

## **The Importance of a Social Insurance Approach to Disability Funding**

### ***Submission to the Productivity Commission's Disability Care and Support Inquiry***

#### **Introduction**

In addition to working full time and raising our two other children, my wife and I have cared for our severely disabled daughter for the last 28 years. We feel well qualified and justified in stating our full support and agreement with the National Disability and Carer Alliance's submission promoting the incorporation the principles of equity, self determination, efficiency and sustainability into the much needed Social Insurance Scheme (shown below in *italics*). We totally agree with the Alliance's submission in that the following points should be the founding principles upon which the desperately need "Social Insurance Approach to Disability Funding" is constructed.

#### ***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 recognize 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 institutionalize mechanisms to ensure people with a disability, their families and carers are able to exercise choice and control. The scheme should be person centered and individualized, 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 recognize 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 recognize 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 maximize 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 maximize 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 maximizing 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 lifecycle. 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 organizations, 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**

Year after year, we are continually reminded of the devastating effect that the current disability support system has on families such as ours. Most marriages fail, elderly parents go to their graves worrying about the ongoing welfare of their disabled child. We see these carers, the walking wounded, struggling to maintain their own health while they provide endless hours of care for their loved ones.

In Australia, improved medical care is thankfully promoting the health of the disabled. Often, children with severe disabilities can now expect to out live their parents. An appropriate ongoing system is needed to care for the disabled long after their initial carers have passed away. Where ever possible the family should be provided with all necessary assistance to provide the ongoing care for their disabled loved ones. However where the family is unable to care every disabled person deserves a secure, nurturing environment provided by the government.

Where medical negligence is involved, in recent years and months the NSW State Government and the Judiciary have almost obliterated any possibility of gaining financial compensation for injuries resulting in a disability. The NSW government has passed legislation that severely limits compensation payouts for those made disabled in most cases. Also the courts have made rulings relating to “loss of a chance” that effectively prevent most plaintiffs from seeking financial compensation. As a result the family and to a lesser extent the community are left to fund the care for the disabled. This in its self is a totally unacceptable and unsustainable situation. A Social Insurance approach to disability funding will alleviate to some extent this unjust situation that has developed in NSW.

Enough is enough, please seize this opportunity to deliver a just, well funded system of care for the disabled members of our society.

*Simply tinkering with existing system will not deliver the required 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.*

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15<sup>th</sup> August 2010