, in this study, only four people were so identified. All four were psychologists and all were based in Sydney.

3.45 These four psychologists were agreeable in principle to providing funded mentoring or coaching to other colleagues with less experience providing behaviour support. In fact, some were already doing so for rural and remote colleagues and reported that recipients viewed this as helpful. This was provided both face to face and via the internet.

3.46 There was broad agreement for the need for a standardised approach to training in core skills underpinning good behaviour support at both the practitioner level and the attendant care worker level. There was agreement that a core standards training programme would be helpful in NSW that was underpinned by assessment, mentoring and coaching.

3.47 A practitioner at a more remote centre talked about how helpful a visiting neuropsychiatry day clinic had been previously. This service ceased due to funding difficulties. Attempts to re-introduce the service had been unsuccessful.

Consultation with stakeholders: The appreciative inquiry summit day

3.48 At the appreciative inquiry summit day held on 26 August 2014 there was discussion of the literature review findings and emergent themes from the AI interviews. These were condensed further on the day until there was broad support for developments in five areas. These are outlined below.

3.49 **Philosophies of support:** There was agreement for the need to define and communicate throughout the practice community the philosophies, values and legislation that underpin good behaviour support.

3.50 **Well supported families:** There was agreement on the substantial role often played by families in behaviour support after traumatic brain injury. There was recognition of the stress borne by families and the fact that this is amenable to psychosocial interventions, both face to face and internet based. There was a clear focus on the need to include and respect the lived experience and contributions of carers when designing

behaviour support approaches.

3.51 **Skilled behaviour support practitioners and skilled attendant care workers:** There was agreement that behaviour support practitioners do not initially come 'work ready' to this area. It was felt that core standards training would be helpful.

3.52 There was a clear recognition that attendant care workers play a critical role in behaviour support and their knowledge and experience needs to be respected and included. A smaller set of core standards training derived from the practitioner training might be developed for attendant care workers to help underpin behaviour support team work.

3.53 Whilst all practitioners providing behaviour support in this project were psychologists it was felt that behaviour support could be provided by other professionals with appropriate training and support.

3.54 **Evidence based training:** It was agreed that training ought to be informed by the evidence on how to enhance professional skills, in particular the provision of coaching, mentoring and feedback on work practice.

3.55 There was also a request from a medical practitioner to include in any training information on medications commonly used post brain injury.

3.56 **Recruitment**: There was acknowledgement that it can be difficult to attract professionals to work in behaviour support. Possible approaches to enhance recruitment include improving access to structured training in core skills that are marketed as transdiagnostic, i.e. that can be used in TBI rehabilitation as well as in other work areas, the provision of coaching and mentoring from content experts and supported placements in the major urban brain injury units. Focused recruitment campaigns might target professionals who already have similar work experience and core skills, in particular behaviour support practitioners working in intellectual disability services and also social workers given the emphasis in their training on working with families.

3.57 At the AI summit day participants worked in groups on these five themes and helped to develop provocative propositions for each one. A provocative proposition is a shared vision written in the present tense outlining how things will be when the positive core is fully effective. These are set out in Appendix 6.

4. RECOMMENDATIONS

4.1 Develop a risk assessment guideline to help determine the need for early intervention and behaviour support.

4.2 It is recommended that LCSA promote the following set of risk factors as a guideline for consideration when identifying the need for early behaviour support intervention:

The person with a brain injury

- Current or previous challenging behaviour
- Current drug and alcohol problems
- Cognitive impairment in particular impaired executive functions
- Depressive symptoms
- Other mental health problems
- Impaired communication
- Poor community integration, and
- Reduced engagement with brain injury services when this is contra-indicated

The carer and/or attendant carer

- Higher levels of stress
- Aversive response styles
- High control and responsibility attributions for challenging behaviour
- Poor access to supports to help ameliorate the above three factors

4.3 Where there is evidence of planned, or predatory violent or unwanted sexual behaviour it is recommended that LCSA support more specialised risk assessment. This ought to be from a practitioner with skills and training in the use of validated forensic risk assessment measures in both of these areas.

4.4 **Promote a minimum behaviour support practice standard.**
It is recommended that LCSA promote a checklist of minimum standards for behaviour support based on those factors identified in the literature review and by stakeholders as important to good practice. Items for consideration include:

- All behaviour support is grounded in a positive philosophy that is person directed and is guided by relevant legislation including the NSW Carers (Recognition) Act 2010.
- There is evidence of risk assessment. Behaviour support guidelines reflect consideration of common risk factors and recommendations are included aimed at reducing, or ameliorating the impact of those risk factors that can be

changed.

- There is an assessment of family and carers' psychological needs and evidence of appropriate supports being sought to address these is provided.
- Behaviour support guidelines are written by the behaviour support practitioner in close collaboration with relevant stakeholders including the person with the brain injury, carers, paid support workers and other involved practitioners.
- Intervention recommendations are based on principles of positive behaviour support. Recommended supports are sensitive to alterations in learning and memory, planning, initiation, self awareness, self monitoring and impulsivity caused by the brain injury.
- The initial behaviour support plan includes agreed criteria for when to cease, reduce or postpone behaviour support.
- There is evidence of clear teamwork with frequent communication between the behaviour support practitioner and those expected to carry out recommendations.
- There is a case manager included in the team to facilitate co-ordination and timely completion of agreed tasks.
- The behaviour support plan includes a clear functional analysis of the challenging behaviour being addressed.
- There is a case formulation with clear hypotheses stated to explain the maintenance of the behaviour based on this analysis.
- Behaviour support recommendations are based on these hypotheses.
- Interventions have a strengths based focus that includes strengthening adaptive behaviours and functional equivalence training where appropriate, i.e. teaching alternative more appropriate behaviours to secure the person's desired outcome(s).
- Data is collected to inform assessment and reviews. When collection of reliable data is not possible or the risk of delaying a service precludes initial data collection hypotheses for the maintenance of challenging behaviour are still formulated. These are based on the available evidence for example, consumer interviews, file review and behavioural observations. Behaviour support recommendations are then formulated, implemented and monitored.
- The positive behaviour support approach is overseen by the practitioner who wrote the report. Thus, there is evidence of the practitioner responsible for the guidelines providing ongoing instruction, modeling of intervention recommendations, monitoring of their application by others and giving feedback to those expected to carry out these recommendations.
- Where indicated, cognitive behaviour therapy is considered

for altered mood states, in particular depression and/or anger and also for substance misuse.

- When indicated, substance abuse treatment is integrated into the positive behaviour support with appropriate advice and guidance. It is not viewed as beyond the remit of the behaviour support practitioner and the support team.

4.5 **LCSA endorse a guideline for suspending or ceasing behaviour support services.**
It is good practice to cease or postpone a service that is not benefitting the recipient of that service.

4.6 It is suggested here that the criteria for cessation of a service is agreed between the provider, the consumer and the funder during the goal setting stage and therefore occurs during early assessment and engagement.

4.7 Where agreement cannot be reached then an independent opinion be sought by LCSA.

4.8 **LCSA consider appointing a project manager to work with a smaller focus group to oversee the development of a training and recruitment initiative. This group ought to include practitioners as well as carer, attendant carer and case manager representatives. This initiative can cover the following four parts:**

4.9 **Part 1.** Fund and co-ordinate the development of, or access to, discrete brief training modules in recommended core standards. These modules can introduce key principles in short interactive courses, with an agreed minimum knowledge assessment and skills review. The focus group ought also to consider avenues for accreditation of courses.

Suggested recommended core standards are:

- **Philosophies of support**
  This addresses positive behaviour support, teamwork, communication, disability and carer legislation, evidence based practice and outcomes measurement.

- **Motivational interviewing**
  This addresses the working alliance, core micro skills in the therapeutic relationship, person directed practice, evoking and working with a person's internal motivation for change. It's use with both the person with TBI and their significant others can be covered.

- **Positive behaviour support (PBS)**
  Introduces the theory, practice and evaluation of PBS.

- **Brain behaviour relationships after TBI**
  Establishes the primary neurobehavioural changes after moderate and severe TBI with a focus on underlying changes in executive functions, learning, memory and mood. Discusses assessment, psychosocial treatment and an overview of pharmacology treatments often seen in challenging behaviour.

- **Cognitive behaviour therapy for mood management**
  Introduces the theory and practice of CBT for depression, anxiety and anger management.

- **Cognitive behaviour therapy for substance abuse after TBI**
  Introduces the theory and practice of CBT for substance abuse. Includes a module on how greater planning may be required after TBI to assist behaviour change after motivational enhancement including identifying and overcoming obstacles.

- **Problem solving therapy**
  Introduces the theory and practice of problem solving therapy for both families and individuals with a brain injury.

- **Goal setting and outcomes measurement**
  Introduces the importance of goal setting, data collection and outcomes measurement and how these can be used to inform decisions about ongoing service provision. A particular focus ought to be on goal attainment scaling and the SMAARTAAR goal process set out in the Agency for Clinical Innovation's goal training project. There ought also to be a focus on obtaining regular feedback from consumer's regarding their satisfaction with the behaviour support service they are receiving.

4.10 **Part 2.** LCSA establish an approved provider list for behaviour support services: A marketing campaign be agreed to attract practitioners with skills in any of the core standards to apply for entry onto this list. This can include free brief training in core standards, funded mentoring by experts in core standards, preferential referrals by LCSA for provision of services covered by the core standards, and continuous assistance from a case

manager on current cases. A small monetary stipend when first enrolled on the provider list might also be considered.

4.11 LCSA promote enrolment on the preferred provider list to practitioners with skill and experience in the core standards. Two particular target groups may be former ADHC psychologists and general social workers in both urban and remote areas. Over the next four years ADHC services will close as disability support moves to the private sector. A core standards programme with similar modules to those above has been in place at ADHC for over three years. Social workers are already familiar with working with families in a systemic way.

4.12 **Part 3.** Establish a panel of expert practitioners willing to provide funded coaching and support to less experienced practitioners: A marketing campaign be agreed to attract mentors with expert skills in any of the core standards to apply for entry onto this list.

4.13 **Part 4.** Develop a minimum set of brief core standards training courses for attendant carers that facilitates good practice in behaviour support. These can be designed in such a way that they are also helpful for family members and other carers to attend.

4.14 These might cover the following modules:

- Philosophies of support
- Brain behaviour relationships
- An introduction to the principles of positive behaviour support, including data collection, and
- Communication skills in traumatic brain injury rehabilitation

4.15 **Future developments LCSA may wish to consider:**

4.15.1 **PhD Scholarships**

4.15.2 LCSA consider providing scholarships for a small number of PhD students to develop and trial further family interventions based on problem solving approaches when challenging behaviour is an issue.

4.15.3 LCSA consider further scholarships to support pilot research on the use of acceptance and commitment therapy in carer support and also mood management for individuals with brain injury.

4.15.4 **Pilot rural and remote behaviour support clinics** LCSA fund and evaluate rural and remote

neuropsychology and neuropsychiatry day clinics at two rural and remote sites. These might occur once every three months for a trial period. A limited discretionary fund be made available to the clinic's providers to support recommendations when lack of funding is an obstacle to meeting agreed goals.

4.15.5 **Pilot evidence based internet therapy programmes** LCSA consider inviting tenders for the development and evaluation of internet cognitive behaviour therapy courses for depression after brain injury and also for family problem solving. Tenders can be required to include proposals built upon already established programmes with known positive outcomes. In the case of depression any proposal ought also to include a component that acknowledges some symptoms of brain injury are consistent with depression for example difficulty with initiation, diminished motivation and problems with memory.

4.15.6 Proposals ought to include regular therapist support to facilitate consumer engagement and completion of any programme.

APPENDICES

Appendix 1

Steering group members

Jamie Berry – Senior Clinical Neuropsychologist, ANTS Sydney

Naomi Brookes – Clinical Psychologist Sydney Children's Hospitals Network

Cassandra Carswell – Community Rehabilitation Clinician, Mid North Coast Brain Injury Rehabilitation Service

Rachel Cotter – Royal Rehabilitation Centre Sydney

Jason Cusack – Clinical Psychologist Illawarra Brain Injury Rehabilitation Service

Samantha Grant – Senior Clinical Psychologist, ARBIAS

Judy Heyworth – Hunter Brain Injury Rehabilitation Service

Dr Patricia Jungfer – Psychiatrist Private Practice

Michelle Maitz – Clinical Psychologist Liverpool Brain Injury Rehabilitation Service

Barbara Merran - ACiA

Dr Gaston Nguyen – Liverpool Brain Injury Rehabilitation Unit

Paula Olymbios – Clinical Psychologist Private Practice

Mohammed Rafat – Advocate BIA NSW

Paul Rodriguez – Clinical Psychologist Westmead Brain Injury Rehabilitation Service

Alex Walker – Clinical Neuropsychologist Westmead Brain Injury Rehabilitation Service

Robert Scherf – Psychologist New England Brain Injury Rehabilitation Service

Vicki Solomon – Occupational Therapist North Coast Brain Injury Rehabilitation Service

Melissa Staples – Clinical Neuropsychologist Private Practice

Barbara Strettles – Network Manager Brain Injury Rehabilitation Directorate Agency for Clinical Innovation

Naomi Walker Case Manager ABIS

Beverley Taylor – BIA NSW

Deborah Toffolo – Access Brain Injury Services

Professor Leanne Togher – University of Sydney

Don Ferguson – General Manager LCSA

Suzanne Lulham – Director Service Delivery LCSA

Neil McKinnon – Senior Manager LCSA

Lesley Radbron – LCSA Service Development and Review

Appendix 2

Annotated literature review

Aboulafia-Brakha, T., Greber Buschbeck, C., Rochat, L., Annoni, J. (2013). Feasibility and initial efficacy of a cognitive-behavioural group programme for managing anger and aggressiveness after traumatic brain injury. Neuropsychological Rehabilitation, 23,2, 216-233. *10 community patients with moderate to severe TBI finished a cognitive behaviour programme for aggression of eight once a week sessions. Groups were small with two to four persons in each group. Self reported anger was reduced and the programme had high acceptability.*

Alderman, N. (2004). Disorders of behavior. In J. Ponsford (Ed.), Cognitive and Behavioral Rehabilitation (pp. 269-298). New York: Guilford Press. *An overview of the causes of behaviour difficulties after brain injury is given and treatment approaches are discussed. This includes an overview of neurobehavioural rehabilitation units.*

Agency for Clinical Innovation (2013). Goal Training Participant Workbook. *Outlines a structured training for goal setting in rehabilitation consistent with best practice in goal setting as identified in the literature. The workbook is part of a seven month goal training project funded by LCSA, the Motor Accidents Authority, and Workcover NSW. It includes an adaptation of SMART goals, SMAARTAAR goals aimed at improving communication amongst services around goal setting after brain injury.*

Alway, Y., McKay, A., Ponsford, J., and Schonberger, M. (2012). Expressed emotion and its relationship to anxiety and depression after traumatic brain injury. Neuropsychological Rehabilitation, 22,3, 374-390. *Levels of expressed emotion (EE) in families affects psychiatric and medical recovery in a range of conditions. This study investigated the relationship between levels of family (EE) and anxiety and depression in patients who have sustained a traumatic brain injury. Higher EE was associated with patient anxiety and depression. It was also associated with family members levels of depression and anxiety. The authors suggest interventions targeting EE may help to reduce psychological difficulties following TBI.*

Baguley, I., Cooper, J., and Felmingham, K. (2006). Aggressive Behaviour Following Traumatic Brain Injury: How Common Is Common? Journal of Head Trauma Rehabilitation, 21,1, 45-56. *228 TBI patients followed up over five years. Depression was the factor most significantly associated with aggressive behaviour at all times post injury, followed by a younger age at the time of injury.*

Barrowclough, C., Haddock, G., Tarrier, N., Lewis, S., et al. (2001). Randomized controlled trial of motivational interviewing, cognitive behaviour therapy, and family intervention for patients With comorbid schizophrenia and substance use disorders. American Journal of Psychiatry, 158, 1706-1713. *17/18 patients completed the integrated treatment approach. Significantly better than other treatment completion rates in the literature. Integrated treatment improved symptoms and reduced substance use compared to*

standard care group. The authors could not rule out attention effect as treatment group had substantially more therapist contact time.

Barrowclough, C., Haddock, G., Wykes, T., Beardmore, R., and Conrod, P., et al. (2010). *Integrated motivational interviewing and cognitive behavioural therapy for people with psychosis and co-morbid substance abuse: Randomised controlled trial. British Medical Journal, 341:c6325. Large RCT with 327 patients. Therapy consisted of up to 26 individual therapy sessions over 12 months at location of person's choice. Integrated treatment did not improve outcomes overall in comparison to standard psychiatric care. A sub analysis showed those with psychosis who reported only alcohol abuse or dependence significantly improved in terms of days abstinent and maintained over two year follow-up.*

Behn, N., Togher, L., Power, E., and Heard, R. (2012). Evaluating communication training for paid carers of people with traumatic brain injury. Brain Injury. 26,13-14, 1702-15. *10 paid carers in a post acute rehabilitation facility randomly assigned to training or control. Training was a 17 hour programme with structured and casual conversations across 8 weeks. Conversational interactions improved in training group in structured conversation only. Gains maintained at 6 months.*

Berry, K., and Haddock, G. (2008). The implementation of the NICE guidelines for schizophrenia: Barriers to the intervention of psychological interventions and recommendations for the future. Psychology and Psychotherapy: Theory, Research and Practice, 81, 419-436. *With regards to family interventions (FI) the study noted poor use of FI in those trained to use it. Barriers reported were low access to suitable families, lack of managerial/organisational support, and lack of supervision. The authors note families may not know about the available FI interventions or may feel blamed stigmatized. Recommended practical training with ongoing supervision, training supervisees in supervision and individual and group support. Also recommended assessing psychosocial needs of families and tailoring training accordingly.*

Bombardier, C.H., Bell K. R., Temkin, N. R., Fann, J. R., Hoffman, J., and Dikmen, S. (2009). The efficacy of a scheduled telephone intervention for ameliorating depressive symptoms during the first year after traumatic brain injury. Journal of Head Trauma Rehabilitation, 24,4, 230-238. *171 participants with TBI after discharge from a hospital rehabilitation unit. Provided up to seven scheduled telephone sessions over nine months. Discussed current concerns, gave information and helped with problem solving. Used behavioural activation, motivational interviewing, and included significant others. Control group participants became more depressed whilst telephone group improved on depression. The intervention was especially effective for those most depressed at baseline.*

Brake, J., and Gunn, L. (2006). Support worker training. An example training package – 'Supporting an individual with an acquired brain injury.' In J. Parker (Ed)., Good Practice in Brain Injury Case Management, 171-184. London: Jessica Kingsley Publishers. *Discusses training needs and suggested curriculum for support workers in brain injury. Considers linking training with accreditation bodies.*

Brooker, C., and Brabban, A. (2006). Effective training in psychosocial interventions for work with people with serious mental health problems. The Mental Health Review, 11,2, 7-14. *The authors note the gulf between evidence-based practices in psychosocial rehabilitation and the ability of practitioners to deliver these. They note the 10 essential shared capabilities promoted by the National Institute or Mental Health in the UK are not always found within basic mental health training. They reviewed 37 studies that evaluated training in psychosocial interventions. Whole teams trained together tend to do better than individuals who attend a training. Access to skilled supervision is likely to be critical as are supportive team members and managers. The authors quote Lipsky, "Worker training is less important than the nature of training conditions themselves. Without a supportive network of working peer relationships, training to improve the service capacity of workers is likely to washout under the pressure of the work context."*

Brown, F. L., Whittingham, K., Boyd, R. N., McKinlay, L., and Sofronoff, K. (2014). Improving child and parenting outcomes following pediatric acquired brain injury: a randomized controlled trial of Stepping Stones Triple P (SSTP) plus acceptance and commitment therapy (ACT). Journal of Child Psychology and Psychiatry, 55,10, 1172-1183. *Fifty nine parents of children with acquired brain injury and with at least mild behaviour problems were randomly assigned to active treatment or care as usual over 10 weeks. Treatment was provided in groups and included six SSTP group sessions and three phone sessions and two ACT group sessions. Child behavioural and emotional symptoms and parenting response styles improved in the treatment condition on parent ratings. These gains were maintained at six months follow-up except for child emotional functioning. Breaks were scheduled around school holidays and make up sessions were offered when sessions were missed by parents. The SSTP programme was delivered by practitioners with accreditation in SSTP. Brown explained in a personal communication to the report writer that although not specifically designed for brain injury the SSTP was well accepted by parents. Materials were not adapted but it was outlined to parents that issues identified in groups such as autism in the training materials were relevant to brain injury. The ACT component was only two 2 hour sessions but feedback from many parents was very positive with several parents saying it was the most valuable part of the intervention.*

Cameron, J., Lee, N., and Harney, A. (2007). Translating research into practice. PsyCheck Dissemination. Final Report. Turning Point Alcohol and Drug Centre. *The authors note that in psychiatry integrated treatment (i.e. same practitioner, same service) is recommended for the effective treatment of co-occurring disorders. It is therefore important that drug and alcohol*

practitioners are able to effectively manage mental health symptoms among their clients. PsyCheck was designed specifically as a basic screening tool and intervention for AOD practitioners who do not have a background in mental health treatment. The authors report on a national dissemination strategy using a workforce development approach. Managers and supervisors as well as practitioners were included in the training. Managers received half a day's training, supervisors a day, and practitioners received two days training. An extensive evaluation was undertaken across six sites with positive outcomes for implementation including high satisfaction amongst managers and practitioners and increases in knowledge, skills and confidence. High staff turnover necessitates maintaining a whole of workforce approach to implementation within a service. Effective supervision was a key factor in implementation.

NSW Carers (Recognition) Act 2010. New South Wales Government. Available at http://www.austlii.edu.au/au/legis/nsw/consol_act/ca2010197/ *The purpose of the Act is to increase recognition and awareness of carers and to acknowledge the valuable contribution they make to society. It highlights their critical role in providing daily care and support to people with disability, medical conditions, mental illness and those who are frail and aged.*

Cooperrider, D. L., Whitney, D., and Stavros. (2008). Appreciative Inquiry Handbook For Leaders of Change. Second Edition. Brunswick and San Francisco: Co-published by Crown Custom Publishing Ohio and Berrett-Koehler Publishers. *This core text on appreciative inquiry reviews its theoretical basis and sets out its processes and their application.*

Corrigan, P., Steiner, L., McCracken, S., et al. (2001). Strategies for disseminating evidence based practices to staff who treat people with serious mental illness. Psychiatric Services, 52,12, 1598-1606. *The authors ask why do practitioners fail to use evidence-based practices? They identify barriers at the individual and organizational level. They recommend a variety of strategies to overcome these including user friendly learning packages for practitioners, reinforcing new skills use, improving leadership commitment to new practice, total quality management, and interactive staff training.*

Corrigan, P. W., Mueser, K. M., Bond, G. R. et al. (2008). Dual diagnosis. In P. Corrigan., K. T. Mueser., G. R. Bond., et al. (Eds.), Principles and Practice of Psychiatric Rehabilitation. An Empirical Approach (pp. 331–345). New York: Guilford Press. *The authors highlight that a consistent principle of care across recent studies is that effective dual disorder interventions, i.e. interventions for both mental illness and substance abuse integrate or combine treatments. Support for both disorders is provided by one clinician or team. Interventions are thus blended into one coherent package. This avoids difficulties with fragmented or disparate treatment approaches or delays to accessing support from one or other service.*

Dagnan, D., and Cairns, M. (2005). Staff judgements of responsibility for the challenging behaviour of adults with intellectual disabilities. Journal of

Intellectual Disability Research, 40, 95-101. *The link between staff attributions and subsequent response is considered and evidence provided that blame attributions can lead to reductions in helping behaviour.*

Demark, J., and Gemeinhardt, M. (2002). Anger and its management for survivors of acquired brain injury. Brain Injury, 16,2, 91-108. *Reviews treatment approaches for anger derived from CBT including relaxation training, behavioural skills training and stress inoculation training. Also considers pharmacotherapy. Stresses advantages of group psychotherapy approaches.*

Family and Community Services, Ageing, Disability and Home Care, (2014). Core Standards for Practitioners Who Support People With a Disability. *The core standards have been designed by ADHC's Clinical Innovation and Governance Unit to help practitioners in their work with individuals with a disability. There are discipline specific core standards in psychology, nursing, occupational therapy, physiotherapy, speech and language therapy and also for behaviour support. There are also common core standards that apply across all these professional groups. They can be accessed at:* www.adhc.nsw.gov.au/sp/delivering_disability_services/core_standards

Feeney, T., and Ylvisaker, M. (2006). Context sensitive behavioural cognitive-behavioural supports for young children with TBI: A replication study. Brain Injury, 20,6, 629-645. *Two case studies implementing positive behaviour supports in a school setting for two children with escalating behavioural problems. Combined cognitive, behavioural and executive function routines. Reduced aggressive behaviour and increased work completed. The authors noted that staff participation with the consultant in the functional behaviour analysis was critical in staff training and securing compliance with the intervention plan. They recommend multi-component interventions.*

Giles, G., and Manchester, D. (2006). Two approaches to behaviour disorder after traumatic brain injury. Journal of Head Trauma Rehabilitation, 21, 2, 168-178. *The paper outlines the neurobehavioural treatment approach in residential rehabilitation units and considers how this may be blended with motivational interviewing, changing staff attributions and including the therapeutic relationship as an active treatment factor.*

Graham, D. P., and Cardon, A. L. (2008). An update on substance use and treatment following traumatic brain injury. Annals of the New York Academy of Science, 1141, 148-162. *In this review the authors note that motivational interviewing was not especially effective in isolation. Financial incentives and barrier reduction approaches showed early promise.*

Graham, A. C., Birchwood, M. J., Mueser, K. T., et al. (2004). Cognitive-Behavioural Integrated Treatment. A Treatment Manual For Substance Misuse in People With Severe Mental Health Problems. Chichester: Wiley. *A comprehensive treatment manual covering assessment, engagement,*

motivation, treatment and support. It also includes a chapter focusing on working with families and other network members. Another chapter considers common obstacles to implementation and suggests possible solutions.

Hart, T., Vaccaro, M., Hays, C., Maiuro, R. (2012). Anger self management training for people with traumatic brain injury: a preliminary investigation. Journal of Head Trauma Rehabilitation, 27,2, 113-122. *Describes a fully manualised eight session treatment for irritability and anger after TBI. 10 patients with chronic cognitive impairment after moderate and severe TBI. Eight had significant others participate in some sessions. Self reported anger improved. Qualitative feedback was positive and drop out was low.*

Health Workforce Australia. (2013). National Mental Health Core Capabilities. Focus Testing Background Paper. Adelaide, www.hwa.gov.au *Presents draft core capabilities to support practitioners working in mental health across Australia. Reflects a very wide consultation and review process to enhance stakeholder investment.*

Hsieh, M, Ponsford, J., Wong, D., et al. (2012). Motivational interviewing and cognitive behaviour therapy for anxiety following traumatic brain injury: a pilot randomized controlled trial. Neuropsychological Rehabilitation, 22,4, 585-608. *27 TBI clients randomly assigned to Mi+CBT, non-directive counseling (NDC)+CBT and treatment as usual (TAU). Both active treatments did better than TAU on self report. Mi conferred additional improvement.*

Jackson H, Manchester D. (2001). Towards the development of brain injury specialists. NeuroRehabilitation, 16,1, 27-40. *Outlines possible curriculum and a model for training for families, practitioners and support workers in community brain injury rehabilitation.*

Khan, F., Baguley, I. J., and Cameron, I. D. (2003). Rehabilitation after traumatic brain injury. Medical Journal of Australia, 178, 290-295. *Highlights the social burden of TBI and stresses the importance of family education, counseling and ongoing support. The authors also emphasise the role of drug therapies post TBI in particular for depression and anxiety.*

Laatsch, L., Harrington, D., Hotz, G., et al. (2007). An evidence based review of cognitive and behavioural rehabilitation treatment studies in children with acquired brain injury. Journal of Head Trauma Rehabilitation, 22,4, 248-256. *28 studies met the authors' inclusion criteria including 366 children and youth with ABI. Eight studies assessed interventions for behavioural targets. All used single subject design. The authors conclude multi-component interventions incorporating contingency management, positive behaviour supports and executive function routines are effective at reducing disruptive behaviours and improving social functioning.*

LaVigna, G., and Willis, T. (2012). The efficacy of positive behavioural support with the most challenging behaviour: The evidence and its implications. Journal of Intellectual and Developmental Disability, 37,3, 185-195. *Reviewed*

12 outcome studies covering 423 cases. Concluded positive behaviour support was effective with both severe and high rate behaviour problems, was cost effective, used a methodology that was easily trained and widely disseminated, worked in institutional settings in which the most difficult problems are thought to be, as well as in the community.

Lyon, A. R., Stirman, S. W., Kerns, S. E., and Bruns, E. J. (2011). Developing the mental health workforce. Review and application of training approaches from multiple disciplines. Administration and Policy in Mental Health, 38,4, 238-253. *In their review of effective training for evidence based practice approaches across multiple disciplines the authors note that a robust and consistent finding is that single exposure training models or the simple provision of information in manual or guideline form are ineffective methods in producing practitioner behaviour change. Even so, single shot classroom based workshops lasting between a few hours and a few days continue to be the most common method used for training practitioners. They conclude that the use of traditional workshop models or any single strategy are unlikely to result in success. In summary they suggest that certain approaches are well established and should be considered when developing a training and workforce development plan. Intensive coaching or mentoring is likely to be necessary to realise the complex behaviour change required when implementing new therapies. This can be supported by the use of checklists ands reminders which are moderately effective and can be relatively low cost. As expert coaching fades over time it may be supplanted by peer coaching and reminders. Checklists are a particularly potent form of reminder. They observe that in the area of surgical medicine there use has been shown to reduce complications and deaths and reinforce practitioner competence as well as team functioning in complex interventions.*

Malec, J. F. (1999). Goal attainment scaling in rehabilitation. Neuropsychological Rehabilitation, 9,3, 253-275. *The author considers multiple possible advantages of using goal attainment scaling in brain injury rehabilitation including its sensitivity to change and sensitivity to the values of the person with brain injury, its excellent inter-rate reliability and satisfactory concurrent validity. He recommends its inclusion as one part of a comprehensive outcomes measurement system.*

Manchester, D. (2002). Staff attributions for aggression and the acceptability of psychological treatments in brain injury rehabilitation. Doctorate thesis. The University of Surrey, United Kingdom. *113 brain injury rehabilitation staff made attributions for aggression post TBI. Those who made internal personality attributions were significantly more likely to consider the most restrictive behavioural treatment approaches as appropriate.*

Manchester, D., Hodgkinson, A., and Casey, T. (1997). Prolonged, severe behavioural disturbance following traumatic brain injury: What can be done? Brain Injury, 11,8, 605-617. *Presents the case of a young man with severe TBI and very high frequency challenging behaviour who could not be supported in the community or in standard treatment settings. Subsequent*

rehabilitation in a small unit run on the principles of neurobehavioural rehabilitation saw aggression reduce to zero after several months, the removal of behavioural medication and eventual discharge to his own home in the community. The case for establishing such a service in NSW is made and common criticisms of such services are considered.

Medd, R., and Tate, R. (2000). Evaluation of an anger management therapy programme following acquired brain injury. A preliminary study. Neuropsychological Rehabilitation, 10, 185-201. *Eight TBI clients in the treatment group received between five and eight one hour sessions. A wait list control monitored their anger. Therapy was CBT and was based on Novaco's self instructional training. Self reported anger improved as did anxiety scores which reduced from moderate to mild. Depression scores did not change.*

Miller, W., and Rose, G. (2009). Toward a theory of motivational interviewing. American Psychologist, 64,6, 527-537. *Provides an overview of motivational interviewing's treatment rationale as well as its effectiveness across multiple behavioural domains.*

Miller, W. R., Yahne, C. E., Moyers, T.B., Martinez, J., Pirritano, M. (2004). A randomized trial of methods to help clinicians learn motivational interviewing. Journal of Consulting and Clinical Psychology, 72,6, 1050-1062. *Found the most efficacious training for integration of motivational interviewing into practice is one that is longer in duration and that integrates training, observation, feedback, and coaching.*

National Trauma Research Institute. (2013). Developing a research programme to address behaviours of concern following traumatic brain injury. Dialogue Summary. Monash University. *This paper summarises the outcomes of a day long dialogue with key stakeholders held to develop a research programme for behaviours of concern after TBI. Three major research areas were identified covering models of care, biological interventions and behavioural interventions. Next steps identified included providing an opportunity for researchers and other stakeholders not present at the stakeholder dialogue to contribute to further development of the program and consider leveraging, interstate and international collaboration opportunities in development of any research program.*

Nock, M. E., and Kazdin, A. E. (2005). Randomized controlled trial of a brief intervention for increasing participation in parent management training. Journal of Consulting and Clinical Psychology, 73,5, 872-879. *Demonstrates that a brief intervention based on motivational interviewing significantly increases parent engagement in parent management training and contributes to improvements in child behavioural difficulties.*

Otto, R. K., and Douglas, S. (2010). Handbook of Violence Risk Assessment. New York: Routledge, Taylor and Francis Group. *Provides a thorough overview of forensic risk assessment in violence and sexual violence. Risk assessment measures in both adult and juveniles are reviewed.*

Oyebode, J. (2003). Asessment of carers' psychological needs. Advances in psychiatric treatment, 9, 45-53. *The author considers factors associated with carer stress and reviews measures that can assist in identifying carers' psychological needs. Whilst the focus is on carers of those with dementia given that the primary impairment is neuro-cognitive the measures reviewed here may be helpful in brain in jury rehabilitation.*

Ponzio, V., and Williamson, M. (2013). A partnership service model for people with cognitive impairment and severe mental disorder. NSW Ageing, Disability and Home Care. Department of Family and Community Services. *Reviews service models for people with intellectual disability whose challenging behaviour precludes living in the community. Proposes development of a more secure facility that would a have a strong therapeutic and skills development focus. It is envisaged it would deliver a range of programs including positive behaviour support, trauma counselling, psychiatric care, psychological therapies, educational, employment and living skills. The service would be staffed by a multidisciplinary team drawing together expertise in disability and mental health to ensure that a holistic approach is adopted with a view to securing the best outcomes for this population.*

Repper, D., and Brooker, C. (2002). Avoiding the washout. Developing the organizational context to increase the uptake of evidence based practice for psychosis. Northern Centre for Mental Health, ncmh.org.uk. *The authors review how best to translate training into frontline practice. They identify factors that help with this but in particular note, "…change can only take place and have a meaningful impact when organisations identify those factors that enable change to endure and critically, take responsibility for making it happen."*

Rietdijk R, Togher L, Power E. (2012). Supporting family members of people with traumatic brain injury using telehealth: a systematic review. Journal of Rehabilitation Medicine, 44,11, 913-921. *Concluded telehealth (telephone, internet and video conferencing) could be used to access families in rural areas and to train family members in skills required to facilitate recovery after TBI, to pre-empt problems arising and to create a forum for peer support. Several studies indicated interactive skills based programs appeared more effective than general information giving. In one study family members found coaching sessions with a therapist via video-conferencing more helpful than self guided web sessions.*

Sabaz, M., Simpson, G. K., Walker, A. J., et al. (2013). Prevalence, Comorbidities, and Correlates of Challenging Behavior Among Community-Dwelling Adults With Severe Traumatic Brain Injury: A Multicenter Study. Journal of Head Trauma Rehabilitation. May 1. [Epub ahead of print] *The authors review prevalence of challenging behaviour in NSW brain injury rehabilitation programme participants. They note inappropriate social behaviour, aggression and adynamia were the three most common individual*

behaviours. Over a third of the sample displayed more than one challenging behaviour. They conclude challenging behaviours are widespread among community-dwelling adults with severe traumatic brain injury. They suggest services need to deliver integrated anger management, social skills, and motivational treatments.

Sabaz, M. (2012.) NSW brain injury rehabilitation program challenging behaviour project adults: Using the analysis of prevalence, course, co-morbidity and burden to inform the model of care. NSW Agency for Clinical Innovation. *Reviewed 659 clients and found prevalence to be high. 53% of clients in the study met criteria for challenging behaviour. The most prevalent challenging behaviour was inappropriate social behaviour (30%), followed by verbal aggression (26%); adynamia/lack of initiation (23%), perseveration/repetitive behaviour (13%); physical aggression against others (11%); physical aggression against objects (7%); physical acts against self (5%); inappropriate sexual behaviour (4%); and absconding/wandering behaviour (3%).* S*uggests eight principles and 41 recommendations to facilitate community integration and behaviour support. The importance of early identification and intervention is principle number one. A major recommendation (recommendation 41) is the establishment of a behaviour support and development service (BSDS) that would initially focus efforts in more remote parts of the state. It was expected the BSDS would provide the following:*

- *Assessment of needs of challenging behaviour clients*
- *Development of behaviour management plans*
- *Intensive program implementation for mentoring in certain circumstances*
- *Support and supervision to families, ancillary carers and BIRP staff implementing behavioural management*
- *Development and support of participation opportunities for clients with challenging behaviour*
- *Education and training to families, ancillary carers and BIRP staff*
- *Education and training of other non-BIRP service providers.*

Sanders, M. R., Pidgeon, A, M. Gravestock, F., et al. (2004). Does parental attribution retraining and anger management enhance the effects of Triple P-positive parenting program with parents at risk of child maltreatment? Behaviour Therapy, 35, 513-535. *In this randomised trial with 98 parents researchers taught parents experiencing difficulties managing their own anger in their interactions with their preschool aged children attributional retraining and anger management in addition to a behavioural family intervention. At six months follow up these parents showed positive outcomes on all measures of child abuse potential, parent practices and parent adjustment as did the treatment comparison group who received a standard behavioural family intervention programme . However, the experimental group continued to show greater change in negative parental attributions.*

Scott, S., and Dadds, M. R. (2009). Practitioner review: When parent training doesn't work: theory driven clinical strategies. Journal of Child Psychology and Psychiatry, 50,12, 1441-1450. *Briefly reviews the favourable evidence in the general population for parent training programmes in behavioural strategies based on social learning theory. They note that still a quarter to a third of families do not benefit. They suggest practical strategies based on attachment theory, structural family systems theory, cognitive attribution theory, and shared empowerment/motivational interviewing can help here.*

Sharrock, R., Day, A., Qazi, F., and Brewin, C. R. (1990). Explanations by professional care staff, optimism and helping behaviour: an application of attribtion theory. Psychological Medicine, 20, 849-855. *Explores the link between staff optimism and willingness to help patients. More optimistic staff offer more help.*

Sholomska, D. E., Syracuse-Siewart, G., et al. (2005). We don't train in vain: A dissemination trial of three strategies of training clinicians in cognitive-behavioural therapy. Journal of Consulting and Clinical Psychology, 73,1, 106-115. *78 community based practitioners assigned to one of three training conditions, manual only, manual+access to a CBT training website, manual+didactic seminar+supervised casework. Those provided with supervision did best when assessed on ability to demonstrate key CBT interventions.*

Simblett, S. K., Ring, H., and Bateman, A. (2011). Computerised cognitive behaviour therapy (cCBT): A possible treatment for mood disorders experienced by people with neurological disorders. Neuropsychological Rehabilitation, 21,6, 925-928. *Computerised CBT has consistently been shown to reduce levels of depression in the general population. The authors review two studies of cCBT with neurological populations for effectiveness, acceptability and appropriateness. One study was in multiple sclerosis (MS). Another was mild to moderate TBI. The MS study was poorly accepted as the content was considered inappropriate by participants. However, the TBI package "MoodGYM" fared better. It had additional weekly telephone support and was part of a specialist rehabilitation service. They state that the studies authors, "Topolevec-Vranic et al. (2010)…found significant decreases on measures of depression during completion of the package and after 12 months, with half of the group assessed at the 12 months (4/9) no longer scoring in the clinical range." Overall acceptability was good. Suggestions were made to improve the content including ensuring access to required equipment and accommodating cognitive and physical difficulties.*

Tarrier, N., Haddock, G., and Barrowclough, C. (1998). Training and dissemination: research to practice in innovative psychosocial treatments for schizophrenia. In T. Wykes., N. Tarrier., and S. Lewis (Eds.), Outcome and Innovation in Psychological Treatment of Schizophrenia (pp. 215-236). West Sussex: Wiley. *The authors review the evidence for psychosocial interventions in schizophrenia and consider how best to get evidence based*

approaches into frontline practice. They consider key aspects to ensure practitioner behaviour change include supervision and organizational commitment.

Togher, L., McDonald, S., Tate, R., Power, E., Rietdijk, R. (2013). Training communication partners of people with severe traumatic brain injury improves everyday conversations: a multicenter single blind clinical trial. Journal of Rehabilitation Medicine, 45,7, 637-45. *Training partners of a person with brain injury was more helpful in improving communication than only training the person with TBI. Outcomes were blind assessments on a rating of communication participation after a 10 week programme. Gains were maintained at six months follow-up.*

Twomey, C., O'Reilly, G., Byrne, M., et al. (2014). A randomized controlled trial of the computerized CBT programme, MoodGYM, for public mental health service users waiting for interventions. British Journal of Clinical Psychology, 53,4, 433 – 450. *A trial of self help internet CBT with 149 participants. It was not therapist guided and provided only automated email prompts for participants to complete modules. There was a very high drop out rate. There was no change in depression, anxiety or impaired daily functioning in those who did complete although general psychological distress did reduce. The authors point out that when internet CBT is therapist assisted it does yield a large effect size.*

Wade, S. L., Carey, J., and Wolfe, C. R. (2006a). An online family intervention to reduce parental distress following pediatric brain injury. Journal of Consulting and Clinical Psychology, 74,3, 445-454. *Forty families of children with moderate to severe TBI were randomly assigned to either online family problem solving therapy (FPS) or internet resources (IRC). Parental distress reduced significantly in the FPS group and this was maintained at follow-up. It is worth noting that the IRC group did not improve or worsened over time on measures of clinical symptoms. As the authors note this indicates that parental distress does not improve with access to internet resources alone.*

Wade, S. L., Carey, J., and Wolfe, C. R. (2006b). The efficacy of an online cognitive behavioural family intervention in improving child behaviour and social competence following pediatric brain injury. Rehabilitation Psychology, 51,3, 179-189. *Thirty nine families of children with moderate to severe TBI participated in this study and were randomly assigned to an online family problem solving (FPS) group or an internet resources comparison (IRC) group. All participants received computers and internet access. In the FPS the therapist met once in the family's home at the beginning of treatment and conducted a structured interview regarding how the injury had affected the child and the family and derived current concerns and goals. They reviewed the content and the structure of the intervention and entered goals into the website. Future meetings with the therapist occurred every 1-2 weeks via videoconferencing. Inbetween sessions the family completed self guided materials on the website. The FPS group reported greater child self management/compliance at follow up than did the IRC group. Older children*

and those from lower socioeconomic status showed greater gains in self management and behaviour problems.

Wade, S. L., Michaud, L., and Brown, T. M. (2006). Putting the pieces together. Preliminary efficacy of a family problem solving intervention for children with traumatic brain injury. Journal of Head Trauma Rehabilitation, 21, 57-67. *The authors demonstrate that teaching families problem solving increases knowledge of TBI, problem solving skills, family relationships and child behaviour as reported by the parent. Depression, anxiety and withdrawal in children improve. Results are better than the standard treatment control group.*

Waldron, B., Casserly, M., and O'Sullivan, C. (2013). Cognitive behavioural therapy for depression and anxiety in adults with acquired brain injury. What works for whom? Neuropsychological Rehabilitation, 23,1, 64-101. *A review of 24 studies across neurorehabilitation including TBI, acquired brain injury and cardiovascular accident. Studies demonstrated improvement within groups and compared to controls. However studies indicated only a partial reduction in symptoms.*

Walker, A., Nott, M., Doyle, M., et al. (2010). Effectiveness of a group anger management programme after severe traumatic brain injury. Brain Injury, 24,3, 517-24. *12 weekly sessions of two hour group therapy based on cognitive behaviour therapy with adaptations for brain injury. There was an additional two hour follow-up session. Family members also attended information sessions. Approximately half the group's families attended. Participants who completed the course 52/69 were more likely to be living with parents, partners or other supports. Participants were living in the community. 52 people completed training over an eight year period. 31 attended a follow-up session. Self reported anger experience and expression reduced and changes were maintained at follow-up.*

Watkins, C. L., Auton, M. F., Deans, C. F., et al. (2007). Motivational interviewing early after acute stroke. A randomized controlled trial. Stroke, 38, 1004-1009. *411 consecutive stroke patients at the same unit were randomly assigned to up to four sessions of motivational interviewing or usual stroke care. Interventions were commenced within the first four weeks post stroke. Mood was assessed at three months post stroke with the General Health Questionnaire – 28. Therapists were trained in motivational interviewing and worked under close supervision. The study included fidelity checks to ensure validity of the motivational interviewing treatment. Results demonstrated better emotional functioning in the motivational interviewing group.*

Weiner, N. (1995). Judgements of Responsibility. A Foundation for a Theory of Social Conduct. New York: Guilford Press. *Discusses the strong link between a person's attributions for behaviour in others and their subsequent emotional and behavioural reactions. In particular, judgements of responsibility and control for challenging behaviour reduces the likelihood of*

helpful responses and increases the likelihood of aversive responses in others.

Willis, T., and LaVigna, G. (2003). The safe management of physical aggression using multi-element positive practices in community settings. The Journal of Head Trauma Rehabilitation, 18,1, 75-87. *The authors make the point that after TBI learning from consequence-based contingencies may be impaired. They present a case that used positive behaviour supports and antecedent controls to maintain a client with challenging behaviour in the community.*

Winstanley, J., Simpson, G., Tate, R., and Myles, B. (2006). Early indicators and contributors to psychological distress in relatives during rehabilitation following severe traumatic brain injury: findings from the Brain Injury Outcomes Study. Journal of Head Trauma Rehabilitation, 21,6, 453-466. *Tracked relatives' psychological functioning and needs after a person's TBI. (N=134). Relatives' distress was not directly linked to extent of neurobehavioural impairments but was mediated by the degree of community participation the person achieved. The authors suggest more respite or case management services may be helpful.*

Wood, R. Ll., and Thomas, R. H. (2013). Impulsive and episodic disorders of aggressive behaviour following traumatic brain injury. Brain Injury, 27,3, 253-261. *Present two subtypes of aggressive behaviour post TBI to assist decision making for treatment. These are impulsive and episodic aggression. The authors consider different neuropathology and treatments are indicated and discuss the role of anticonvulsants in episodic aggression.*

World Health Organisation (2006). WHO Traumatic Brain Injuries. Geneva; WHO.

Ylvisaker, M., and Feeney, T. (1998). Collaborative Brain Injury Intervention. Positive Everyday Routines. Singular Publishing Group, London. *A book that explains the positive behaviour support approach of the authors and their colleagues. An emphasis is on functional collaborative assessment and establishing positive routines for executive functions including cognitive and behavioural routines. On page 311 they outline communication and behavioural competencies for rehabilitation staff.*

Ylvisaker, M., Turkstra, L., Coehlo, C., et al. (2007). Behavioural interventions for children and adults with behaviour disorders after TBI: a systematic review of the evidence. Brain Injury, 21,8, 769-805. *Reviewed 65 studies with 172 participants including children and adults. Behavioural interventions were effective for both groups. Both traditional contingency management and positive behaviour support could be said to be evidence based treatment options. They noted a large number of negative behaviours appeared to have a communication function. 11 of the studies discussed training given to*

everyday communication partners e.g. family members, teachers and nursing assistants to help deliver the interventions.

Appendix 3

Appreciative inquiry interview questions

Q.1 In your experience what factors give life to behaviour support in the community for individuals with brain injury or those who support them when you have seen that support most alive and effective?

Q.2 Without being modest, what is it you value most about yourself and your role in this area?

Q.3 What are the core factors that make the system work at its best without which support would cease to be helpful?

Q.4 What three wishes do you have to enhance the health and vitality of the system to provide community behaviour support for individuals with brain injury?

Practitioners were also asked follow up questions addressing their personal development in the area, indicators for early behaviour support, outcomes measurement and training and practice guidelines.

Appendix 4

Emergent themes taken from the appreciative inquiry interviews

The Themes

Part 1

Appreciative inquiry Interviews with steering group members and other practitioners

1 Person directed support
2 Teamwork
3 Positive behaviour support
4 Skilled work
5 The working alliance
6 Mentoring
7 Tele-health
8 Education and changing attributions
9 Behaviour support plans
10 Continuity of care and training
11 Early exposure to brain injury work
12 Attendant care workers
13 Family, friends and peers
14 Depression
15 Data

Part 2

Themes from service recipients' appreciative inquiry interviews

LCSA themes: **Person directed support**

Many interviewees discussed good practice as having a particular focus on person directed support. This was true when working with the person with the brain injury as well as when working with the person's significant others. Good behaviour support practitioners asked the person what his or her goals were and then sought to help the person achieve these. Thus, whilst an outcome may have been the reduction of a particular behaviour the best support had as its central focus the achievement of a person directed goal.

LCSA themes: **Teamwork**

A common theme in interviews was that good behaviour support occurrs in the context of well co-ordinated teamwork. This was exemplified by circles of support meeting regularly to discuss goals, review progress and agree changes as required. A particular emphasis was on everyone's voice being heard and respected. This was seen as central to motivating participants to attend and to contribute. Behaviour support practitioners associated with good practice listened well to others, recognised the skills and expertise of others and incorporated others' ideas and knowledge into guidelines.

LCSA themes: **Positive behaviour support**

Behaviour support practitioners identified at interview the necessity to understand principles of behavioural assessment, applied behaviour analysis and positive behaviour support (PBS). In particular the ability to perform functional analysis of behaviour and to understand principles of antecedent control and differential reinforcement of other behaviour was emphasised. Interviewees who were not familiar with PBS talked about support in more generic terms akin to good case management.

LCSA themes: **Skilled work**

An aspect that was also stressed by several interviewees was the fact that attendant care work is skilled work. In the best programmes attendant carers were encouraged to contribute to behaviour support plans and were well supported by case managers and behaviour support practitioners. They were an integral part of the team and received training and support in client specific aspects of support in addition to more generic brain injury training.

LCSA themes: **The working alliance**

Many respondents pointed to the therapeutic relationship as a core factor in successful behaviour support. They talked about liking the person they provided support to and being genuinely concerned for peoples' welfare. Although no one used the term 'the working alliance' they discussed the three themes that underpin a strong working alliance. In addition to the affective bond (i.e. liking and feeling listened to and understood), they frequently asserted that agreement on goals and tasks underpinned examples of good behaviour support that they observed.

LCSA themes: **Mentoring**

A common theme in interviews with behaviour support practitioners when discussing how they achieved competence in behaviour support was early access to mentors. Interviewees talked about being anxious and uncertain when first working in this area. Learning from other practitioners helped to build ability and confidence in this work. A major focus for this support was the expertise of the three major urban brain injury centers in Sydney. Independent providers of behaviour support also talked about providing mentoring to others often via internet services such as skype and email. It was their view that this was helpful and that it was well accepted.

LCSA themes: **Tele-health**

Most interviewees mentioned the use of tele-health to provide support to clients and their significant others. Those who were using these resources tended to be independent practitioners. Hospital based practitioners volunteered the belief that live internet meetings would be helpful but observed they were precluded from doing this by hospital firewalls.

LCSA themes: **Education and changing attributions**

Interviewees placed an emphasis on the need for behaviour support practitioners to understand brain behaviour relationships so as to change people's less helpful mis-attributions for particular behaviours. For example, understanding that impulsive behaviours and emotional dyscontrol are common after orbito-frontal brain injury helps people to reduce the tendency to blame others for exhibiting these difficulties. Similarly, knowing that disorders of drive and motivation are common sequalae of ventromedial frontal brain injury reduces the likelihood that others will attribute lack of initiation to laziness. Appreciating that the ability to learn after TBI can adversely affect responses to contingency management programmes helps too. Appreciating that using errorless learning can be especially helpful when working with a person with impaired memory is useful. Understanding what is often well preserved after brain injury, for example pre-morbid habits and

routines, the ability to benefit from procedural learning approaches and being able to build this into behavioural programmes further contributes to good practice.

LCSA themes: **Behaviour support plans**

Good practice was underpinned by behaviour support plans based on thorough assessment, careful observation, interviews with consumers and person directed goals. Good plans were responsive to changes in a client's needs. They set out clearly how to respond to particular behaviours. They had a focus on building alternative positive behaviours and enhancing community participation.

LCSA themes: **Continuity of care and training**

The point was made by both inpatient and community interviewees that good practice often linked behavioural supports and routines established on the hospital ward with planned community supports. Rather than seeing the two settings as mutually exclusive clinical approaches found to be positive were translated by ward staff to community case managers, behaviour support workers and attendant carers often via relatively brief i.e. one to two hour group meetings around the time of discharge. When behaviour support specialists were able to help implement, monitor and change behaviour support plans collaboratively as necessary outcomes appeared especially beneficial.

Others suggested that it may be helpful to give a person time away from support once they get home just as a break from rehabilitation. An advantage of this is that insight tends to improve once the person leaves the highly structured setting of the ward. However, this also brings with it the risk of emergent depression as the person becomes more aware of impairments induced by the brain injury and their functional implications.

Consumers talked about the usefulness of ongoing support after discharge from hospital and how helpful it was not just to hear, "See you later." Consumers also mentioned the value of having easy access to a brain injury service for support and listening, for example a go-to person for behaviour support.

LCSA themes: **Early exposure to brain injury work**

Several behaviour support practitioners talked about becoming more interested in the work once they had exposure to providing behaviour support in brain injury. For people early in their career this was often on the brain injury wards where they had the opportunity to work with clinical teams and to learn from other more experienced practitioners.

LCSA themes: **Attendant care workers**

A clearly communicated point in interviews was the high value contribution of good attendant care workers. This was stressed in many of the interviews. Attendant care workers provide the greatest support outside of the family. They are an invaluable source of motivation, support and feedback. A consistent theme emerged in the desirability of an agreed set of minimum standards for training of attendant care workers. The lack of a uniform and industry accepted standard was highlighted.

LCSA themes: **Family, friends and peers**

There was broad recognition of the need to engage well with and to support family members and interested peers. Some of the most common ways to do this included being person centred, including family members in team meetings and listening well to family members. These same points were made in consumer interviews. Recognising the expertise of carers in designing and implementing behaviour support plans was stressed.

Effective behaviour support was noted to be most effective when it was embedded in context and in particular when involved family members and peers were actively included in the support regimen. In addition, it was important to note that family members may also require respite or a break from providing support to allow time to recover from what can be a cumulative sense of stress. Family members talked about the usefulness of having more respite options in particular more regular, short and frequent breaks.

A family member talked about the importance of establishing a therapeutic relationship early on. This allowed for difficult information to be given that even if rejected initially was easier to accept later as problems emerged. Consumers talked about the importance of brain injury services listening to clients, the family and support workers.

LCSA themes: **Depression**

A particular theme that emerged from the interviews was the importance of addressing depression in behaviour support services. Depression was cited by community behaviour support practitioners as being a common pre-cursor of behaviour deterioration usually between one and two years post injury. This is likely to reflect the observation in the literature that impaired self awareness of deficits subsides after increasing time in the community as the person is confronted by repeated evidence of their neuropsychological difficulties and their functional implications. As self awareness improves it brings with it an increased vulnerability to depression and subsequent behavioural deterioration.

Both consumers and practitioners discussed the need to be able to provide more activities for people with brain injury. This was with a view to increasing the opportunities available to do more normal things and to reduce boredom and increased isolation.

LCSA themes: **Data**

Behaviour support practitioners and case managers emphasised the need to collect relevant data not only for assessment purposes but also to aid in service monitoring and review. Interviews with non practitioners did not cite this as central to good behaviour support. This may mean that more work needs to be done to ensure that the usefulness of data collection is covered more fully in any core standards training for practitioner and also attendant care workers.

Part 2

LCSA themes from service recipient's appreciative inquiry interviews

A person centred approach, e.g. including client at seminars

Establish the **therapeutic relationship** with families early, and give information early even if it s not accepted

Easy **access** to brain injury services for support and listening, for example a go-to person for behaviour support

The **brain injury service listening** to clients, the family and the support workers

The importance of **providing activities** and the opportunity to do more normal things, for example hobbies and holidays

Increasing **respite options**, for example regular, short and frequent respite

Teamwork with regular meetings and good communication

Behaviour support plans that use **clear language** and explain professional terms

Clear criteria for reporting and responding to behaviours of concern

Working towards **positive goals**

Recognising and supporting **risk taking**

Responsive management that always has time to debrief staff

Ongoing training for support workers especially in behaviour management

Development of **internet or video training** packages that include role plays because there isn't always time in formal training for this

Ongoing **support after discharge** from hospital, "…not just see you later."

Appendix 5

Summit day participants 26 August

Naomi Brookes – Sydney Children's Hospitals Network

Belinda Carr – Occupational Therapist – Carr Rehab

Mathew Conroy - Clinical Neuropsychologist, Kaleidoscope: The Children's Health Network

Rachel Cotter – Clinical Psychologist, Royal Rehabilitation Centre Sydney

Jason Cusack – Clinical Psychologist, Illawarra Brain Injury Rehabilitation Service

Janet Doubleday - Clinical Psychologist, ARBIAS

Don Ferguson – General Manager LCSA

Samantha Grant – Senior Clinical Psychologist, ARBIAS

Professor David Giles - Dean School of Education, Flinders University

Joe Hanna - Neuropsychologist, Royal Rehab BICRT

Dr Adeline Hodgkinson - Director Brain Injury Rehabilitation Unit, Liverpool Hospital

Dr Jill Hummell - Manager Community Integration Program, Westmead Hospital

Sarah Judd - Policy Officer, Carers NSW

Dr Patricia Jungfer – Psychiatrist Private Practice

Inbal Luft, - Occupational therapist, Encompass

Suzanne Lulham – Director Service Delivery LCSA

Neil MacKinnon - Manager Service Coordination, LCSA

Michelle Maitz – Clinical Psychologist Liverpool Brain Injury Rehabilitation Service

David Manchester-Clinical Psychologist Private practice

Dr Kathleen McCarthy – Rehabilitation Physician Westmead Brain Injury Unit

Dr Gaston Nguyen – Rehabilitation Physician Liverpool Brain Injury Rehabilitation Unit

Paula Olymbios – Clinical Psychologist Private Practice Sydney

Dr Melanie Porter - Senior Lecturer Neuropsychology Macquarie University

Lesley Radbron – LCSA Service Development and Review

Corinne Roberts - Neuropsychologist, Mid North Coast Brain Injury Rehabilitation Service

Nick Rushworth - Executive Officer Brain Injury Australia

Marina Sallese - Attendant Care Worker, Southern Cross Community Health Care

Robert Scherf – New England Brain Injury Rehabilitation Service

Deborah Serratore - Rehabilitation Case Manager, Arbias

Dr Grahame Simpson - Senior Research Fellow and research leader, Brain Injury Rehabilitation Research Group, Ingham Institute

Vicki Solomon – North Coast Brain Injury Rehabilitation Service

Barby Strettles – Network Manager Brain Injury Rehabilitation Directorate Agency for Clinical Innovation

Beverley Taylor – BIA NSW

Deborah Toffolo – Access Brain Injury Services

Professor Leanne Togher – University of Sydney

Neale Waddy - Department of Education and Community

Naomi Walker - Care Coordinator, Acquired Brain Injury Services

Appendix 6

Summit day themes and provocative propositions

1. Philosophies and values

"Our service adopts an integrated person directed approach to maximizing the person's everyday lived experience. The work is person directed, and culturally competent. Built on the principles of positive behaviour support, our work promotes human rights and social justice principles and it is strengths based. Our practitioners value the contribution of all involved, and promote a team approach that is responsive to the views of clients, their families and support staff. We advocate for evidence based practice promoting inclusion and participation and we collect data that informs our progress towards these goals."

There was strong agreement at the summit day with the need to promote and communicate a clear set of principles underlying the philosophy of support that the practice community advocates. This includes values that guide behaviour support and personal beliefs that underpin these. The group working on philosophies and values considered the following as important.

- Document principles and circulate widely
- Operationalize principles and educate
- Principles underpin service provision, education of staff, supervision, mentoring, and performance appraisals
- Supports disability legislation
- Promotes consensus on core standards
- It is person directed practice
- Commitment to a strong working alliance
- Practitioner's use reflective practice to review their work
- Continuous quality improvement with data collection and analysis on service provision, i.e. we measure the effectiveness of what we do
- Evidence based practice and a commitment to ongoing research
- Provision of ongoing educational opportunities for all stakeholders
- The contributions of all involved are valued
- LCSA service providers demonstrate they work within these principles
- LCSA listens to and responds to clients, families, staff and stakeholder comments

2. Well supported families and significant others

"Our service views brain injury as a family affair. The natural support network is an important resource and has a right to be heard. Families we support feel included and listened to. Their experience is respected and validated. We recognise the primary role played by carers and we support their rights as enshrined in the NSW Carers (Recognition) Act 2010. We seek to be flexible and innovative in reaching out to support families. We regularly measure family satisfaction to check how well we are doing and we use this feedback to improve our service."

The group working on this theme advocated for an identified key person to meet regularly with the family to review progress and to encourage feelings of being heard. It also suggested training for family members to increase awareness of what to expect when the person with brain injury returns home.

3. Skilled practitioners

"Our service supports practitioners to have the skills and confidence required to provide effective behaviour support in the community. We demonstrate this by a commitment to standardised training in core skills. We use implementation science to support practitioner skills development in particular helping to provide coaching and mentorship. We acknowledge too the importance of supporting placements in brain injury rehabilitation teams to help develop experience and establish relationships with peers from the same and other disciplines. We seek feedback from our behaviour practitioners on what will further enhance their practice and we use this to further develop our training approach."

4. Recruitment

"Our service believes in a focused approach to recruiting people who can demonstrate a passionate understanding of people with disability and cognitive impairment, who are team players and who are optimistic. We demonstrate our commitment by supporting financial incentives for doing this work, standardised induction, placements with service providers, professional development and access to continued mentoring."

5. Training

"Our service believes in a robust training programme that covers agreed core standards in behaviour support for both behaviour support practitioners and attendant care workers. We understand that effective training requires work practice with ongoing coaching, mentoring and support from those with expert knowledge. We expect this to produce skilled practitioners able to engage consumers, build rapport and provide evidence based approaches that help consumers to achieve their goals."

There was general agreement that most practitioners providing behaviour support do not come to brain injury work ready. It was felt that core standards training in a minimum set of factors/approaches would help to raise the confidence, ability and motivation of those seeking to provide behaviour support in the future.

This group considered it best to engage in further consumer consultations to with a view to the resource being available within one year.

Further, the group thought it would be helpful to create a certificate in enhanced behaviour support with core modules. This would include clinical placement, supervision and mentoring. Some of these modules could be tailored to form a shorter standardised training course for attendant care workers. This might be formally credentialed by an RTO or TAFE.

The group working on training suggested developing an induction package for new staff coming to work in this area and that this be supported by web based materials in multiple languages. This package could also be accessible and meaningful to carers, for example partners, parents and children.

They outlined the following as tasks to achieve accredited certificates:

- Appoint a project manager
- Include key stakeholders
- Design a training programme with multidisciplinary team input
- Inclusion of an IT expert
- Inclusion of an e-learning expert
- Secure accreditation of the training e.g. TAFE
- Develop competencies
- Define outcomes assessment
- Pilot the process over three years

The group suggested possibly offering financial incentives to attendant carer agencies to promote the training of attendant care workers.

One stakeholder explained that they have found professional learning that has been accredited is well received by their organisation. Their staff attendance at registered courses counts toward maintaining accreditation at various levels. The organisation provides numerous courses which are accredited. It also provided scholarships for staff to undertake further tertiary study. This too has been well received.

Appendix 7

NSW Carers Charter

(a) The valuable social and economic contribution that carers make to the community and the persons for whom they care should be recognised and supported.

(b) Carers' health and wellbeing are to be given due consideration.

(c) The views and needs of carers and the views, needs and best interests of the persons for whom they care must be taken into account in the assessment, planning, delivery and review of services provided to persons who are cared for.

(d) Carers should be referred to, and made aware of, appropriate services to assist carers in their caring role. Such referrals should be made after an assessment of the needs of carers or as part of the assessment or provision of services to the person being cared for.

(e) The relationship between carers and the persons for whom they care should be respected.

(f) Carers are to be acknowledged and recognised as having their own individual needs within and beyond their caring role. This acknowledgement and recognition is to take into consideration Aboriginal or Torres Strait Islander culture, age, disability, religion, socio-economic status, cultural differences, gender identification and place of residence.

(g) Children and young people who are carers have the same rights as all children and young people.

(h) Children and young people who are carers face additional difficulties and burdens and should be supported in overcoming these difficulties and burdens.

(i) Carers should have the same rights, choices and opportunities as other Australians.

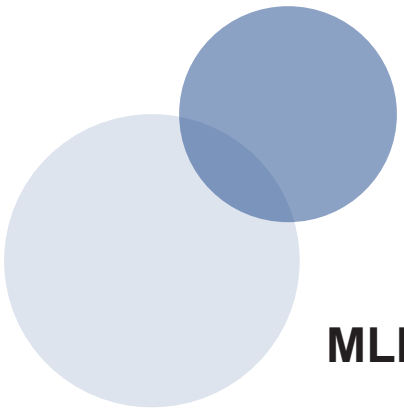
(j) Carers' choices in their caring role should be supported and recognised, including the recognition of carers in the assessment, planning, delivery and review of services that impact on carers and their role as carers.

(k) The additional difficulties faced by remote and rurally based carers

caused by isolation should be recognised and acknowledged.

(l) Support for carers should be timely, responsive, appropriate and accessible.

(m) Carers' unique knowledge and experience should be acknowledged and recognised.



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