Submission to the Productivity Commission’s Disability Care and Support Inquiry

Dear Sir,

I would like to extend my support for the concept of an insurance based national disability scheme as the most effective and productive way to fix the current approach to supporting those who are disabled.

I have a 12 year old daughter who was born with a congenital brain injury. My husband and I have worked extremely hard to give her the best chance in life. Despite all our efforts she will never be independent and we worry about her future especially after we are no longer able to care for her due to our age.

Whilst we dearly love our daughter, her disability has cost us greatly, not just financially, but also emotionally and socially. Our lives are very different to a normal family and most people would not know how much we have given up because our daughter was born this way. Some days I feel it is just not fair. We have managed to keep our marriage together, but that has been tough, given the strain and constraints that comes with being full time carers.

I find it remarkable that if some one is injured at work (or somewhere where public liability is in place) and becomes permanently disabled they are covered by insurance and will receive hundreds of thousands, or possibly millions of dollars to support them for all their medical treatment and living expenses because of their lack of ability to earn an income. However those who are unfortunate enough to be born disabled, through no fault of their own, are left basically with only the support that their parents can afford until they are old enough to receive a moderate pension.

The current disability system is a like a rabbit warren, little pockets of funding here and there. It is a case of who you know and what strings they can pull. There is little or no strategic planning. The system is dominated by what you need right now and there little or no consideration of the future. Also if your needs don’t match the current medical template then there is NO support. This is extremely frustrating for parents who have educated themselves and searched further a field to find innovative new approaches. The Australian medical field is light years behind in its approaches to common disabilities such as cerebral palsy.

But just as importantly, we are as a nation, so far behind in our concept of caring and supporting the disabled. Countries such as Canada and the UK have community based supported living programs for disabled youth as they approach their adult years. These types of programmes put to shame Australia’s current situation of many disabled adults still being cared for by elderly (pensioner aged) parents or alternatively disabled adolescents being dumped into old aged homes.

There needs to be comprehensive, flexible strategic planning to assist carers with their responsibilities through out the life of the disabled person they are caring for.

In the current system the needs of the carer are often overlooked. In most cases our lives have been dramatically impacted through no choice of our own, it is not only the disabled person’s life style and choices that have been limited but also our own. Recently a local community group sent me and 3 other carers to a day spa resort for 4 days. It was totally wonderful, and the first real rest that I had had in 12 years. It was a beautiful gift and I finally had some time for myself and felt appreciated.

I have attached some information from the National Disability and Carer Alliance which I believe outlines the need to completely re structure the entire disabilities sector and gives some of the key points that need to be addressed. Twelve years on, I am tired of having to fight for every bit of help. Not only is it exhausting but it is also degrading. I am fed up spending my precious spare time filling out a multitude of forms with the same questions for multiple agencies, support groups and the like. There is no co-ordination between various entities nor any sense of administration of the entire system. Some thing has to change … the current system is not adequate, is not sustainable and does not work.

Regards,

Vicky Mackey

National Disability and Carer Alliance

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).

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 of Australian Governments. The role of the strategy is to address the systemic changes that must be made so that people with a disability, their families and carers are able to enjoy the same rights as other members of the community. This includes making provision for a strong independent advocacy movement.

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, 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 life course. 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 continuing 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 need 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 will become 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. A sustainable system must also address such issues as capacity, workforce development, infrastructure, research and innovation etc. It must ensure supports and services are available through a diverse range of organisations, which must be viable and sustainable.

And finally the entire system itself 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.

Material prepared by the National Disability and Carer Alliance
www.disabilitycareralliance.org.au