Inside and out — comparison of Queensland and Victorian systems of healthcare and support for persons with acquired brain injury

How many times have those with severe injuries looked to their health professionals and wondered if they truly knew what it was like to travel the system themselves?

Just over three years ago I took a position as a Senior Manager with a leading state based personal injury scheme in Victoria to improve the systems and processes for those with disability covered by that scheme. My daughter was an Occupational Therapist working with persons who sustained brain injury in Queensland.

My 20 year old son, a final year engineering student, had a car accident in Queensland just after I moved to Victoria. He acquired a major head injury and was hospitalised for eight months. The first five months were in public hospitals in Queensland and the latter three in a private hospital in Victoria. He also attended a transitional rehabilitation service in Victoria for a month. He then received rehabilitation services privately and publicly in Victoria and more recently in Queensland when he returned there.

My son has been accessing rehabilitation services for three years and is now at work gradually increasing his hours to full time. His story is one of courage, determination and miraculous recovery. I am so proud of him. He still has challenges ahead and his determination continues. He has written to you of his story.

This submission provides a perspective from the inside as a parent and from the outside looking in as a health professional and manager of health and insurance professionals. Our family's experience highlights the inadequacy of the current public health and support systems for persons with acquired brain injury (ABI) and their families, reveals serious inequity in essential service delivery between states and proposes the desirable features of a new scheme to address these issues.

Knowledge of healthcare

The majority of persons receiving services do not have knowledge of what services they need at different stages in recovery from brain injury or how to acquire them. Our experience revealed that once out of intensive care, medical, allied health and nursing expertise in brain injury was ad hoc. Specialised brain injury services were lacking and in these instances I had to speak to more senior staff or even write to regional directors or the Minister to access the services my son needed. In those early days it was all we could do to ensure my son had what he needed. We were aware that many others who did not have dedicated family or the knowledge of health systems were making do, believing they were receiving the best of care.

Service inadequacies in Queensland

Whilst in acute care at the Royal Brisbane Hospital the attention my son received from medical registrars, nurses and allied health staff was of a high standard. As he stabilised however there were few staff with knowledge of the recovery process for ABI in the specialised neurosurgical ward. Questions were reserved for the more experienced nurses and therapy staff who were able to confidently manage difficult questions about my son's slow recovery from coma and post traumatic amnesia (PTA). He was unable to walk, talk, respond to commands, eat and attend to basic functions for himself. We had to constantly remind nursing staff to put splints on his arms and monitor removal and replacement as advised by the therapy staff. He received botox injections for the spasticity in his right arm. One of the junior nurses attending thought this was for cosmetic reasons. Medical registrars and nursing staff did not know what PTA was. The commitment and dedication of staff was excellent. The problems were with a system that failed to equip them with basic induction knowledge for their role and reliance on agency nursing staff to fill shifts.

There were excellent facilities at the Royal Brisbane Hospital. Each time we went to the hydrotherapy pool and the gym I noticed that few patients were utilising the rehabilitation facilities. The physiotherapists had excellent skills but resources were for acute care as the Royal Brisbane Hospital does not focus on longer term rehabilitation.

Rehabilitation services

My son needed to be transferred to the Brain Injury Rehabilitation Unit (BIRU) at the Princess Alexandra Hospital for rehabilitation. We were told that this would be a waiting period of six to eight weeks. As health professionals we knew the importance of early intervention so wrote to the Minister about the long waiting period. We were advised by phone that there was nothing that could be done. My son started to improve and was able to transfer from bed to wheelchair so he was then accepted into the service a short while afterward.

The brain injury service in 2007 was 26 beds for all of Queensland, Northern Territory and northern NSW. There were two nurses on staff overnight. This meant that disoriented and unbalanced patients (common for ABI) could not be monitored appropriately. The expertise of the nursing staff was inconsistent. Some had excellent knowledge and experience whilst others were totally unskilled. Some relied on archaic and inappropriate nursing practices to manage disoriented persons with ABI and my son was almost given someone else's medication on one occasion if I had not intervened.

The BIRU was noisy making it difficult for patients to rest, a factor essential for persons in PTA.

The medical and allied health professionals were dedicated and skilled but there were days when my son did not receive therapy. This was because therapy resources were prioritised for new admissions. This is understandable but means that the rehabilitation services so essential for recovery were delayed and expensive hospital bed days were spent waiting for services. The therapy staff worked long hours and many are not paid for the hours they work trying to balance the heavy caseloads in under resourced units.

The impact of too few beds for rehabilitation in Queensland leads to the early discharge of persons with ABI to few outside services. Many families are on their own, negotiating services that are not

equipped for ABI and giving up long term employment to care for the person with ABI. This leads to further stress on the family and financial strain.

Infrequent outpatient appointments do not provide the assistance needed and persons outside Brisbane are disadvantaged. Many of the patients hospitalised with my son in Queensland received few or no rehabilitation services after discharge from BIRU other than outpatient appointments for a period ie even the Gold Coast has limited services for adolescents with ABI.

Brain Injury Rehabilitation in Victoria

The Epworth Hospital in Victoria runs a specialised ABI service. We organised for my son to be transferred there from BIRU in Queensland. The difference in service delivery was eye opening. My son received six hours a day intensive rehabilitation and made substantial improvement during his time there. The medical, allied health and nursing staff were equipped to support the rehabilitation program six days a week. The physiotherapy program included a running clinic. My son dreamt of leaving hospital and running with his dog. Imagine how wonderful it was for my son to learn to run again. As we had private health insurance hospital cover we were able to access this service.

The majority of the patients in the Epworth service were covered by the Transport Accident Commission in Victoria. This is a no fault personal injury scheme that funds medical and lifetime support services for persons injured in motor vehicle accidents in Victoria. A similar scheme exists in Tasmania. In recent years NSW has adopted a Lifetime Care and Support Scheme for persons with severe and profound injury as a consequence of a motor vehicle accident.

Schemes such as the TAC provide funding for the establishment of a private sector service that is responsive to the needs of persons with ABI. Without this additional funding the situation in Victoria would be very similar to Queensland.

In Queensland persons injured in motor vehicle accidents are able to claim costs at common law if there is a negligent or at fault party to sue. This can take over two years to settle. In the meantime the public health system bears the costs and often will bear future costs where the common law settlement is expended or is inadequate to meet lifetime support needs. A fairly basic improvement to alleviate the burden on the public health system in Queensland is to make changes for consistency of Motor Accident personal injury insurance schemes.

The Accident Compensation Scheme (ACC) in New Zealand is a universal scheme for acquired injuries and provides a

Post hospital cover

As private health insurance has limited cover for outpatient rehabilitation and my son required further rehabilitation we entered the public system in Victoria for funding of a transitional rehabilitation program. He was eventually accepted on the Disability Services Register (DSR) and then advised he was eligible for an Individual Support Package (ISP) but there was no funding available (in Feb 2008 – 4 months remaining in the financial year).

We had no access to support carers or supervision for access to our local area when my son returned home. He was unsafe on his own and I relied heavily on my family to stay with us and assist so that I could stay employed. By applying for assistance to a regional director in the Department of Human Services (DHS) funding was found for his admission to the transitional rehabilitation program. Most families would have accepted the letter of "no funding" and access to the right services should not be so difficult.

My son continued to use rehabilitation services at the Epworth and the local hospital when he was home. We had a great deal of assistance from an ISIS Case Manager. As I was able to keep working I was able to pay for services we could not otherwise access.

More recently he returned to Queensland where he is being assisted by the Commonwealth Rehabilitation Service (CRS) and an extremely helpful employer to return to work.

Proposed Disability Support Scheme

The current system for health and support services is disjointed and inequitable. Of paramount importance is the capacity to support families to stay gainfully employed, reducing the burden on social welfare systems and the strain on families to survive the years of recovery from ABI.

A National Scheme could assist to resolve the issues above. The key responsibility of the scheme would be to provide support services in the community for persons with profound and severe disability.

These comments are untested and subject to exploration by the Commission.

Governance and structure for a new scheme

Reserves will need to be collected and set aside to provide support services for current and future persons with disability. This could be achieved by collection of current premiums for workers' compensation, motor accident personal injury insurance, medical indemnity insurance, sporting injury insurance, other relevant insurances and a tax levy for victims of crime and other disabilities.

A level playing field for a suite of support services could be provided with additional top up funding through insurance agencies and personal health insurance. This will assist to start a scheme of the magnitude required and set clear expectations about what can and cannot be funded.

The new scheme could be a Disability Support Scheme regulated and funded by a Commonwealth Disability Commission that allocates funds to state based case management agencies and monitors performance of each agency. The Commission would have a state based presence. Accreditation as a Disability Support Scheme agency would be required as established by the Commission.

The Accident Compensation Scheme (ACC) in New Zealand is a universal scheme for acquired injuries and provides a model of governance and operations that could be adapted to meet Australian disability support needs.

This is a radical change to the way that workers' compensation, motor accident personal injury insurance, medical indemnity insurance and sporting injury insurance is currently managed in each state. However, for workers' compensation the numbers of claimants with profound and serious injury are minor. Transfer of these claims to a specialised Disability Support Scheme is not unrealistic.

Bodies like the TAC could lead the way by establishing state based agencies for case management.

A staged implementation that engages the current insurers and disability services for each state can be achieved, gleaning the positives from each system.

It is important that compensation based entitlements under common law are separate to the scheme. The Disability Support Scheme would not be an insurance scheme for negotiation of entitlements at law. It may be a palatable option to allow those currently covered by common law schemes to buy into the Disability Support Scheme and commence legislative change progressively for all new entrants to access the scheme.

Eligibility and separation from hospital based care

Responsibility for the new scheme should commence post hospital discharge or on assessment revealing active intervention is required. This does not prevent hospitals participating in community based rehabilitation funded by the new scheme.

Individual assessments can be undertaken by hospital and allied health service providers in the community who have satisfied the Disability Support Commission they are qualified to use the assessments nominated by the Commission.

Disputes regarding eligibility should be managed by a disability specific medical and allied health dispute resolution service. Progression to a legal adversarial system will erode capital from a Disability Support Scheme and distracts from the priority to focus on recovery and long term support.

An information service

The early stages of traumatic brain injury are a period when families are in shock and seeking information to navigate the services they need. A variety of information sources are needed. Having access to information about the different stages of ABI when recovery is slow is essential for families. New information about how to access services and what to do if services are delayed or unavailable following discharge from hospital is lacking. This information could be provided by funding community agencies to provide assistance. Such arrangements should be on a performance based contract that is subject to renewal only on satisfaction of performance measures.

Improved community based rehabilitation services

A review of existing service delivery and projection of needs in each local government geographical location for all persons with disability will assist to set targets for appropriate services and resourcing and timeframes for their achievement. The initial review outcomes and progress against targets can be monitored by a central agency in each state of Australia with overall reporting to a National Disability Commission.

Improved coordination of community services through general practitioner agencies

Discharge from hospital care to the community is not supported well. It is essential to move services from the medical based model for illness and high levels of care to a social rehabilitation model that supports recovery to home, community and work. Coordination of services through specialised General Practitioner agencies that qualify for having achieved expertise and standards in disability service delivery will increase the numbers of health practitioners who take interest is disability services and work with case management agencies in ensuring persons with disabilities have continuous support arrangements.

Medical, allied health, nursing education

Essential rehabilitation induction of all staff working in neurosurgical and neuro-rehabilitation units regarding the stages of recovery from ABI is required. Where possible, having persons with ABI and their families speak during undergraduate and post graduate training programs would assist to build a better awareness and a greater respect for patients and their families.

It is the practice of Qld Health to rotate allied health staff every 6 months. Development of specialised skills in traumatic injury takes longer than 6 months. Where individuals desire to specialise opportunities could be created. This is so at the Alfred Hospital in Victoria where some allied health therapists had over seven years experience in ABI.

Better access to quality support services in the Community

A greater investment in support services for persons with lifetime needs of personal at home support and care is overdue. Whilst our family does not require these services many families in Australia struggle alone. Remaining at work reduces the financial strain on families and also prevents the isolation and health issues experienced by family carers. By ensuring that professional support services are available and having set standards that limit the use of family as paid carers in their own homes the social and economic burden of able workers leaving employment to support their disabled family members can be reduced.

Increasing options for supported care can also be achieved by ensuring that disability accessible benchmarks are met in social housing and general construction of infrastructure. There are efficiencies in economies of scale for shared support that can be achieved with smart planning of accessible accommodation and facilities in the community. For a scheme to cover all persons with disability efficiency of resources is essential.

The attendant care industry is not subject to mandatory accreditation like most professional bodies. This is the subject of information additional to this submission.

Occupational Therapists in Victoria are soon to be subject to registration like Occupational Therapists in other states. This necessary to uphold service standards, particularly for independent services offered in the community.

Allied health professionals with disability specific skills

Medical practitioners and nurses have long been the subject of increased rates of pay and funding of student places to address projected demand. Allied health providers are essential to rehabilitation services have not received the same attention. Disability remains an underinvested area so only a limited number providers work in the area. Projections and the numbers of places for allied health providers should be reviewed and increased for future service demands. Disability specific education should be expanded to set standards in undergraduate and post graduate courses curriculum.

Additional training and utilisation of Therapy Aides who work under instruction from allied health therapists will assist to control the costs of care and reduce waiting periods for allied health treatment.

Set aside funding to establish specialised services in areas of high need

Partnerships with Health can be utilised to develop priorities for new services such as a brain injury rehabilitation service in North Queensland. Upfront investment in new services rather than indirect funding through individuals will assist to address unmet need. By tendering to private hospitals and service providers the capacity of the market to respond to disability specific needs can be increased over a few years.

Suggestions for Queensland

1. Increase beds and allied health resources at the Royal Brisbane Hospital to establish a rehabilitation service for severely and profoundly injured persons with ABI and other neurological conditions. The rehabilitation facilities are already in place.
2. Transfer the existing BIRU to a new location with facilities and updated nursing training appropriate for the management of head injuries. Training from professionals at Epworth Hospital in Victoria can be provided to the teams in Brisbane and other new centres.
3. Take immediate action to increase the numbers of hospital beds for ABI rehabilitation in Queensland and ensure staffing ratios are consistent for patient safety and care of individuals with ABI.

Further information

I am available to provide further information and clarification of any of the above areas of comment.