

PRESIDENTIAL ADDRESS

Thinking small and big: integrating individual, clinician and systems levels of understanding to improve outcomes after acquired brain injury

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‘Thinking small and big’ is, some might say, an ambitious topic for a Presidential Address; but one I felt compelled to tackle. The idea started to take shape when I attended a neuropsychology conference in Sydney last year, which was co-run by the Australian Indigenous Psychologists Association. One of the keynote speakers was Professor Pat Dudgeon, who presented her team’s Social and Emotional Wellbeing (SEWB) model (Gee, Dudgeon, Schultz, Hart & Kelly, 2014), which has many appealing characteristics. One of those is that it is a circle. Circular models capture holistic concepts in a way that box and arrow models do not. The SEWB model also highlights the importance of social connection for wellbeing.

The other thing that I noticed when Professor Dudgeon spoke was that when audience members asked questions, she always responded by inviting her colleagues to give their thoughts. The answer to the question thereby became a conversation, and a more complete and nuanced answer arose as a result.

At that conference, I also participated in my first yarning circle, which was a profoundly enriching experience. What I noticed was that everyone’s individual contributions joined up with each other and brought about a rich and meaningful discussion, from which a message was conveyed about the central importance of culture to our work. This message would have been much less powerful if it had come in the form of a didactic instruction.

While I was reflecting on this on my way back from the conference, I perused the airport bookshop, and one of the books leapt off the shelf at me: *Joined-Up Thinking: The Science of Collective Intelligence and its Power to Change our Lives* by UK neuroscientist Hannah Critchlow. My eyes were drawn to these sentences:

Collective intelligence is precisely the approach we need to overcome our individual brains’ limitations and hit new heights.

It’s time to return to thinking of intelligence as a collaborative act, not an individual’s test score. We must develop ways of collaborating across groups of people with different perspectives and experiences from our own.

When we make this shift, from ‘me’ to ‘we’ thinking, our worldview changes, our imagination is unleashed and every single one of us is able to contribute our unique viewpoint to humanity’s pool of intelligence. It’s exactly this exhilarating joined-up thinking that we need now. (Chapter 1, pages 3-4)

In the remainder of this address, I will share some ideas about how we might do this joined-up thinking in our work in acquired brain injury (ABI) rehabilitation.

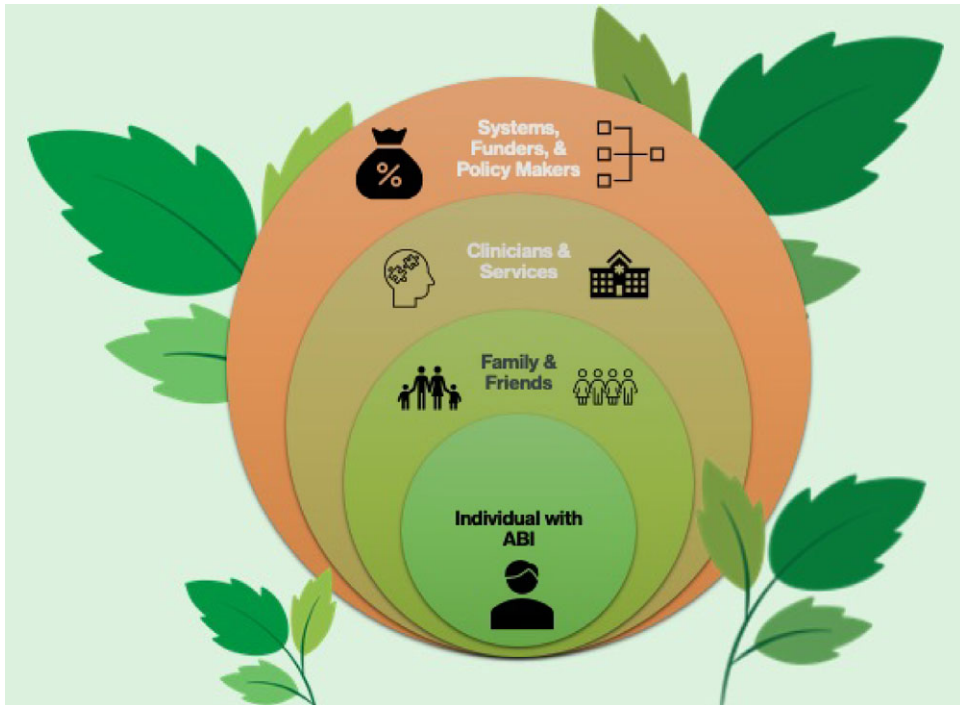


Figure 1. The ecosystem of support for individuals with ABI.

The ecosystem of ABI care and support

Figure 1 shows my attempt at a circular holistic model that is intended to reflect the embedment of the individual with ABI in an ecosystem that includes family and friends, clinicians and services, systems, funders, and policymakers. While putting together this model, I recalled a recent tour through a Tasmanian forest which was covered in a stunning layer of moss. Our tour guide told us there were 342 individual species of moss that covered the forest floor, and that those mosses enriched the soil underneath and bound it together. He told us that if the moss wasn't there, the whole forest could collapse. The notion of these small individual elements joining up to support the whole forest ecosystem struck me as a fitting metaphor for our systems of care and support for people with ABI.

Exploring the ecosystem of support using qualitative methodology

Qualitative research has a crucial role in uncovering the systemic factors that are at play in our work. In quantitative research, by choosing our measurement tools in advance, we are predetermining the range of possible findings. In qualitative interviews, we can listen to the voices of people with ABI and all the things that are affecting them. Systemic factors often come to the fore in these conversations.

This was certainly the case in a qualitative study where we interviewed 18 people with ABI about their experiences in lockdown during the pandemic (Wong, Sathanathan & Douglas, in preparation). These interviews were done just after the final set of lockdowns had ended. Using reflexive thematic analysis, we generated six themes from the interviews about lockdown experiences.

The first theme is that *Life with ABI is like lockdown*. Participants spoke about the fact that living with restriction and limitation was something that they had been doing for a long time, and during the pandemic they were able to share that experience with everybody else. This often helped them feel better understood. Another theme was about *Isolation and building community*. Being alone and isolated in lockdown shed light on the value of our community, and many formed new online or local

neighborhood communities to fill that gap. Another key theme was about *The inflexibility of systems to support individual needs*. One participant talked about the limitation that she faced because of her sensory sensitivities, whereby she would go for walks at night because she wasn't being blinded by the light. During the lockdowns that included an 8pm curfew, she was unable to go out on her walk, which significantly affected her health and wellbeing. The lack of flexibility in the system to tailor lockdown rules to individual needs had a significant negative effect on the vulnerable.

The importance of individual and systemic health and societal factors was also identified in another qualitative study examining the impact of health literacy on engagement with stroke information and services (Wong, Sanders, Beauchamp, Formby, Smith, McKinley, de Jongh, & Borschmann, in preparation). We interviewed 10 survivors of stroke, two of whom were Vietnamese-speaking and several of whom had cognitive and communication difficulties. We presented them with case vignettes that had been constructed from survey data from the same (but larger) cohort to reflect common profiles of health literacy and asked them to comment on each case's barriers and enablers to understanding, recalling and acting on information related to their stroke.

Five themes were generated. One was *Having a support network to rely on*, and the importance of this for personalising information to the individual, which was especially important for people from non-English-speaking backgrounds or who had communication difficulties. Another was *Feeling like I'm in safe hands*, which spoke to the importance of a trusting relationship with the clinician and the clinical team, which helps the person engage with the information being conveyed and feel comfortable to ask questions when they do not understand something. Another theme was *Systemic and societal context influencing individual stroke literacy*, whereby a lack of community awareness and stigma about what it means to have a stroke can inform individual expectations about stroke recovery.

These two qualitative studies both highlight the importance of understanding the social and systemic context that surrounds each individual with ABI. They also point to the need for integrating that understanding across all levels of the ecosystem of support, so the person with ABI has the skills and tools that will enable them to navigate their rehabilitation journey supported by family and friends, clinicians and services, and a system with suitable policies.

From problem to implementation in ABI rehabilitation research: Integrating individual, clinician and systems levels of understanding

Figure 2 shows the problem to implementation cycle in ABI rehabilitation research. Most of the research that I do fits somewhere in this cycle.

The cycle starts with identifying the problem. The key problem I seek to address, with many multidisciplinary collaborators, is the lack of access to evidence-based interventions for cognitive and emotional difficulties after ABI. To start addressing this problem, we might pilot cognitive and psychological interventions with feasibility studies and single-case experimental designs. If the findings are promising, we then expand up to a larger randomised controlled trial evaluating that cognitive or psychological intervention. As part of that step, we may also need to develop or adapt our existing outcome measures to ensure they are suitable for the population and the intervention target. These first few steps in the top row of the cycle are therefore intended to figure out what might work for the individual and their family – the centre circles in the ecosystem of support (see Fig. 1).

In the next step in the second row of the cycle, we often then need to identify the clinician competencies that are required for intervention delivery. This is especially important for cognitive and psychological interventions, because for the majority of these, it is the clinician who is the intervention delivery instrument. A competency framework is helpful for guiding clinicians to deliver interventions effectively. For new interventions, we might need to develop an appropriate competency framework, which would also serve as a measure of treatment fidelity. Using that framework, the next step is to identify methods for training competent clinicians. For most cognitive and psychological interventions, training involves observation and supervised practice.

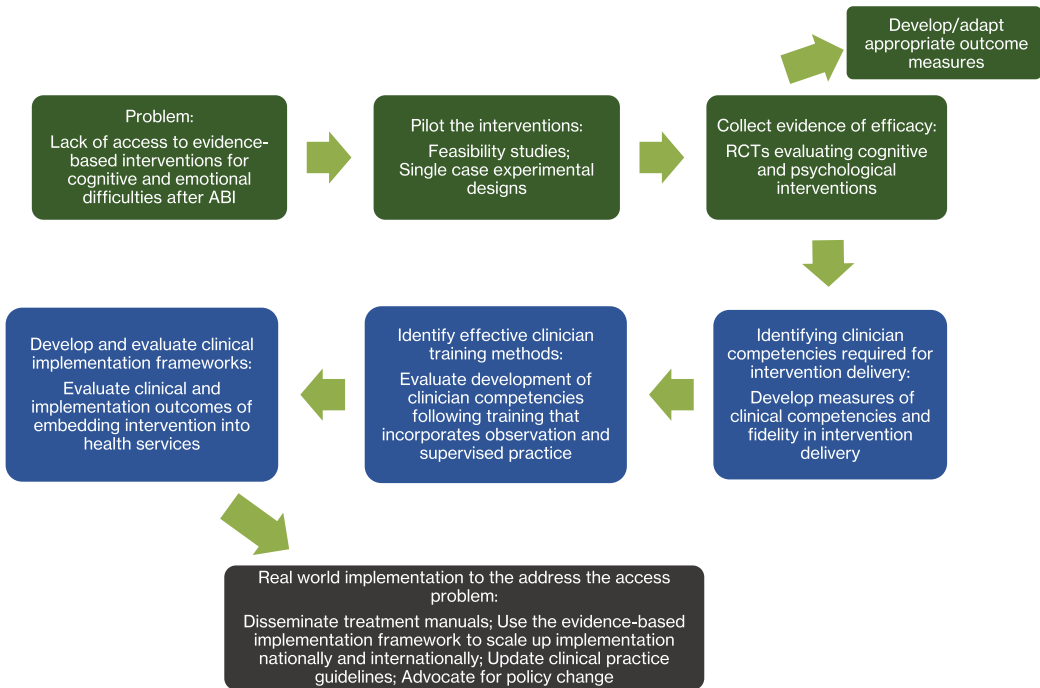


Figure 2. The problem to implementation cycle in ABI rehabilitation research. The top (green) row relate to individuals and families; the second (blue) row relates to clinicians and services; and the bottom (dark grey) row relates to systems.

These trained, competent clinicians can then implement the intervention into clinical services, guided by a suitable implementation framework. The success of the implementation would be evaluated using measures of both clinical effectiveness and service implementation. These few steps in the middle row of the cycle are therefore designed to ensure that clinicians and services are equipped to deliver the intervention – the middle layer in the ecosystem of support (see Fig. 1).

Finally, the bottom row of the cycle is about real-world implementation to address the access problem. This might involve disseminating treatment manuals, using the evidence-based implementation framework to scale up dissemination nationally and internationally, potentially updating clinical practice guidelines, and importantly, advocating for policy change. If the policy framework is such that it will not support the clinicians and services to deliver the evidence-based intervention with the available resources, then that is a significant barrier to implementation of evidence-based practice.

Because of the potential to face a final hurdle that prevents completion of the implementation cycle, when we embark on identifying the problem and formulating an intervention to address it, it helps to keep an eye on all the other steps of the cycle. If we develop an intervention that clinicians cannot deliver or that is not readily resourced within the health system in which it will be implemented, then the potential of the work to bring about widespread improvements in practice will be stymied. Planning for implementation from the beginning can be crucial for enabling successful implementation.

The problem to implementation cycle in action: the case of memory rehabilitation

I will now work through an example of the problem to implementation cycle in memory rehabilitation post-stroke. In this case, the key problem is that memory problems are very common and are linked with poorer outcomes (Stolwyk, Mihaljcic, Wong, Chapman & Rogers, 2021), but access to cognitive rehabilitation remains a great area of unmet need.

The memory skills program that has been the subject of our research is based on the Making the Most of Your Memory manual (<https://assbi.com.au/Making-the-Most-of-Your-Memory>), though it is adapted in several ways, mainly to ensure it is accessible and suitable for people with moderate to severe memory impairment. This group program incorporates education about memory and how it works, training in internal and external compensatory strategies, and lifestyle improvements to optimise memory function. Importantly, group interventions enable collaboration and joining up of thinking and experiences among people with ABI and clinicians. We first evaluated this program in a single-case experimental design (Withiel, Stolwyk, Ponsford, Cadilhac & Wong, 2020). We then scaled up to a randomised controlled trial, in which we found that the intervention resulted in significantly greater attainment of memory-specific goals than computerised brain training (Withiel et al., 2019). We also evaluated telehealth delivery of the program and found that it was at least as effective as in-person delivery (Lawson et al., 2020). So this evidence suggested it was an effective intervention for individuals affected by stroke and memory difficulties (reflecting the green top row of the cycle in Fig. 2).

As I was delivering the groups with student co-facilitators, I needed to guide them to develop competencies in facilitating groups. I searched for a competency framework for group facilitation and was unable to find one, so then developed the eNACT Group Facilitation Competency Checklist using the Delphi method of expert consensus (Wong, Grace, Baker & McMahon, 2019a). It includes four categories of competencies: i) *Facilitating focused group discussion*, or guiding the group to focus on the topics that are most important; ii) *Communication skills*, which are important for making the content accessible and relevant to the participants; iii) *Interpersonal style*, which should be warm and encouraging; and iv) *Session structure*, which incorporates enough breaks and signposts to ensure clear and well-paced content delivery.

Guided by the Knowledge to Action implementation framework and equipped with our competency checklist, we then implemented the memory skills group into two stroke services (Wong et al., 2021). Clinicians were trained to deliver the intervention through observation and supervised practice. First, they watched a full 6-week memory skills program and rated the facilitators on the competency checklist. They then delivered a group themselves and were rated using the competency checklist and a session content adherence checklist. Supportive feedback about their competencies was provided together with supervision as needed. This training approach resulted in competent clinicians who delivered a group with the same effectiveness as in the original trial, indicating successful implementation by clinicians and services (the blue middle row of the cycle in Fig. 2). We have subsequently followed this same implementation approach with five other health services across Victoria.

Based on this evidence, we were able to update the Stroke Foundation's Living Clinical Guidelines for Stroke Management for memory rehabilitation. Previously, they had included restorative memory training as a consensus-based recommendation. We changed that based on our trials to instead focus more on compensatory memory strategies. Embedding these recommendations in the guidelines is a key step in implementing the evidence into practice (as shown in the bottom dark grey row of the cycle in Fig. 2).

We have also been in conversation with a range of public health services and community-based private practices about partnering with us in trials focusing on how to sustain the benefits of the memory skills program over time. In discussions with those services about how we might design a hybrid implementation-effectiveness trial, several potential implementation barriers have arisen. For example, some public services identified that the time from admission to discharge is becoming increasingly short, for community and acute services. One of the services that we spoke to said that stroke patients being seen by the community rehabilitation team may be discharged from the service in less than six weeks. This means there may not be enough time to run the 6-week memory skills group program or any subsequent booster or maintenance interventions. This is concerning because the service structure (underpinned by funding pressures) does not allow delivery of an evidence-based memory rehabilitation intervention.

When we spoke to private practices, they indicated that it is difficult for them to run group interventions because the NDIS funding structure requires that the service splits the fee between participants. This means that if somebody does not attend a group session, the clinician does not receive their portion of the fee and the group program may therefore run at a loss. That poses a high risk for private practices and serves as an active disincentive to run groups, despite them being a potentially cost-effective method for service delivery. This may explain why the groups we have run at university clinics have been so popular. However, university clinics rely on university funding, which is inconsistent, and therefore not a sustainable service model. Again, the system of funding does not support the delivery of evidence-based practice.

Another systems-level issue is that we are facing major workforce shortages of clinicians to run these interventions. In my profession of clinical neuropsychology, three training programs have closed in the last 10 years. That is because of inadequate government funding of postgraduate psychology programs, which means that these programs make a loss, which is not sustainable for chronically underfunded universities (Wong, Davis-McCabe, Wrench, Lawrence & Burton, 2022a). This reduces the number of trained clinicians who are competent to deliver these interventions.

A final key issue to mention is that groups are not always accessible for people with access barriers relating to English not being a first language, transport, aphasia, or low technological proficiency (for a telehealth intervention). Group programs are not necessarily the best option for people facing these barriers. If we advocate for changes to the way groups are funded, we do not want the consequence to be that individuals with these different needs are neglected. This speaks to the need for flexible, tailored systems.

The problem to implementation cycle in action: the case of adapted psychological therapies

A similar problem to implementation cycle was followed for Cognitive Behaviour Therapy adapted for depression and anxiety following brain injury (CBT-ABI), a program of work that again has been done with a fantastic team of collaborators. In brief, a pilot trial (Hsieh et al., 2012) and then a larger definitive trial (Ponsford et al., 2016) were conducted, which established the efficacy of CBT-ABI for improving mood, anxiety and psychosocial functioning. We then evaluated methods for training competent clinicians to deliver CBT-ABI and found that a workshop that incorporated videos of CBT-ABI in practice (i.e., observation) and subsequent supervised practice improved confidence and competence (Wong et al., 2020). We also then surveyed workshop participants 16 months later and found that the barriers to implementing CBT-ABI in the workplace had changed. Prior to training, the key barriers were related to low clinician confidence and lack of training. At the 16-month follow-up, the barriers were related to clinicians not having enough time or delivery of psychological therapy not being part of their role – that is, systemic factors. It is relevant here that most of our participants were clinical neuropsychologists working in public health services, where their caseloads were predominantly focused on conducting assessments. That is at least partly because there are no Medicare rebates for neuropsychological assessments conducted in private practice, so the burden falls on the public system. That means that our already small workforce of neuropsychologists does not have the time to conduct interventions and is not adequately resourced to do so. This serves as another example of how systemic factors prevent the delivery of evidence-based psychological support for people with ABI.

We have attempted to implement CBT-ABI as widely as possible by running regular workshops and short courses and publishing a treatment manual (Wong et al., 2019b). I am also working with an excellent group of researchers, clinicians and people with lived experience of ABI to develop clinical guidelines for improving psychosocial functioning (including mental health) in adults with moderate to severe traumatic brain injury, which is being led by Dr Cynthia Honan. This

represents an opportunity to guide practice, to highlight gaps in evidence and service provision and advocate for systemic changes to enable the delivery of evidence-based practice.

I am also excited to be able to implement CBT-ABI into practice in a new young stroke service (<https://www.youngstrokeservice.org.au>), co-designed with another excellent team including researchers, clinicians and young adults with lived experience of stroke, led by Professors Julie Bernhardt and Vincent Thijs. The service is built around a digital platform and is designed to fill service gaps for young adult survivors of stroke, including neuropsychological assessment and intervention services. In our neuropsychology intervention hub, we are implementing the delivery of both the memory skills program and CBT-ABI. The service is funded by an MRFF grant, but the hope is that the service will be sustainable beyond the funding period. We are therefore collecting service evaluation data to take to policymakers and funders to support those advocacy efforts.

Thinking small and big: how to join up, collaborate and integrate

What are some ways we can connect, collaborate and join up our thinking to optimise outcomes for people with brain conditions? One way is to join communities of practice like BRAINSPaN (<https://www.assbi.com.au/BrainSPaN>). Our survey of BRAINSPaN participants (Wong, Steel, et al., 2022b) found that increasing interaction with others in the brain impairment field was one of their main goals for participation, and they reported having achieved that goal when we surveyed them again a few months later. These online communities of practice are easy to join and enable us to communicate quickly and efficiently to share knowledge.

Another way is to participate in conferences. ASSBI conferences, for example, are multidisciplinary and transdiagnostic, which means we can join up lots of different lines of thought together and learn from each other to enhance our own practice. We investigated whether conference participation could lead to changes in clinical and research practice using a survey of participants at a 2018 stroke conference (Wong et al., *in press*). Participants were 120 researchers, clinicians and doctoral students from seven different disciplines. The overwhelming majority of clinicians said that their clinical practice had changed as a result of attending a conference, and 62% said that their clinical practice had changed as a result of the stroke conference specifically. They provided numerous relevant examples of how their practice changed as a direct result of the conference presentations. The factors in the conference presentations that were considered important for influencing clinical practice included the strength of the evidence, the relevance to their clinical practice, and the likely benefit to their patients, but importantly, not the presenter status or profile or the discipline of the presenter. We also asked them about the types of information dissemination that impact clinical and research practice, and participants indicated that their clinical practice was most influenced by attending conferences. This was rated more highly than reading articles in peer-reviewed journals or reading textbooks and book chapters. This suggests that if researchers would like to influence clinical practice, presenting our work at conferences is one of the most effective ways to do that, despite conference presentations not being valued as highly as peer-reviewed journal articles in terms of academic track records.

In considering all this evidence, below I propose five ideas for how we might join up our thinking and integrate individual, clinician and systems levels of understanding to optimise outcomes for people living with ABI. Undoubtedly, a better list would be generated by asking everyone reading this what they think too and having a conversation about it, but hopefully these ideas can serve as a starting point.

1. Connect and collaborate: form links and bridges, join communities of practice, and keep going to conferences.
2. Work with diverse teams and listen with curiosity to others, including those with different perspectives and opinions and from different cultural contexts to our own.

3. Think small AND big – delve into small individual details and consider the bigger ecosystem surrounding the individual.
4. Consider not just the individual, the clinician, and the system, but how they interact and influence each other.
5. Advocate up, down, across and between, for change.

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