



## **DISABILITY CARE AND SUPPORT: Response to the Productivity Commission's Draft Report. April 2011**

Sharing Places Inc. welcomes the Productivity Commission's Draft Report on Disability Care and Support. Sharing Places Inc is a not for profit disability service in the ACT which provides community access and social participation services to people with disability who have very high support needs. The service, through these activities, assists the participants to develop and maintain functional life skills.

Importantly, the draft report concurs with four key national reports over the last four years that underline the case for fundamental reform of the disability services system.

- The 2007 **Report of the Senate Inquiry into the Commonwealth State Territory Disability Agreement (CSTDA)** that found the system to be crisis-driven, disjointed and unable to meet current and future demand for disability services. The report's principal recommendation was a substantial increase in funding from Federal and State/Territory governments. It recommended improved indexation rates for service organisations and growth funding to respond to the increasing need for services. The Government's response, released in late 2010, agrees with most of the report's 29 recommendations.
- The **Federal House of Representatives carers inquiry** that concluded that many carers are experiencing isolation and financial and emotional stress as they struggle—without access to sufficient services—to support family members. Lack of recognition, poor information, dissatisfaction with community care systems and lack of choice in relation to workforce participation were commonly-reported experiences.
- The 2009 report, ***Shut out: The experience of people with disabilities and their families in Australia***, compiled by the National People with Disability and Carer Council, that painted a similarly bleak picture. Australians with disability, it found, are socially, culturally and politically isolated.

A lack of social inclusion and the multiple barriers to meaningful participation in the community faced by people with disabilities were the most frequently raised issues in the submissions and consultations... People with disabilities and their families, friends and carers reported daily instances of being segregated, excluded, marginalised and ignored. At best they reported being treated as different. At worst they reported experiencing exclusion and abuse, and being the subject of fear, ignorance and prejudice.

The report lists major barriers to participation experienced by people with disability—access to support services; employment; transport; education; built environment; housing; rights and

justice; assistive technologies. *Shut Out* graphically describes a service system in disrepair—broken and broke: chronically underfunded and under-resourced; crisis-driven; road blocks where there should be pathways; queues where there should be services.

- The Disability Investment Group's 2009 report, *The Way Forward*, that estimated growth in demand for specialist disability services at 7.5 per cent a year in real terms and notes:

Government spending on disability services has not kept pace with this. With increasing numbers of people with disability, decreasing availability of informal carers, and an ageing population, there will be even greater stress in future on the fragmented service system and a growing liability for families and governments.

To recognise that current arrangements are inequitable and unsustainable is not to deny or devalue the significant effort of stakeholders and participants across the disability sector or to deny that progress has occurred. But incremental change will be insufficient to bridge the gap between service capacity and demand; the system needs fundamental reform. After the numerous inquiries that have described the failings of the system, Sharing Places Inc. hopes the Productivity Commission's final report into Disability Care and Support is the necessary catalyst for action. Unlike other reports it will provide a comprehensive plan for transforming how people with disability are supported. Delivering a system to support people with disability and their families and carers to live an ordinary life of their choosing is long overdue.

In relation to the NDIS, Sharing places Inc. support an approach based on national policy setting and local decision-making. A national scheme would deliver consistency and equity across all Australia: the same eligibility criteria would apply to all; nationally consistent assessment would allocate support packages equitably, based on people's needs; policies and guidelines would apply in all jurisdictions. Importantly, however, is that the Scheme would be delivered locally. Local decision-making is critical to providing the flexibility that people with disability and their families and carers require. Local contacts to answer queries, to solve problems, to agree support plan changes and to address complaints are essential to delivering a responsive disability support scheme. National policy-making should be supported, wherever possible, by local management.

The NDIS represents an important paradigm shift towards conceptualizing disability support as an investment in people. While requiring an immediate and substantial funding boost, the NDIS should produce long-term benefits by enhancing the independence, productivity and participation of people with disability. It should reduce the inefficiency of having people with disability stuck in hospitals because they can't get the support services they need to live at home; or over-represented in the homelessness, justice, and aged care systems because they can't access adequate support from the disability system.

It is important that the Productivity Commission's reform proposal is seen in the context of the National Disability Strategy, released earlier this year. The NDIS would be a key plank within the Strategy, an ambitious, whole-of-government, 10-year plan, which will help give practical effect to the UN Convention on the Rights of Persons with Disability. It covers key domains of social, economic and civic life: health and well-being; economic security; learning and skills development; rights and justice; accessible communities; and personal support.

Although much of the National Disability Strategy relates to the exercise of rights rather than the provision of services, the capacity of many people with severe disability to exercise their rights will hinge on their access to disability support services.

Sharing Places Inc. would like to see the reform proposal of the Productivity Commission implemented as soon as is practicable. Unnecessary delays would see people with disability and their families and carers continue to bear the burden of a failing system. That said, the conduct of a pilot is critical to reform of this magnitude. For this reason, together with the differences among disability systems across the jurisdictions, Sharing Places Inc. recommends that at least three pilots are conducted, each in a different State or Territory. Multiple pilots would provide richer information and help ensure the successful implementation of the National Disability Insurance Scheme across all of Australia.

The draft report demonstrates a strong faith in the open market however, Sharing Places Inc. believes that significant value is added by not-for-profit providers. This additional value includes community building capacity, volunteering and awareness raising which are important to the successful implementation of both the NDIS and the National Disability Strategy. All service providers should be required to meet the Disability Service Standards.

## **Specific Comments**

### **Chapter 3: Who is the NDIS for?**

- **Eligibility and available supports**

Sharing Places Inc. asks the Commission is to reconsider how Tier 3(b) is defined. While aware that the Commission has clearly responded to the findings of the 2008 AIHW report—that indicates that people with intellectual disability encounter special challenges associated with dealing with changed circumstances and making and maintaining friendships—there are other people, such as some people with acquired brain damage and autism (for example) who experience similar difficulties as people with intellectual disability; they may also need support in these areas.

Sharing Places Inc. recommends that Tier 3(b) be defined by functional need rather than a specific diagnosis—to do otherwise would be inequitable.

While Sharing Places Inc. supports the concept of a tiered approach to the NDIS, it is concerned about the possible magnitude of the gap between supports available under Tiers 2 and 3—the difference between receiving 'information and referral services' under Tier 2 and significant supports under Tier 3. Sharing Places Inc. believes it may be warranted to provide greater assistance to some people who just miss out on meeting eligibility for Tier 3 support.

One approach could be that for people seeking support under Tier 3 but who are denied (or who have significant functional needs associated with their disability but would fail to meet eligibility criteria for Tier 3) a low cost response could be offered. A limited program similar to Local Area Coordination could assist people to develop community-based options (with access, where necessary, to a relatively small amount of funding to help achieve good results). This funding could be provided once-off or be potentially available to support people move through periods of transition (such as entering school; moving to secondary school; leaving school; leaving home; demonstrating the impact of ageing).

Once connected to a service similar to Local Area Coordination, the monitoring of the changing needs of this population group would be relatively easy; the identification of increased support needs could trigger an assessment for Tier 3 supports.

## Chapter 4: What Individualise supports will the NDIS fund?

- **Specialist disability support**

Sharing places is pleased to note that the intent of the NDIS is to meet disability related needs. The scheme should be structured around a co-contribution approach to the provision of some services or technology; for 'ordinary life expenses or items' the individual would be expected to contribute what other people could be expected to provide. The scheme would be limited to covering the extra-ordinary living costs of an individual or the cost differential between the price of an adequate piece of equipment or technology and the upgraded version that might be preferred.

### *Health:*

The report noted that the rate of disease and comorbidity increased with the severity of the disability and that people with disability were four times as likely as others to report severe or very severe levels of pain, the rates increasing with the severity of the disability. "Nearly 40% of people aged 15–64 years with a severe or profound core activity limitation had such pain compared with just 4% of other Australians."

The recent report by the ABS adds to this disturbing picture. Almost 69 per cent of people with profound or severe disability report having four or more long term health conditions, six times that rate reported by people without disability. This same group tends to have higher rates of most conditions, across most age categories—arthritis; ischaemic heart disease; hypertensive disease; cardiovascular disease; Type 2 diabetes; asthma; and be taking medication for a mental health condition. Of people aged 18 years and over with profound or severe disability, only 17.4 per cent considered their overall health to be very good or excellent, compared with almost 69 per cent of people without disability.

Sharing Places Inc. is pleased that the Commission recognises that the NDIS could have a role in reducing disability-specific barriers to receiving good health care. An important example of this is when some people with disability are hospitalised (particularly those with communication difficulties and/or cognitive impairment). While hospital staff need to be adequately trained in disability issues to minimise the distress these people experience, there is often a need for people to receive additional support from disability support workers they know. The NDIS may be able to make this service available.

Negotiating appropriate arrangements—with Medicare Locals and Local Health Networks—for the provision of health care for people with disability will be an important function of the NDIA.

Sharing Places Inc. would also like to see clear arrangements be put in place with the health system for the provision of aids and equipment; the respective responsibilities need to be clearly delineated.

## **Chapter 5: Assessing care and support needs**

- **What is being assessed?**

Sharing Places Inc. supports the notion of assessment being focused on needs, particularly to identify 'reasonable needs', but agrees with the Commission that taking account of an individual's aspirations is also important (and in some cases would warrant a greater level of support for a period of time). An example of this could be the provision of more support or services while a person undertook tertiary education with a view that it would assist them to gain future employment; the investment would be warranted.

The proposal to use the International Classification of Functioning, Disability and Health as the framework for identifying the domains to be considered in a needs-based assessment is valid; the choice of assessment tools is, however, more complex.

- **What is the purpose of the assessment process?**

NDS supports the purposes of the assessment process as outlined:

- a screening for eligibility (so that only those likely to be eligible for the NDIS undertake more formal assessment);
- determining the type, intensity and frequency of support needed;
- determining the availability (and willingness) of informal supports
- determining an individual budget;
- determining suitability for self-directed funding;
- providing a referral to other schemes; and
- providing data for program planning and cost management.

- **Desirable features of assessment tools**

The role of assessment in the operation of fair, efficient and sustainable scheme is clear; it needs to identify the people eligible to receive support, and the types and levels of support they require. It needs to allocate resources fairly and equitably right across Australia. The establishment of an NDIS provides the opportunity to establish a more unified approach. This is desirable and overdue.

Nationally-consistent assessment and equitable resource allocation is required. This assessment must, however, be as streamlined as possible. Individuals (and their carers) must be subjected to less assessment rather than more (the minimal required to provide necessary and adequate information). Scarce resources should, as far as is practicable, be directed to supports or services.

- **A single tool or a 'toolbox'**

No current assessment tool or process appears to be adequate for adoption as a sole tool for use within the NDIS. For this reason, Sharing Places Inc. supports the suggestion that the NDIS begin with a suite of tools. The weakness of this approach, however, is that the greater the number of tools, the greater the possibility of inequitable outcomes.

Sharing Places Inc. also suggests further work be undertaken—following the introduction of the Scheme—into determining the most reliable and valid assessment tools and processes

(with an additional aim of minimising assessment time/processes for people with disability and their families and carers).

- **When should assessments occur?**

Sharing Places Inc. requests that assessment processes are effective, adequate for purpose and minimalised; likewise any processes implemented for the re-assessment of needs. Sharing Places Inc. believes that the reaching of certain life stages should trigger consideration of the need for re-assessment. Individuals and their families and carers should also be able to initiate this process.

- **Should carers have their own assessment**

Given the extraordinary level of engagement of families and other informal carers in the lives of people with disability, Sharing Places Inc. supports the suggestion they have their own assessment (when they request it and ensuring it is linked to the needs of the person they support).

The best arrangements for people with disability are generally those that arise from formal and informal supports working cooperatively and in partnership. Assisting families and carers to continue to be active in the life of their friend or family member with disability is a priority.

Sharing Places Inc. supports assessment processes that:

- are timely;
- have mechanisms to help ensure consistency when used by many assessors;
- are as comprehensive as is necessary (covers all relevant domains);
- use existing information about the degree of disability and the supports required;
- seek permission to share information with necessary partners/providers;
- use an initial screening tool to determine likely eligibility;
- minimalise assessment tasks (but gives valid and reliable results);
- consider information provided by the person with disability (on needs and aspirations);
- consider the availability of informal supports (and, where possible, engages them in discussion);
- seek to re-assess at important life transitions or when instigated by the person with disability, their families or carers; and
- provide for review or appeal.

## **Chapter 6: Who has the decision-making power?**

Sharing Places Inc. supports the trend, seen both here and overseas, to giving people with disability more choice over their supports—the type of support, from where it is sourced, and how it is delivered. Well-designed and well-operated self-directed services should be embraced.

Sharing Places Inc is aware that self-directed services or programs vary significantly in how they are structured, how effective they are, and the impact they have on the quality of service delivery. Recent experiences in Victoria highlight three broad and interrelated issues:

- transition to self-directed approaches requires investment in support to organisations, workforce development, and to support people with disability and their families and carers;
- investment is also needed in systems such as those to manage financial and client data, invoicing and remittance advice, cash flow and planning;
- consideration has to be given to how to fund 'less visible' yet vital activities such as transport, community capacity building, volunteer support and infrastructure investment. These activities are funded most efficiently when developed and costed in relation to a group of people; it is difficult and often expensive to allocate them to an individual.

- **What services should be covered?**

As assessment would identify disability-related support need/s; the supports or services provided should be directed to meeting these needs. While this shouldn't eliminate flexibility in support provision, it should limit what is available. A support must address an identified need.

Excluding 'ordinary life expenses' from the scheme would mean that expenditure on items such as food, utilities, recreation and clothing would not be covered. The exception would be where expenditure on these items was high due to a disability—in these cases expenditure above the norm could be funded by the scheme. The scheme could, for instance, fund modifications to a vehicle to enable wheelchair access, but not cover the base cost of the vehicle itself. It could cover the difference between the cost of a commercial washing machine and the cost of an ordinary washing machine for a family with incontinent children.

The scheme, therefore, should be structured around a co-contribution approach to the provision of some services or technology; for 'ordinary life expenses or items' the individual would be expected to contribute what other people could be expected to provide. The scheme would be limited to covering the extra-ordinary living costs of an individual or the cost differential between the price of an adequate piece of equipment or technology and the upgraded version that might be preferred.

**The supports available under a new scheme should be clearly listed and regularly reviewed**

While difficult, the transparency and clarity of a new scheme would be enhanced by clear articulation of 'legitimate supports' and any associated restrictions – just as Medicare specifies the medical interventions that it will fund and the PBS the drugs that receive public subsidy. Such an approach would assist accountability for the use of public funds and equity for those in need, as well as minimising the use of complaint mechanisms, appeals and litigation.

The list should be reviewed regularly by an independent panel which would be guided by available evidence on efficacy.

Sharing Places Inc. supports self-managed services. Such a model needs, however, to be well structured to enable good outcomes for people with disability to be achieved without compromising the requirement that a Scheme meets public expectations of reasonableness; effort needs to be put into avoiding stories of funding mismanagement without being overly prescriptive.

Accountability requirements should be established for self-managed services. These requirements should be proportional to the size of the support package, giving confidence that the funds have been appropriately expended without being unnecessarily onerous. Expenditure should (largely) be able to be matched to a support plan.

A self-managed package of support, where it involves the direct employment of staff, should be required to operate as a small business; OHS and other work/industrial arrangements should be put in place. Sharing Places Inc. is pleased to see that support for self-management would be available from Disability Support Organisations.

Individualised funding is not the only route to the personalisation of services. Person-centred planning, for example, is re-shaping services to reflect the needs and aspirations of individuals, without necessarily relying on individualised funding. Moreover, if poorly implemented, individualised funding can actually restrict individual choices and service flexibility. This would occur if individual budgets were inadequate; or if the financial viability of services were undermined; or if the quality of services were depleted; or if the funding model could not accommodate unpredicted circumstances.

While many people with disability will want to direct the supports they receive, few will want to become the employers of disability support workers and be responsible for all that that entails—e.g. the establishment of a small business, compliance with legislation (including Occupational Health and Safety, taxation and industrial relations laws) and providing staff with the training, supervision and professional development opportunities they require.

A National Disability Insurance Scheme should recognise diversity of choice and of service patterns. It should allow a range of options for the management of supports, which include self-directed planning, self-directed supports and self-directed funding. People should have choice about how active they are in the administrative aspects of the support they receive. Direct funding to individuals should be available alongside options such as the use of a financial intermediary and direct funding of service providers.

Any direct payments to individuals for the purchase of disability support services should not affect the level of any income support payments received.

Sharing Places Inc. is concerned about arrangements for the employment of family members and agrees with the suggestion by the Commission that family members who are resident in the same household as the service user should not be paid to deliver services. To do so risks a conflict of interest and blurs professional boundaries.

The payment of non-resident family members needs careful oversight. It is warranted in some circumstances—such as in rural and remote areas when the availability of support workers is limited—but should not generally be the arrangement of choice. Approval and review processes should be in place.

## **Chapter 7: Governance of the NDIS**

Sharing Places Inc. believes the governance arrangements proposed by the Commission are broadly appropriate but recommends

- the entry to the NDIS needs extensive review and simplification;
- for people eligible for Tier 3 support, the National Disability Insurance Agency (NDIA) should be responsible for establishing the policy framework for the Scheme, the setting of efficient prices, undertaking assessments, and allocating support entitlements (planning should not occur at this level); and



- the role of DSOs should be: the planning and assembly of the package of supports; assisting people to self-manage their package; providing financial brokerage or intermediary services; case management for the small proportion of people who need it; care co-ordination as required (for example, providing the contact point for people wishing to be re-assessed or wanting to significantly change their support
- further consideration needs to be given to the capital expenditure needs of organisations, particularly associated with the need for new supported accommodation for the thousands of people currently on waiting lists around the country and for the growth of facilities such as ADEs.
- the importance of community capacity building needs greater acknowledgement—both the community-wide activities that build a greater awareness of disability and help remove barriers; and the one-on-one work that many disability organisations undertake to identify, establish and support a good community participation activity for a person (for example as a volunteer or to participate in a community-based recreation group). These activities need to be funded.

Sharing Places Inc. contends that many service providers are currently performing many of the services proposed for DSOs. Under an NDIA they should be allowed to continue to perform this task (and be funded to do so) where an individual and/or their family or carers would like them to do so. The availability of independent DSOs (who are not service providers) would provide the necessary choice for people with disability. This element of choice should be built into the final proposal.

## **Chapter 8: Delivering disability services**

### **• Disability support services**

A sustainable disability service system is essential to support people with significant disability to have certainty and choice in their lives: to decide what they will do, when, how and with whom they will do it. This requires service funding levels that reflect the actual costs of service delivery. The proposed NDIS is the must deliver this.

An NDIS must invest in system capacity, workforce development, and service infrastructure. It must ensure that consumers have meaningful choice and supports through the maintenance of a diverse range of viable organisations. Services must be available to support people living in rural and remote areas.

### **• Navigating the disability system**

Encouraging people with disability to have greater choice and direction over the services they receive requires an investment in information, resources and advocacy. People with disability, their families and carers need to have the information they need—in forms that suit them—to make rational choices. Improved information provision will require a significant investment but it is essential to operating within a more market driven environment.

The NDIS should also recognise that some individuals will require greater support to plan and exercise choice than others. This should be available through DSOs and advocacy organisations (which should receive funding to provide assistance).

### **• Safeguarding quality**

Sharing Places Inc. accepts the need for a quality system to support the delivery of services to people with disability. This quality system needs to be effective, relevant and affordable. It

must also demonstrably improve the lives of people by supporting the delivery of high-quality services, and be a mechanism to ensure that public funds are well spent. Quality service delivery is in the interest of all parties: people with disability, service providers, governments and the broader community.

Monitoring or accreditation should be independent from government and service provider. Governments should acknowledge that a robust system to deliver quality outcomes for people with disability is expensive to implement and maintain and should therefore fund the accreditation process as well as ensure that the cost of establishing and managing a quality system is adequately incorporated into the funding provided for service delivery.

The review of the Disability Services Standards and the subsequent finalisation of the National Quality Framework for Disability Services should proceed and be implemented for every provider of a disability support service—not-for-profit, for-profit and government. Operating a quality system in the current inadequately funded service environment is difficult; operating one in an environment which does not require all providers of disability support to be quality assured would be inequitable.

In keeping with a commitment to quality, all therapies and rehabilitative services must be delivered by accredited professionals.

Information about service quality should be available to assist decision-making by people with disability, their families and carers.

- **The implications of consumer choice for block funding, government-run services and rural areas**

The NDIS, as proposed, will mean a move away from block funding; it will accelerate a trend that has been evident in a number of jurisdictions and services over recent years.

Sharing Places Inc. acknowledges this development but know it can have an impact on the sustainability of our services, can limit flexibility to direct funds to provide a crisis response, and can restrict innovative practices. Efficient and fair prices will help address sustainability issues but will not provide for crisis situations or fund innovation. Quick approval to implement crisis support will be required if block funding is not available.

Innovation is essential to continually improve how we support people with disability. It will, however, require funding support if it is to be prioritised. Sharing Places Inc. is pleased to see the Commission acknowledge that there may be a need for block funding for some services, notably those in low population rural and remote areas. Quality service provision will depend on it.

## **Chapter 13: Workforce issues**

Sharing Places Inc. identifies several overarching and continuing trends which shape the environment in which the disability services workforce operates:

- The demand for disability services is growing at a rate of about 7.5 per cent per annum in real terms. Because this rate of demand is not matched by an equivalent (or larger) increase in service provision, the gap between supply and demand is growing. An increasing number of people with disability are not receiving support or are receiving it at inadequate levels. Their ability to be active citizens is unfairly curtailed, and service providers find themselves in the position of always trying to do more with less. The financial sustainability of service providers is under pressure.

- The profile of people with disability being supported is gradually changing. A growing proportion of the clients of disability services have complex health needs, dual disabilities, drug and alcohol problems and challenging behaviours.
- Person-centred planning and personalized approaches to support are expanding and the provision of standardized services in specialist facilities is declining. Disability workers need to be able to work in unsupervised environments and negotiate—with people with disability, with families, with people in the community—to achieve good outcomes.
- The paperwork requirements on disability workers continue to grow as accountability requirements on government-funded service organisations grow. Support workers need to be excellent record keepers to manage the growing number of compliance tasks. The skills required to meet compliance requirements differ markedly from the skills required to provide personal support

These trends are likely to be exacerbated under the NDIS which will require many more skilled workers. While the Commission has acknowledged that the size of the workforce will need to increase, Sharing Places Inc. believes workforce issues warrant greater analysis in the final report.

- **Attracting more workers to the disability services industry**

Sharing Places Inc. is pleased that the low wages of disability workers has been acknowledged in the draft report; inadequate funding for disability services has constrained the ability of organisations to pay appropriate wages.

Obtaining an appropriate wage increase under the Pay Equity Case currently before Fair Work Australia is a critical element in assisting the sector attract and retain workers. Any award increases handed down by Fair Work Australia must be fully funded (and be part of the setting of 'efficient prices').

Sharing Places Inc. is concerned by the draft report's suggestions for ways to 'maintain low barriers to working in the sector' and 'alternatives to increasing the formal workforce'—relax restrictions on the scope of practice; reducing the screening requirements for potential workers; paying family members; productivity increases; using volunteers; and the direct hiring of friends and neighbours to provide support.

All of these proposals require greater analysis before being part of a final report. Sharing Places Inc. is particularly concerned about possible implications that could arise from relaxing restrictions on the scope of practice (for example, in medication management) and are adamant that the screening requirements for potential workers should be reduce (this would be in conflict with the legislative requirements of some jurisdictions).

- **Qualifications, working knowledge and career paths**

Sharing Places Inc. is concerned about the Commission's lack of recognition of the importance and impact of training. We feel the quality of disability support work and the likelihood it will be viewed as a desirable career choice will be undermined.

Sharing Places Inc. greatly appreciates the opportunity to respond to the Productivity Commissions's Draft Report "Disability Support and Support.

Susan Healy  
Executive Director

April 2011