



COSS Network Submission | August 2010

**Australian
Council of
Social Service**

Productivity Commission inquiry into a long-term disability care and support scheme

16 August 2010

This submission has been coordinated by the Australian Council of Social Service on behalf of the national COSS network:

Australian Council of Social Service (ACOSS)
ACT Council of Social Service (ACTCOSS)
Council of Social Service of NSW (NCOSS)
Northern Territory Council of Social Service (NTCOSS)
South Australian Council of Social Service (SACOSS)
Queensland Council of Social Service (QCOSS)
Tasmanian Council of Social Service (TasCOSS)
Victorian Council of Social Service (VCOSS)
Western Australia Council of Social Service (WACOSS).

About the COSS Network

The Councils of Social Service (COSS) are the peak bodies representing the needs and interests of service providers and their clients in the non-profit social service sector in Australia. Our members comprise community service providers, professional associations and advocacy organisations.

We provide:

- independent and informed policy development, advice, advocacy and representation about issues facing the community services sector;
- a voice for all Australians affected by poverty and inequality; and
- a key coordinating and leadership role for non-profit social services across the country.

We work with our members, clients and service users, the non-profit sector, governments, departments and other relevant agencies on current, emerging and ongoing social, systemic and operational issues.

This submission involves policy analysis developed through consultation with our members and policy advisors in the states, territories and federally; from our experience working with people with disability, carers, the community sector and governments; and from our ongoing policy and advocacy work towards achieving social security for all Australians.

For further information or to discuss this submission, please contact:
Tessa Boyd-Caine, Senior Policy Officer, Australian Council of Social Service
+61 2 9310 6200 or email: Tessa.Boyd-Caine@acoss.org.au

Key Questions raised in Productivity Commission Issues Paper, May 2010

1. What kinds of services particularly need to be increased or created? How could the ways in which services are delivered — including their coordination, costs, timeliness and innovation — be improved?
2. Are there ways of intervening early to get improved outcomes over people's lifetimes? How would this be done?
3. How could a new scheme encourage the full participation by people with disability and their carers in the community and work?
4. How can a new system ensure that any good aspects of current approaches are preserved?
5. What should be done in rural and remote areas where it is harder to get services?
6. How could a new system get rid of wasteful paper burdens, overlapping assessments (the 'run around') and duplication in the system?
7. How should a new scheme be financed?
8. How can it be ensured that there is enough money to deliver the services that are needed and provide greater certainty about adequate care in the future?

A new disability scheme will change the way that people get services and how much they get. That will mean many decisions will have to be made about a new scheme, such as:

- the roles of service providers, people with disabilities, their carers and governments (eight governments are heavily involved in providing and funding current disability services);
- how existing arrangements would fit in with a new scheme;
- how risks and costs would be managed to make a scheme sustainable for the future;
- what workers would be needed in a new scheme, where they would come from, what training requirements would be appropriate and what could be done in the short-run to boost their numbers; and
- the transitions to a new scheme.

1. Introduction

The COSS network welcomes this timely and important reference to the Productivity Commission to inquire into the possibility for a long-term disability care and support insurance scheme. The COSS network strongly supports the rights and entitlements of people with disability as set out in the Convention on the Rights of Persons with Disabilities.¹ ACOSS has also expressed concern about the denial of social security entitlements to migrants with disability.² The present inquiry by the Productivity Commission comes about in part as the result of sustained advocacy about these issues by people with disability and their carers. We reaffirm our support for the principles of human rights and acknowledge their importance in consideration of how best to support people with disability and their carers.

There are different reasons for providing support to people in our community. Australia provides support to older people to ensure a quality of life in their declining years and in recognition of their life's work and contribution. Yet historically, we have supported people with disability out of benevolent compassion only. People with disability are citizens and they have the same rights and entitlements, expectations, opportunities and responsibilities as non-disabled citizens. The difference is the support needed to exercise these rights.

We welcome the support that has been given by the Government to organisations representing people with disability, carers and service providers, to address the key issues at stake in this Inquiry. Many of those organisations are extremely well-placed to address some of the key issues at stake, including the experience of living with disability or caring for someone who does. Consequently, we have taken as the focus of our submission the principles and priorities for the design of a disability social insurance scheme and the implications that would have for service delivery.

2. Productivity Commission's terms of reference

i. Terms of reference of PC Inquiry

The PC's terms of reference specify that the scheme should cover disability present at birth, or acquired through an accident or health condition, but not due to the natural process of ageing. This means that the size of the relevant group is much smaller than all people with disability. Additionally, the numbers in this smaller group are projected to grow more slowly than those whose disability is ageing related. While this inquiry mainly emphasises people with disability aged less than 65 years, population ageing will significantly raise the overall number of people with severe or profound disability, placing even more pressure on services, including for people who are not old (Productivity Commission Issues Paper, p.6).

We take it that the terms of reference do not exclude those Australians with care and support needs due to long-term disability, whose ageing places a burden on their families or carers that can no longer be met within existing support structures. The terms of any social insurance scheme must make provision for people with disability whose ageing changes or increases their care and support needs.

¹ See for example ACOSS submission to the National Human Rights Consultation, June 2009,

http://acoss.org.au/images/uploads/ACOSS_submission_to_NHRC_Final.pdf.

² ACOSS submission to the *Joint Standing Committee on Migration*, 'Inquiry into the migration treatment of people with a disability', November 2009,

http://acoss.org.au/images/uploads/Joint_COSS_submission_migration_treatment_of_disability_inquiry.pdf.

Beyond that, the impact of age related disability is very different on the older person than the younger person with disability. For instance, the objective of support for an older person might be comfort and minimising deterioration, while support for a younger person with disability might focus on their progress, potential and contribution. Additionally, older people already have a system designed to provide supports to them. While the aged care system may have its own inadequacies, they should not be the liability of the disability system.

There is also a risk of significant cost shifting between schemes for disability and for old age, whereas the priority should be ensuring adequate support for people experiencing either and both. There is great potential that the care needs of older aged people, if included in this scheme, could overwhelm supports to people with disability. There are lessons to learn here from other initiatives such as the Home and Community Care (HACC) program in this regard.

At the same time, there is scope for the Productivity Commission to determine that the application of a national insurance scheme for disability should be determined by how an individual experiences disability. That would mean that the criteria were not determined by the acquisition of the disability but how the experience of living with a disability is taken into account. Moreover, the need for excellent coordination between the NDIS and the aged care system cannot be over-stated. This is particularly important to ensure that people with a disability are supported to age 'in place', in other words to be able to remain in their homes or where they choose to live for as long as possible.

ii. Consultation

The Productivity Commission has already engaged in widespread consultation through the current process of submissions and oral hearings and we note considerable contributions from industry bodies and consumers to date. We have iterated our support for resources provided to representative bodies in this regard.

In addition, we strongly urge the Productivity Commission to ensure that the bureaucracy is able to make input into the development of this proposed policy, as these issues interact with a range of areas and processes across government.

3. COSS priorities in the consideration of a long-term disability care and support scheme

The core objective of the Councils of Social Service is to develop policies and advocate for the interests of low income Australians to ensure the effectiveness of the services that support them. In this submission we advocate a policy framework that will ensure that the needs of low income people with disability and their carers are *met as well as possible by the best possible systems of social service and social security*. In the following discussion we raise some key policy questions about the proposal for a social insurance scheme, before setting out key principles and priorities in its design.

i. Who makes the decisions? Self-directed services and the funding model

Access to funding and resources is critical to long term well-being. Historically in Australia most funding available to people who live with a disability has been directed to organisations that then provide support to a nominated group of people. The mid-1980s saw the emergence of a number of new organisations throughout Australia that grew from communities of interest and, unlike many more traditional organisations, were very clearly

directed toward helping people remain and become valued members of their local community. In the most innovative of these services funding became a mechanism for tailoring support around the person concerned. Decisions about how and where support was required became highly personalised and as a result funding became a mechanism of liberation.

Clearly, there is a minimum to funding levels that will ensure sufficiency. In order to be genuinely enabling, funding must also be clearly framed to respond to the particular needs of the individual who lives with a disability. It needs to be delivered in a way that gives it flexibility and in a manner that ensures that funding available can change with minimal red tape if circumstances change. For example, assessments of need should not start again, re-inventing the wheel every time a person's needs change.

Ultimately, the priority in any policy reform must be the effectiveness *for clients* of their support mechanisms. The nature of service delivery is an important issue in this context. While any social policy needs to be mindful of sustainability, people with disabilities often have minimal choice and very little alternatives available to them. It is important to ensure that funding models do not allow service providers to cherry-pick between clients and types of supports. Equally important is the capacity to manage competition between providers to ensure adequate and accessible supports are available to all who require them.

The challenge before the Productivity Commission is to investigate the best mechanisms for funding, delivery and effectiveness of social services for people with disabilities and their carers. While there are many possible models to be considered, one of the most commonly cited at the moment is that of self-directed funding.³ This is referred to in the PC Issues Paper's discussion of who makes the decision (p. 21). The Commonwealth Government has also signaled its interest in this direction, with Parliamentary Secretary Bill Shorten comments that: 'Individual funding is not nirvana but we think it's the way to go.'⁴

It is important that the meaning of these concepts is clarified and understood, particularly if they are to inform policy development or reform. For instance, client-directed services do not necessarily require client-directed funding. As a result, we advocate the consideration of funding models as separate from service models. A national disability social insurance scheme would present the opportunity to reframe the "service provision" aspect of disability supports away from the often unresponsive system towards the needs of the person with disability. The structure of any policy for a social insurance scheme should focus on the model of support, ensuring its effectiveness and accessibility. Once that has been designed, the funding model can be determined.

The idea of a universal self-directed support scheme is that it allows choice to people with disability to determine what level of support they need and how it should be delivered. People may choose not to make any decisions by handing over their entire personal budget to a provider to manage and operate in the interests of their support needs. This would be similar to direct funding to services with the important distinction that it is the person with disability who is choosing to do this. On the other hand, people may choose not to use the service system at all by creating their own supports and managing and operating their personal budgets completely separately from existing systems. While these may be extreme alternatives falling at either end of the spectrum, they are options that should be acceptable under a universal scheme. The likelihood is that most people will fall somewhere

³ See for example In Control Australia (www.incontrol.org.au) or Julia Farr Association (www.juliafarr.org.au).

⁴ Horin, A (2010) 'All in the family: a new, morale-boosting way of helping those with disabilities', *Sydney Morning Herald*, 5 July, p. 4.

in the middle. Most people are likely to make varying choices within the realm of a funding package where people employ technical and professional advice to recommend support options and also employ a financial intermediary to fulfill the legal, contractual and accountability requirements of the personal budget. Under this arrangement, people will be free to make decisions about their support needs but will have expert advice and assistance in their choices and obligations.

In this context, then, services have a much clearer role. The outcomes they aspire to and should be measured against should be based on how well they manage to support someone to take their place and to become included in the life of their local community.

Service practices that result in people who live with a disability being congregated together and segregated away from other members of the local community need to be supported to engage in radical re-design. Services that already go some way toward this ambition need a way in which to test this.

To achieve the objectives of effective support for clients, services themselves need a range of supports. These include support to understand how current practice might measure against a much more desirable objective of ensuring people are in every way helped to be valued members of their local community.

Services should be conceptualised in two different arenas accordingly. The first is the services all community members need in order to get by in everyday life, including for example transport, housing, banking, entertainment, health and education. The second arena is the services and support one might need to address the specific issues that arise from a person's disability.

In the first instance, the services all citizens need must be oriented to ensure they include and welcome people who live with a disability. This may well mean support needs to be made available to this section of our community to ensure they start to understand and appreciate the vital role they can and must play. Indeed the evidence is there. People who have a physical disability still experience a significantly unaccommodating built environment, children who have an intellectual disability still find it difficult to get a good education at their local neighborhood school, people who live with deafness still can't often go to movies that are properly subtitled, people who acquire a disability in adulthood still find it extremely difficult adapting to or locating housing that might accommodate their new circumstances, etcetera.

If these ordinary activities of daily life no longer had significant barriers to participation, the issues around which people would need other forms of support would be minimised.

It is also important to recognise that, just as in any social policy, there are risks in relation to self-directed funding. As with any risk the issue is one of balance. A key issue relating to individualised funding is therefore balancing the safeguards and mechanisms to protect vulnerable people with the entitlement to have individual control, choice and flexibility; and ensuring monitoring processes to provide accountability in the use of government funds (Craig and Cocks 2009). Achieving this balance is critical to the success of individualised funding programs. Too many controls and monitoring of expenditure, for example, may interfere or constrain with individual choice, and undermine the opportunities for flexibility and responsiveness (Bigby and Fyffe 2009, 11). On the other hand, inadequate safeguards could present unacceptable risks to vulnerable people, irrespective of the nature of a disability (Laragy 2009, 30). To this end, we advocate that any policy for individualised funding should include funding for intermediaries where necessary.

4. The design of a disability social insurance scheme

A central principle of our submission is the separation of the proposed insurance scheme from Australia's social security system. It is vital that such a scheme be considered separately to the existing instruments of social security, such as the disability pension and the carers' allowance. These are very important elements of social security that must be maintained while we pursue the opportunities presented by a national social insurance scheme for people with disabilities and their carers. This distinction is the first key principle in our submission.

A second key principle of our submission is that the disability social insurance scheme should include cover for the costs of disability, for example via a supplement payment, in addition to any cash entitlement or service guarantee arising from the insurance scheme. The idea of a supplement payment is an ACOSS proposal (not an existing payment within the social security system, although there is a mobility allowance). We have advocated an additional 'safety net' payment for expenses that can't easily be covered, which would most likely be funded through the social security system.⁵ This is equivalent to the carers allowance but offers a minimum payment to people with disabilities. No disability insurance scheme can accurately assess the costs associated with disability and its care needs in advance. There are also some disability-related costs for items not normally associated with disability. For example, people with limited mobility often pay higher rents to live near public transport. As a second example, people with intellectual disabilities may find it particularly difficult to shop for the best deals where comparing the options is a complex task, such as with mobile phone plans. Although there are many schemes to assist with disability related costs, including taxi subsidies, continence aids, and the Pharmaceutical Benefits Scheme (PBS), there are many deliberate or unintended gaps in these schemes (for example access to disability aids and equipment is often rationed and there are co-payments for the PBS). So there is a clear case for a modest cash supplement to pick up those hard to account-for costs.

Importantly, this benefit would be received *in addition to* a working age payment. It would top-up the current system of disability support payments and act against the potential for people with disability to lose out on income as they move into full-time employment. In other words this top-up should remain throughout or at least in the early periods of, full-time employment.

An alternative system would be to provide a second tier of payment supplement which assists with specific disability-related costs, such as those related to mobility and accessibility. We acknowledge that such a proposal may be contentious because the costs associated with such expenses are highly variable. In addition to such foreseeable expenses as wheelchairs, access ramps, information technology and communications instruments, expenses might also include pharmaceuticals that are not available from the PBS, high intensity health care and large quantity disability-related consumables.

⁵ ACOSS (2010) 'Out of the Maze: A better social security system for people of working age', Submission to the Australia's Future Tax System (Henry) Review, http://acoss.org.au/images/uploads/ACOSS_Paper_-_Reform_of_working_age_payments.pdf

The following additional issues are important to consider in relation to the design of a disability insurance scheme, particularly in terms of guaranteeing a range of services.

i. Target group

We have already addressed the gap in relation to mature age people, but beyond that, how is disability to be assessed for the scheme? We advocate the inclusion of all people eligible for the Disability Support Pension in the first instance. With that as a starting point, the PC might then consider all people with significant disability or disabilities with significant impact on life opportunities and choices.

ii. What is the relationship between the scheme and existing insurance based schemes such as worker's compensation or car insurance?

We think it best to keep these separate or the national disability scheme will become a default scheme based on insurance principles rather than a universal one. This would mean that those with workers compensation entitlements relating to services funded under the scheme would not be eligible for those services. However the new scheme could cooperate with workers compensation insurers to pool their resources.

iii. What is the entitlement?

Options here include a cash amount; a guaranteed package of services, or a cash allowance tied to a set of services (similar to the current child care benefit). Acknowledging that this is a controversial issue, there is a case for the third option (a 'benefit' approach). It aids efficient targeting based on certain types of needs and assistance; and clearly separates the scheme from cash income support. There is also an argument for maximum flexibility around how the 'service' is defined. For instance, how does a service vary according to a person's disability and other individual circumstances?

iv. Should the scheme be restricted to certain categories of services, such as personal care or mobility?

This is another controversial aspect of the scheme and is one that causes great consternation amongst our own membership. Clearly, there must be a framework that delineates eligibility and through which the extent of application and funding for the scheme can be determined. One option would be a boundary around the range of needs and services included in the scheme, while keeping the target group wide. This would also allow for the criteria to be the lived experience of people with disability, as canvassed earlier.

v. Coverage of capital items (eg building adjustments)

We advocate for a scheme that can cover certain capital items such as building adjustments to ensure access and support mobility where required.

vi. Should there be a basis for exclusions from the scheme?

This scheme must progress disability supports, not simply alter them. There is a strong view that anything provided to other people should also be provided to people with disability and that the scheme should cover needs relating to the additional requirements of a disability. At the same time, if the scheme was to cover all costs, the scheme would simply replace one funding source with another and arguably the person with a disability would be no better off.

This raises the question of what might be the basis for exclusions or limits on the application of the scheme. One possibility might be types of restrictions that could be applied which would leave more room for innovative approaches to the services being delivered. Examples here might include disability employment services or mainstream health services, on the grounds that these are more efficiently covered by other funding schemes. This also avoids the risk of isolating these services for people with disabilities, which is a criticism that has been made of services and policies too address the needs of Indigenous people.

vii. Ensuring sustainable services

Throughout the sector and indeed amongst our own membership there is strong support for self-directed support funding and individualised approaches for people with disability. That approach requires a strong and vibrant disability sector to support a more individualised approach. However, funding distribution methods will not solve the imminent workforce crisis in human services. Nor are they designed to. Workforce challenges require deliberate and bespoke strategies.

viii. Maintaining parity in access

The scheme must benefit those who most need it the most. Therefore the capacity to pay must not be an eligibility criteria or a prohibitive access criterion. On the contrary, lack of capacity to pay for services may be a criterion for particular or additional support, recognising the particular support needs of low income Australians.

ix. The survival of services with a small client base but in vital areas, either in terms of the needs they meet or the location they service.

Reiterating the necessity of a vibrant disability industry, Government will always have responsibility for specific strategies for small populations, regional and remote groups, and communities with specific needs – as it does now. Again we reiterate our view that the scheme is to provide for the additional requirements as a result of disability rather than “take over” from other schemes available to the population at large. This scheme must be additional to existing supports, not to replace them.

5. Proposals for social security reform

The PC has noted the potential trade offs that might arise from the aspirations of a new system (Issues Paper, pp 10-12). It is important to recognise that these ‘trade offs’ are not unique to social policy relating to disability or caring work. Problems in structure and outcomes persist across all areas of social policy. While we must ensure that people with disabilities and their carers are not disadvantaged as a result, these concerns cannot be put up as barriers to resolving the significant and important policy questions around long term care and support.

In this submission we have advocated for a social insurance scheme to exist separate to the existing instruments of social security. However we know that one of the major elements of increased costs to Australia’s health and welfare will be the needs of an increasingly ageing population. While the Productivity Commission’s reference specifically precludes the issue of ageing, we draw your attention to related policy development by ACOSS to address this problem. We have advocated a taxpayer contribution to the costs of health, ageing and disability through a Medicare-style health and disability services levy that rises slowly as the

population ages.⁶ The levy would increase automatically as the percentage of mature age people in the community rises, with contributions coming straight off their gross incomes.

We know that the structure of our population will radically shift and by 2050 a quarter of the population will be over 65 years. Older people are the biggest users of health services but only a small minority are currently required to pay tax (20%). By 2030, half of all household wealth will be held by Australians over 65 years. Since mature age people are the main beneficiaries of health and aged care, this levy would ensure that those beneficiaries would not be able to offset their contribution to the costs of these services using age specific or superannuation tax rebates. This policy would fund aged care and additional health services costs associated with population ageing. For example, a 1% increase in the Medicare Levy (currently 1.5% of income) could raise an extra \$8 billion. This could be gradually introduced over a period of 5 to 10 years.

This proposal is consistent with the argument that the services funded should extend to disabilities acquired in mature age. A proportion of the levy could be devoted to the disability scheme, with the rest going to health care. This would avoid confusion between the two while ensuring adequate provision for the needs across each area. It also avoids the problems associated with other insurance-based systems of financing such as additional super contributions, which ignore the argument of social good in favour of individual responsibility.

At the same time, there must be a clear “fund” specifically for the proposed disability scheme. This will protect it from incursions that might see funding approaches for health, ageing and disability swallowed up by large scale health and residential facilities which would ultimately come at the expense of providing for the needs of people with disabilities (and older people) outside of institutional care.

⁶ ACOSS (2009) ‘Progressive tax reform: reform of the personal income tax system’, Submission to Review of Australia’s Future Tax System (Henry Review), http://www.acoss.org.au/images/uploads/Personal_Income_Tax_Reform_-final_09.pdf.