National Disability and Carer Alliance

www.disabilitycareralliance.org.au

The Importance of a Social Insurance Approach to Disability Funding

Submission to the Productivity Commission
Disability Care and Support Inquiry

National Disability and Carer Alliance
August 2010

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 while resources are significant, they are 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 and the proposed National Carers Strategy. The role of these strategies 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 of any national long term care and support scheme.

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

Equity between people with a disability

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). Acute care should however remain the responsibility of the health system – the national long term care and support scheme should be responsible for the provision of support to assist with day-to-day needs in the same way as other people with a disability. Support should also be flexible and responsive to the sometimes episodic nature of the disability.

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 individuals 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 of the person with a disability, their family or carer. The scheme should ensure national consistency in eligibility and access. An entitlement based system will also allow people to have the confidence to cease to utilise support when it is no longer required. At the moment the system is so crisis driven that there is a perverse incentive to remain a service user even when there is no longer a need or the need has changed. Having been lucky enough to win the lottery and obtain support, however inappropriate, many individuals and families are reluctant to make any changes in case support ceases altogether.

Once eligibility has been established, the assessment process should focus on functional needs. The assessment process should be comprehensive but not dominated by medical classifications or diagnosis but rather on the assistance required in daily living tasks. The assessment process should take a broad view of an individual and take account of the social, economic and environmental circumstances in which they find themselves. The assessment process must also take into account the needs of families and carers. The assessment process must not be dominated by medial notions of functionality but be nuanced enough to capture the sometimes more subtle, less obvious supports required to establish and maintain independence. This is particularly true for people with an intellectual disability who may require less assistance with daily physical care tasks but require significant support to maintain their independence. The assessment process must straddle the fine line between simplicity and ease of use and ensuring a comprehensive picture of individual need and circumstance is established

In order to achieve equity between people with disability the scheme will also need to account for regional differences. The scheme must make provision for the difficulties in obtaining services and supports in regional and remote locations. People with a disability and their families should not have to bear the additional cost of ensuring services and supports are available in their location. These regional differences should be taken into account when assessing need.

We recognise that it will sometimes be difficult to balance equity with the need for responsiveness to individual circumstances. But there are tools out there that have been shown to be both nuanced and robust. The tool utilised should be the subject of further study before the scheme is implemented.

The need for equity also demands that there should not be significant differences in supports available and outcomes achieved between people who acquire their disability before the age of 65 and those who acquire their disability later in life. In order for this to be true, there must be better linkages and coordination between all systems, but most notably between the disability and aged care system. Cooperative arrangements focused on the needs of people with a disability need to be fostered across sector boundaries. The Alliance is therefore pleased that the Productivity Commission is conducting an inquiry into aged care at the same time as this inquiry, and expects the two reports to share much common ground.

Families and carers should also be entitled to the support they require to continue to fulfil their role in supporting their family member with a disability. The intent of the scheme should not be to replace informal care with paid care. Many families supporting a member with a disability wish to remain actively engaged in the life of their family member. They do not wish to relinquish responsibilities – what they desire is choice. They want to the ability to choose what support and care is provided based on the needs of the family member with a disability, their own needs and the circumstances of the entire family. It is the lack of choice and the assumption that families will continue to provide the level of unpaid care they now provide indefinitely which most angers families and carers. The assessment process must take account of the needs of the entire family and their choices regarding the type and level of unpaid informal care. Families and carers will also need support in their own right, including access to information, alternative care services, counselling, respite, education, advocacy and training.

Equity between people with a disability and the rest of the community
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. The onus should be on systems, policies and programs to better meet the needs of a diverse community, including people with a disability, their families and carers.

The Alliance is concerned that the provision of individualised packages of support may lead to pressure being placed to bear on individuals and families to use that support to facilitate inclusion. The most obvious example is education. The education system is currently failing to meet the needs of many children and young adults with a disability. A lack of teacher training and professional development and a lack of adequate resources and support means the education needs of many children with a disability are not being adequately met. The onus should not however be on families to use their support package to address these failings. While the package may be used to supplement support available in the existing system – provide additional speech or occupational therapy for example - it should not replace a basic entitlement to educational support. It is the responsibility of the broader education system to ensure teachers are adequately prepared to meet the educational and learning needs of all children in their classroom and that both schools and teachers are provided with the resources and support they require to meet the additional needs of children with a disability in their schools and classrooms. It should not be the responsibility of the National Disability Insurance Scheme to make up for the failings of the broader educational system.

Housing is another example where the NDIS should not be responsible for addressing the inadequacies of broader systems. The Alliance believes both state and federal governments should develop and fund a greater range of housing options for people with a disability, their families and carers. This includes the provision of accessible social housing as well as purpose-built housing that conforms with the UNCRPD. The capital costs of developing and implementing these options should remain the responsibility of all levels of government and not for profit agencies. Where the NDIS could play a role is in funding new and innovative models to explore their viability and effectiveness. This could be drawn from a pool of funds established for innovation and research, rather than from the core pool of funds. The role of the insurance scheme should be to provide on going day-to-day support rather than the capital costs of housing provision.

The continuing need for systemic and structural reform is yet another reason why the Alliance is a strong supporter of a social insurance approach. The Alliance believes the insurance scheme will in fact have a strong interest in addressing structural and systemic issues such as inaccessible public transport and inadequate educational support because it would have an interest in reducing costs in the long term. In this way the interests of the scheme, the interests of the individual and the interests of the nation would be aligned. The insurance scheme could become a powerful ally in pursuing and supporting calls for systemic change that would have a profound effect on the lives of people with a disability, their families and carers.

Equity in funding

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 potentially 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". Whether funded through a Medicare style levy, an extension of the levy or through general taxation the Alliance does not have a firm view – there are advantages and disadvantages to each approach. What is essential however is the quarantining and pooling of funds. Both individuals and the system require certainty – something which is sadly lacking in the current system. In order for the scheme to plan effectively and for individuals to plan effectively, certainty is essential. The funds must be quarantined to ensure the current system does not continue – each year is a moveable feast in negotiation over need. The scheme must be quarantined to ensure variability in economic circumstance or political will do not erode its ability to provide certainty.

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. 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. The goal is the empowerment of people with a disability, their families and carers. Self determination will allow people to make choices that better reflect their cultural diversity, their indigenous background, their gender. It will, in short, allow people to make choices that best reflects their individual and family needs.

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. This includes purchasing supports and services from mainstream providers, rather than disability specialists only. The scheme should create and support a marketplace for services and supports which will drive innovation and efficiency, improving value for money. The Alliance recognises that, particularly in the initial stages, the marketplace will work imperfectly. This may be particularly true in regional and remote areas. It may also be true of universal service providers who have not traditionally met the needs of people with a disability and their families particularly well. Further consideration must be given to the role of for profit companies in a sector that has been dominated by government and not-for-profit providers. While some of these issues may be resolved over time as the marketplace develops and matures, other issues such as the need to provide and/or maintain service provision in regional and remote areas may always require additional intervention.

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. The additional cost in supporting people to make choices should not detract from the amount of support to be made available – it should be regarded as a separate cost borne by the scheme itself. The scheme should provide a range of choices to individuals – from complete self management to a brokerage system in which individuals would be responsible for planning but not direct purchasing. The emphasis should be on flexibility and choice. One of the strongest criticisms of the current system is its one-size-fits-all approach – the emphasis in the new system should be the development of a range of models that allow individuals and families to chose the planning and purchasing model which bests suits them and their circumstances.

The Alliance recognises that the move towards self directed and individualised funding is a quantum shift from current arrangements. Even in a state such as Victoria which has made some progress in moving toward self directed funding, the scope and scale of the change will throw up many challenges. There are many operational issues that will need to be addressed before the scheme can be fully implemented - such as ensuring the system has the ability to respond to changed individual circumstances quickly and effectively. Historically, the provision of block funding has ensured organisations have some capacity to respond quickly to changed individual circumstances or emergencies such as illness. Block funding has also enabled the coverage of costs not able to be recovered through individualised packages. These issues will need to be addressed. The transitional issues for the sector should be reflected in the time frame for implementation and the means of implementation.

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 and mobility devices. It is also true of employment support.

One glaring failure of the current system is its inability to adequately support people with a disability, their families and carers who have the capacity and desire for work. The lost productivity and potential and resultant dependence on income support represents a significant cost to the economy and the community. This is to say nothing of the health and wellbeing benefits to the individual of meaningful employment. A particular focus of the new scheme should therefore be adequate training and job support. There are of course many other barriers to employment for people with a disability, including inaccessible infrastructure and negative community attitudes. But adequate system support represents an important step in removing barriers to employment for people with a disability.

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 individuals 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. The Commission has found during its inquiry that there is very little evidence of what works and why beyond limited evaluations of individual projects. While there are examples of good practice and innovative solutions there is no means or mechanism for dissemination or reproduction. The importance of research and its dissemination to an efficient and effective system cannot be overstated, and the Alliance would expect commitment to research would be part of any new model.

The scheme must recognise that there are many measures of effectiveness, and that financial accountability is but one form of accountability. There is a need to establish a quality framework for services and supports which reflects not only fiscal effectiveness but responsiveness to clients. Measured outcomes should reflect the aims and goals of individuals with a disability and their families. The scheme will therefore also require an effective robust complaint mechanism if services and supports do not meet standards or do not achieve negotiated outcomes. In a market place one means of complaint is discontinuing the purchase of a service or support. But there also needs to be a robust complaint mechanism to ensure quality of service and to ensure services remain responsive to clients needs and demands.

Sustainability

Individuals and families should be sustained

Sustainability should be achieved on four levels. Individuals should be sustained over their 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 supported in their caring role, enabled to make choices and equipped with the tools and resources they require to appropriately support their family member with a disability. The provision of adequate services and supports also raises the possibility of further private provision. At the moment many individuals and families use whatever additional private capacity they possess to simply meet basic needs. There is therefore only limited possibility of planning and providing for the future. With the assurance that basic needs for support will be met, there is possibility that some individuals and families will have the capacity to make private provision for individual needs, particularly in planning and saving for future needs. One of the significant advantages of a social insurance approach would be the freeing up of private capacity.

The system should be sustainable

A sustainable system must also address such issues as capacity, workforce development, infrastructure, research and innovation. Workforce development issues are particularly pressing. Although there has been some attention in recent times to the development and training of personal support workers, the issues are far broader. The early evidence from the implementation of the Commonwealth Helping Children with Autism package for example is particularly salient. While parents appreciated the flexibility in being able to chose which services and supports to purchase, some have commented that a lack of services and therapists in their area prevented their children receiving the necessary support. This has been particularly pressing in remote and regional areas. Workforce development issues will cover not just personal care workers but a range of allied health professionals such as occupational therapists, speech therapists, physiotherapists, Auslan interpreters as well as the development of a range of support workers who may be required to assist individuals and families with planning and purchasing. An increase in demand will only exacerbate already long waiting lists in some areas.

It must ensure supports and services are available through a diverse range of organisations, which must be viable and sustainable. The funding model must not only address transitional issues but also the operating costs of organisations that cannot be recovered through individualised packages. Funding levels must reflect actual costs of service delivery.

There has been considerable attention in recent years to the need to reduce the bureaucratic red tape and associated compliance costs on not-for-profit organisations. While it is important that organisations that receive government funding are accountable, excessive red tape and compliance costs adversely affect the viability and effectiveness of many organisations. Any new scheme must address these issues and recognise that organisations are accountable not only to government, but also to clients, families and the communities that they serve.

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 the 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 transformational change has come – the time for a National Disability Insurance Scheme has come.

Appendix One

About the National Disability and Carer Alliance

The National Disability and Carer Alliance brings together people with a disability, service providers and carer organisations to work cooperatively to change the lives of Australians with disabilities and those who care for them.

The founders of the Alliance are the Australian Federation of Disability Organisations, National Disability Services and Carers Australia. The Alliance has come together to pursue the structural and systemic changes necessary to improve the lives of people with a disability, their families and carers.

Our Vision and Mission

Our vision is an Australian society that ensures the equal social, economic, civic and cultural participation of people with disabilities, their families and carers.

Our mission is to:

- Develop and promote policy and programs that provide timely and dignified support for people with disabilities, their families and carers.

- Develop and promote policy and programs for people with disabilities, their families and carers based on the principles of entitlement, individualised responses, self determination, portability and cultural sensitivity.

- Support the implementation of the United Nations Convention on the Rights of Persons with Disabilities throughout all Australian jurisdictions.

- Build broad community support for the full inclusion of people with disabilities their families and carers in all their diversity.