Submission to the Productivity Commission’s Disability Care and Support Inquiry by The James Macready-Bryan Foundation (‘JMB Foundation’)

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Section one

James' story

On 13 October 2006, we received the worst phone call that parents can get. 'Please come to the hospital – your son has been critically injured'. Immediately, when you get this phone call, numbness sets in and the body goes on to autopilot.

The news on arrival at the hospital was that our eldest son, James, out celebrating his twentieth birthday, had been severely assaulted in the streets of Melbourne's CBD. He had sustained brain damage, was unconscious and no one could tell whether he would wake up. Over the next day or so the full magnitude of his plight emerged as, first of all, we fought for his very survival and then had to absorb the reality that he was not going to recover. His brain had swollen extraordinarily from his injuries, resulting in severe hypoxic damage. James did wake up – eventually – but not into a world he knew. While today he sleeps and wakes, his existence is unimaginable. He has absolutely no control over his body. His sight has gone, along with his ability to speak. He is, today, totally dependent on others for all aspects of his life. He is fed through a tube into his stomach, experiences agonising muscular spasms regularly and cannot communicate at all.

The contrast in his life from where he is now to the time before his assault is staggering. James was a second year law student at Monash University, who played high level sport regularly. He was on the editorial committee for the Monash poetry anthology, loved his music and was planning the trip of a lifetime to South America with friends. A much liked young man, he had a sharp wit and a keen sense of humour – he was at the top of his game and looking forward to a promising future involving travel, work and fun. Today, nearly four years on, he exists in a twilight zone where, we think, he is aware of some of his surroundings, but has absolutely no way of involving himself in them. He has very limited inputs, but no outputs at all.

In the long hours spent waiting for news or developments, we speculated as to his future. What will it hold: where will he live, how are we going to pay for his care, who will look after him? These are fundamental questions asked by all families in this position. There were no simple answers. We were exposed to the maze of inter-related structures which make up our health and social support system. Despite having many contacts in this field, it took us months to get answers – and these answers were not the ones we had hoped for! We sympathised with other families who, with loved ones in similar positions to James, did not have these contacts, often struggled with English and found themselves lost.

What was needed, we were told by the medical people, was immediate intervention with a comprehensive rehabilitation programme. Severely brain damaged individuals have a window of rehabilitative opportunity which slowly closes over time. We had no idea what this meant at the time and even now, four years on, we fight for the basic human rights for our son.

In the weeks after James' hospitalisation, we found out that his health insurance was all but useless for his long term care. We discovered that because James had been hit by a fist, and not a car, he became a member of a truly sorry minority of Australians who have what is termed a 'non-compensable' injury. What sort of funding could we expect for him? Apart from a token from his Victims of Crime claim, and a fortnightly disability pension, James would receive nothing. His future care was to be in an aged care facility. He was destined to live the rest of his life, however long that might be, in institutions that focus on the palliative, rather than the rehabilitative aspects of life. Further research told us that, apart from one or two hard-to-get-into programmes, there was no money for therapy or the rehabilitation he so desperately needed.

We, with the help of many dear friends, formed a Foundation to help young people with an acquired brain injury. What we had learned about the fractured disability support structure our society offers told us that there was much that needed doing. We felt privileged, even in our desperate situation, in that we had met many families doing it even harder.

In the four years since that awful night in 2006, we have been thrilled to watch the growing community awareness of the issues affecting us. Our Foundation spawned a group of wonderful young people called Step Back Think who have embraced the challenge to make their peer group more conscious of the potential consequences of risk-taking behaviour, particularly where it involves alcohol-related violence. We have spoken in schools about this issue extensively, we have lobbied both State and Federal parliamentarians about the need for radical change in the disability sector and we have raised money to help families who find themselves struggling to deal with the consequences of ABI.

For us, the introduction of a National Disability Insurance Scheme (NDIS) would mean the opportunity to have long term control over James' rehabilitation. It would take away the worry we feel for James' long term security and for that of so many young Australians in similar circumstances.

James today has been granted a place as a resident in a brand new, very high care facility, specialising in young ABI sufferers. He is one of seven current residents in this ten-bed establishment, but one of thousands of people needing such accommodation and support. We have often asked ourselves why it was that we had to form a Foundation. Just looking at the numbers above tells very clearly that there is still a long way to go.

Section two

The Importance of a Social Insurance Approach to Disability Funding

Introduction

Too many Australians with a disability, their families and carers struggle to achieve a basic quality of life. Without adequate support and resources, many find themselves unable to participate meaningfully in the economic, social, cultural and political life of the nation. While Australia prides itself on being the land of the “fair go” this has not been extended to people with a disability, who find themselves excluded, marginalised and forgotten. This is no longer acceptable. It is time to introduce a disability support system that meets the needs of Australians with a disability, their families and carers in the 21st century and beyond.

Australia ratified the United Nations Convention on the Rights of Persons with Disabilities in 2008. While an historic and significant moment, ratification is simply a first step on a long journey to ensure the rights enshrined in the convention are not only protected but, more importantly, able to be fully realised. While it is clearly not the only factor to be considered, it is important to acknowledge that rights can remain elusive if adequate resources are not provided.

Our vision is an Australian society that ensures the full and equal social, economic, cultural and political participation of people with a disability, their families and carers. The Commission’s concise summary of the goal of any new scheme is therefore a good one – “to enhance the quality of life and increase the economic and social participation of people with a disability and their families” (p9).

It is also important to note that resources are important but not sufficient. Any long term care and support scheme should sit within the National Disability Strategy currently being drafted by the Council on Australian Government. The role of the strategy is to address other systemic changes that must be made before people with a disability, their families and carers are able to enjoy the same rights as other members of the community. This includes a strong independent advocacy movement to make the case for systemic and structural change.

The Commission’s detailed issues paper gives some indication of the depth and breadth of questions that must be answered before a new scheme can be developed and implemented. But equally important to dealing with the detailed questions of design and implementation is establishing the principles which should underpin the scheme. If the foundations are not adequate the scheme will ultimately fail to deliver the kinds of reforms people with a disability, their families and carers and the organisations that support them have long been seeking. We believe the principles of equity, entitlement, self determination, efficiency and sustainability should determine the development and implementation.

Guiding Principles

Commitment to the realisation of the rights enshrined in the UN Convention on the Rights of Persons with Disabilities.
The intent of any disability support scheme should be to ensure people with a disability receive the support they require to be active, engaged, productive and participating members of the community. The scheme should be a mechanism by which people should be able to exercise the full range of their rights as outlined by the UN Convention.

Equity
The system should be fair. All people with a disability should be entitled to the support they require to be full and equal participants in the economy and the community, regardless of how they acquire their disability. People born with a disability or who acquire a disability through accident, illness or progressive medical condition should all be eligible for assistance. The scheme should also provide support to those with a psycho-social disability (mental illness). The scheme should be no fault and should provide support for people who have a permanent disability which has a significant impact on their daily life. Support should not be restricted to people with a severe or profound disability but people with a more moderate disability should also be eligible for assistance.

In other nations around the world there is a legislated entitlement to support. No such right exists in Australia. People with a disability, their families and carers should be entitled to the support they need to be active engaged members of the community. Eligible individuals should be entitled to the support they require based on a simple and transparent assessment of their needs. As needs and circumstances change so too should the support provided. Any assessment process therefore needs to be flexible and responsive to changes over the lifecourse. The scheme should ensure national consistency in eligibility and access.

Families and carers should also be entitled to the support they require to continue to sustain their role in supporting their family member with a disability.

The scheme should not only establish equity between all types of disability but between people with a disability and the rest of the community. In short, the scheme should recognise the additional costs of living with a disability. One of the ways to address the inequity between people with a disability and those without is through the provision of adequate services and support. This should always be a separate consideration to the provision of income support.

It is also important to remember that the provision of adequate support and services should not reduce the obligation on communities and government to become more accessible and inclusive. The onus should not be on the individual to use their entitlements to address inaccessibility and exclusion. We believe the insurance scheme would in fact have a strong interest in addressing structural and systemic issues such as inaccessible public transport because it would have a long term interest in reducing costs. In this way the interests of the scheme and the interests of the individual would be aligned.

Finally the principle of equity should extend to the funding of the scheme. The cost of supporting people with a disability should be borne by the broader community – the determining principle should be that as disability is something facing everyone in the community, the whole community should share the cost of support. As the Commission rightly points out in its issues paper, social insurance is therefore the most appropriate approach as private insurance would function neither "efficiently or equitably".

Self Determination

The scheme should institutionalise mechanisms to ensure people with a disability, their families and carers are able to exercise choice and control. The scheme should be person centred and individualised, based on the choices of the person with a disability, their family and carers. The services and supports able to be purchased through such a scheme should be broad and diverse, determined by the individual needs and circumstances of those assessed as eligible.

There is strong evidence from around the world, including Australia, which demonstrates the positive impact of self determination and control on health and wellbeing. The scheme should create a culture of independence rather than foster continuing dependence. It should create and support a marketplace for services and supports which will drive innovation and efficiency, improving value for money.

The scheme should also recognise that the introduction of choice and control requires an investment in information, resources and advocacy to ensure people with a disability, their families and carers are provided with the tools they require to make informed choices. The scheme should recognise that some individuals will require greater support to plan and exercise choice than others.

Efficiency and Effectiveness

The scheme should redirect attention from short term costs to long term outcomes, identifying and developing those services and supports which maximise independence, productivity and participation. In this way services and supports should be reframed as investment rather than charitable handouts. In this way too the interests of the individual and the interests of the scheme are aligned - both have the goal of ensuring every individual has every opportunity to reach their full potential. While such a scheme would obviously be interested in reducing long term costs, individuals are most interested in identifying and using those services and supports which maximise their independence and participation. This is most obviously seen in investment in early intervention, but is also seen in other services and supports such as home modifications or the provision of timely and appropriate aids and equipment, including communications devices.

In maximising efficiency and effectiveness, the scheme should also establish national standards and ensure portability across jurisdictions. The scheme should also provide an entitlement to services over time rather than a lump sum payment from which individual should pay for the services they require (although larger sums may sometimes be necessary for the purchase of equipment). In this way the scheme would automatically balance the risks that some people will live longer than expected and others shorter, while some will have more severe disabilities than expected, while for others the impact of their disability may be less than anticipated.

Another important aspect of an efficient system is data collection, research, identification of best practice, support for innovation and benchmarking. All of these are currently not in evidence and should be features of the new system.

Sustainability

Sustainability should be achieved on four levels. Individuals should be sustained over the lifecourse. They require certainty in order to plan meaningfully for the future. They need certainty that should their needs and circumstances change, the system will respond appropriately. Families and carers too should be sustained and nurtured in their caring role, equipped with the tools and resources they require to appropriately support their family member with a disability.

And finally the system should be sustainable. Any new scheme must be affordable over the economic cycle and take account of demographic and social trends. The number of people with a disability is increasing and the number of people willing and able to provide unpaid care is decreasing. Any new scheme must ensure the needs of all are able to be met both now and in the future. The scheme must account for both the social and economic needs of the nation and ensure they can be met in a fiscally responsible manner.

Conclusion – The Importance of Insurance

Simply tinkering with existing system will not deliver these outcomes. The current system is fundamentally flawed and far beyond minor reform. It may be possible to design a system that delivers some of these principles. But we believe all of these principles are best achieved by a social insurance approach. That is why we support a National Disability Insurance Scheme.

The scheme is not beyond the nation's capacity to deliver. While there may be additional funding required in the short term, in the long run we believe the scheme will not only deliver better outcomes but also savings over time. In working to ensure people with a disability, their families and carers receive the support they require to be productive, participating members of the community, the interests of individuals, the interests of the scheme and the interests of the nation are all aligned.

People with a disability their families and carers have waited many years for change. And there have been reforms introduced which have made a difference to their lives. But their effectiveness has been limited by their location within a fundamentally flawed system. The time for piecemeal reform is over. The time for a transformation change has come – the time for a National Disability Insurance Scheme has come.

Section three

Why we need a National Disability Insurance Scheme – JMB Foundation perspective

The JMB Foundation works with some of the community's most vulnerable individuals and their families. These are young people who, through catastrophic injury, have acquired a severe and permanent brain injury that has left them needing high level care 24 hours a day, seven days a week. What are the issues they face that could be helped by the introduction of the proposed NDIS?

Inequity

As these young people have not been injured in a car or at work, under current Victorian legislation they are deemed to be 'non-compensable', even where their injury is a result of criminal assault. The legal focus is not on their injury and its consequences, but on how that injury was acquired. They are subject to gross inequity as a result.

In Victoria, a TAC-covered brain injury victim has an as-of-right claim to payment for all treatment and accommodation, but the young people we see with identical needs become low income disability pensioners whose families have to fight to get them the necessary care and support. In a country that prides itself on a fair go for all, how is this acceptable?

Do we honestly believe that some victims are more deserving or more entitled than others? For that is what the current system says. Surely the time has come for a federal scheme in which those with the same needs can expect to be treated in the same way.

Age-appropriate accommodation

Virtually all brain-injured young Australians in need of 24 hour care who cannot live at home face the prospect of life in residential aged care. For these young men and women, for whom intensive therapy and rehabilitation is vital, this is a disaster. There are currently more than 6,700 Australians under 50 occupying places in residential aged care – taking up more than 6,700 places which are then not available for the people for whom they were designed.

Yet state authorities are reluctant to build high care facilities specifically for young people because they say there is no need! These facilities are also expensive to run, and could be seen as a disproportionate drain on limited service resources. Additional funding made available through the proposed NDIS would be vital in helping to address this need.

The Issues Paper makes mention of 'inappropriate models of support' as one of problems facing the disability sector, and one of the most significant 'inappropriate models of support' is the placement of young people in residential aged care. The availability of appropriate accommodation options is a central plank of the Commonwealth and Victorian state governments' 'My Future My Choice' initiative, and the introduction of the NDIS could help to consolidate achievement of this goal.

System inefficiencies

Families trying to cope with the aftermath of a 'non-compensable' catastrophic brain injury face a labyrinth of Byzantine proportions. Disability services is a state responsibility area, while aged care is a federal responsibility — where does that leave the family looking for a residential place for their now-disabled 20 year old?

There are schemes for continence aids, visual aids, hearing aids, housing assistance, enteral feeding support, prescription payment assistance, therapy payment assistance, therapy equipment, general funding assistance, all of which require a separate application and assessment. Schemes are funded by different bodies, and applications have to be made through different offices and different workers.

For families already reeling from the grief and distress of their young person's injury, the load is unbearable.

A more streamlined system must be developed – and the introduction of a nationally-funded, universally-applied insurance scheme would, by its very nature, help bring about this process.

An important part of an NDIS would be the allocation of a case manager to each injured person as soon as possible – and certainly by the time they move out of the intensive medical phase of their treatment. Families need an experienced and caring professional to walk with them through the service access process and they need that person quickly. Training of additional case managers as necessary should be seen as part of the NDIS development process.

Conclusion

With consideration of how best to develop a National Disability Insurance Scheme we have a wonderful opportunity to redress some grave wrongs. The James Macready-Bryan Foundation gives the strongest possible support to the development and introduction of such a scheme.