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Australian Clinical Practice Guideline for the Management of Psychosocial Difficulties in Adults with Moderate-to-Severe Traumatic Brain Injury

Submitted via Email to:

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and Online Survey:

<https://redcap.utas.edu.au/surveys/?s=AgUr4GGMwrRnMbsv>

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Introduction

Lived Experience Australia Ltd (LEA) is a national representative organisation for Australian mental health consumers and carers, families and kin, formed in 2002. Our 'friends' include more than 10,000 people with lived experience of mental health concerns across Australia. This includes lived experiences with all parts of the mental health care system, NDIS, psychosocial disability support outside the NDIS, public and private service options, and service provision across urban, regional, rural and remote Australia. All members of our Board and staff have mental health lived experience as either a consumer, family/carer/kin/supporter, or both.

Lived Experience is core to our advocacy, recognising that the impacts of policy and practice are felt not only by individuals, but also by families and whole communities. Our core business is to advocate for effective policies and systemic change to improve mental health care and psychosocial disability support services and support across the lifespan, across the whole Australian health and social care system, including within State and Territory jurisdictions.

We welcome the opportunity to provide our feedback to this crucially important issue for people with mental health and psychosocial disability, and their families, carers and kin in the Australian community.

Purpose of this Consultation

The Australasian Society for the Study of Brain Impairment (ASSBI) have invited feedback in their public consultation on the draft *Australian Clinical Practice Guideline for the Management of Psychosocial Difficulties in Adults with Moderate-to-severe Traumatic Brain Injury (TBI)*.

The main guideline document comprises 17 evidence and/or consensus recommendations for health professionals treating a range of potential behavioural, and social-cognitive, and mental health challenges. Included with the Guideline are supplementary chapters specifically focusing on First Nations communities, cultural and linguistic diversity, and care in rural and remote settings.

The draft Guideline and associated reports and supplementary documents can be found here:

Guideline and associated reports

- **Main guideline document**
- Summary guideline
- Technical report
- Administrative report
- Dissemination plan

Supplementary chapters

- **First Peoples**
- Cultural and Linguistic Diversity
- Rural and Remote

Our Response to the Consultation

Do you have any conflicts of interests or any possible financial benefits that may arise from the feedback provided?

No.

Do you have any feedback about the draft recommendations or practice points contained in the guidelines?

We have reviewed the Summary Guideline document:

Overall, there appears to be a significant amount of unnecessary repetition across the sections in the good practice statements. Whilst the separation into sections, based on difficulties arising from TBI, the overall format within sections seems to work against this being a useful document to guide practice. The repetition

arising from the format chosen may have the effect of ‘dampening’ health professionals’ ability to engage more meaningfully with the Guideline which is currently very bland, with many statements being so broad that we worry that it will have no impact of genuinely informing health professionals in their practice.

p.9 Anxiety, Depression, Psychological Distress and Suicidality - Conditional Recommendation – I believe ‘mentioning’ is a typographical error, and that you perhaps mean ‘mentoring’. However, the Good Practice Points on this page make no mention of peers, so it is difficult to understand what is intended here, who you are referring to, and where peer mentoring fits.

The wording of the first Good Practice Point could be improved – ‘higher dose and/or booster sessions’ of what. The assumption is that you mean ‘psychological interventions. But written and visual aids, and support to develop and implement change plans could involve a range of interventions and actions by health professionals and others. It’s just not clear.

p.11 Sleep Disturbance - ‘Fatigue management strategies’ could be clarified more. CBT is such a broad term – it would be useful to indicate some detail. Here and throughout the document, there is virtually no mention of working in collaboration with other health professionals (e.g. such as sleep specialists).

p.12 Mental Health Interventions involving Close Others are mentioned, but the good practice statements seem to be written as if the health professionals are at the centre of care rather than the person and their close others. There is a degree of ‘nonsense’ in statement such as ‘should consider working with close others and involving them as members of the care team’. Close others are already part of the care team! They may well be sharing the same home as the person with TBI and providing many hours of practical and emotional support across the day. The person may only be in contact with health professionals for short periods with days or week between each contact, and likely seeing them at a clinic rather than in the person with TBI’s own living environment. It’s time to think differently about how these guidelines are written and stop privileging professional expertise and narrow clinical options as central.

The last Good Practice Point on p.12 about assessing outcomes reflects this inherent bias and blinkered view that positions close others within a clinical lens with potential need for psychological treatment support too! Stress and burden are valid issues, however, there is no mention of assessment of outcomes needing to also include assessing the performance of health professionals and the systems in which interventions are provided. The effectiveness of health professionals and systems is just assumed. Assessing close others’ views on their experiences of being included (or not) by service providers should also be included as important to outcomes of interventions. If any system issues remain ‘silent’, health professional behaviours, skills and attitudes may remain unchanged unless also evaluated. In many areas of mental health service delivery, close other/carer stress and burden arises as much from adverse experiences related to how they are treated by health professionals and services as from their role in providing support to the person with mental health challenges.

The above concern seems to reflect an overall feel of the guideline which frames all issues within a diagnostic lens and the person with TBI (and close others) as largely a recipient of professional expertise and decisions rather than there being a more dynamic and collaborative exchange occurring.

p.15 Physical and Verbal Aggression – the Good Practice Point about cultural and demographic background in relation to behaviour support-based interventions is too broad and vague to provide health professionals with any clear information about what is meant here. Aggressive behaviours are not socially and culturally constructed, but this is how this statement comes across.

p.17 Sexualised Behaviours – The last sentence of the Good Practice Point about the use of restrictive practice doesn’t seem to make sense here. The term ‘Aggressive’ behaviours is written here as if it has simply been a copy and paste formatting error from another section, due to some many statements seeming similar across the Guideline, with minor wording changes to reflect the different section headings. Do you mean to manage ‘sexualised’ behaviours here?

p.18 Inappropriate Social Behaviours – The first Good Practice Point doesn’t seem to be very person-centred in how it is currently worded. Again, it reads as if the health professional is at the centre of actions and decisions, and the person is an ‘empty vessel’ waiting for professional assessment of their capacity for social skill-building. Individuals, including people with TBI, are already located within environments where

they are navigating social interactions every day. The term 'adequate' cognitive, communication and emotion regulation abilities, suggests this is finite and has a clear line that can be determined, and that the health professional has control in determining this. Does this mean that people who are not deemed to have 'adequate' abilities are then not offered social skill-building support?

Why should restrictive practices be considered for use to manage inappropriate social behaviours? Again, this final Good Practice Point cookie-cuts the wording about de-escalation, aggressive behaviours, etc, and seems wholly focused on risk, harm, and dangerousness. Not all inappropriate social behaviours by a person with TBI are aggressive.

p.20 Apathy – seems to be viewed solely within a diagnostic lens. Like the Guideline generally, every potential issue or need that the person with TBI has is viewed this way, and clinical treatments are the dominant/only solutions offered. There doesn't seem to be any sense of the person as a person throughout this document. Whilst apathy is clearly understood as an issue arising from TBI and a diagnosis of depression may be relevant, shouldn't you also flag with health professionals to be aware of the potential for other issues such as self-stigma, low self-worth, feelings of hopelessness, etc too.

Again, the repetitive cookie-cutter approach taken in the final Good Practice Point on this page regarding cultural and demographic considerations comes across as tokenistic.

p.21 Apathy Consensus Recommendation – talks about a comprehensive biopsychosocial case formulation. However, this guideline seems to largely focus on the biological and psychological, with virtually no mention of the social world of the person with TBI. This is a common problem in mental health research and practice, with social aspects often relegated to being secondary measures or priorities. We would argue that they are fundamental, from the person's perspective.

p.22 Adherence – similar to the Apathy section and other sections, the impact of health professionals is largely invisible. For example, in this section, there is no mention of the concept of trust that the person may or may not have in the health professional or the service that could well have a role to play in non-adherence.

p.24 Behaviour Interventions involving Close Others – again the last Good Practice Point about assessing outcomes repeats the earlier statement on p.12 verbatim, and also makes no mention of evaluating potential staff and system influences.

p.26 Emotion Perception and Theory of Mind – the last Good Practice Point seems to read as if emotional dysregulation, mood disturbance, communication, etc are expressed solely through a diagnostic clinical lens as if the person with TBI comes with an absence of former and current personhood and personality. Again, the health professional's clinical assessment is positioned as at the centre, not the person as an individual with TBI. There doesn't seem to be any inclusion of considering individual traits, existing relationship dynamics, coping styles, identity.

p.29 Social Cognitive Interventions involving Close Others – see the same concern as per p.12 and p.24 above and need for outcomes assessment to also include evaluation of the skills, knowledge and quality of health professionals delivering the interventions, and the service culture in which interventions are delivered.

There is a typographical error in the last Good Practice Point – 'cares' should be 'carers'?

Do you have any comments about the strength of the recommendations being made in the guidelines (e.g., strong vs. conditional vs. consensus)?

No comments to make.

Do you believe there is any high-quality evidence we have omitted that would change the recommendations?

Overall, it would be good to include more evidence from the lived experience perspective of people with TBI and their close others/carers/families. It is time to be more inclusive of studies using qualitative research methods. Quantitative research, particularly clinical trials are known to be biased in what they measure, often failing to include measures that people with lived experience perceive as important and relevant.

Do you have any general comments for us to consider regarding the implementation of these recommendations?

They need to be clearer so that health professionals have a better sense of what to do. There needs to be less repetition across the sections so that readers don't lose interest in reading the Guideline.

Do you have any other comments you wish to make about these guidelines?

Thank you for the opportunity to review this Guideline.

As a person caring for a spouse with moderate TBI who has all of these issues playing out on a daily basis, I didn't feel that the Guidelines offered much tangible new information or advice. It was far removed from our day-to-day experiences of living with TBI, alongside multiple mental and physical health conditions. There didn't seem to be much integration of the issues, each being treated as quite separate. In our world, these issues all interact and are enmeshed with each other, one having consequences for the next, etc.

Contact

We thank Dr Honan and the Guideline team at University of Tasmania for the opportunity to put our views forward. We wish you well with the next steps and would be pleased to contribute our lived experience perspectives to any future discussions about this important topic. All the best for revising the Guideline.

Your sincerely

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