



**The South Australian Council of Social Service (SACOSS)  
Submission to**

*The Productivity Commission  
Disability Care and Support Inquiry—Draft Report*

April 2011

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## **Introduction**

As the peak non-government representative body for the health and community services sector in South Australia, SACOSS believes in justice, opportunity and shared wealth for all South Australians. We have a strong membership base representing a broad range of interests in the social services arena. Our core activities include analysing social policy and advocating on behalf of vulnerable and disadvantaged South Australians; providing independent information and commentary; and assisting the ongoing development of the health and community services sector.

SACOSS has a key interest in disability care and support, with a number of members being disability service providers, consumer/client groups and people living with disabilities. SACOSS's Disability Policy Advocacy Group has considered the Productivity Commission Disability Care and Support Draft Report and contributed their knowledge and expertise to this submission. In addition, SACOSS has co-hosted a number of meetings with people living with disability, service providers and academics to consider the proposed changes and the effects on stakeholder groups. SACOSS's learning from these meetings has also contributed to this response.

## **Important aspects of the proposed disability support system**

SACOSS is supportive of many aspects of the proposed system and has encountered much excitement from the disability sector. Generally, it seems to take an inclusive and personalised approach that reflects an understanding of the needs of people living with disability and also their valuable social contribution. As highlighted in our previous submission to the Inquiry, SACOSS still believes a greater investment is needed to ensure a complete overhaul of the way in which our community embraces people who live with a disability, and the way support services are arranged so as to ensure people are assisted to live, participate and truly belong in their local community.

It is encouraging that the scheme is designed to cover all the needs of a person living with disability and also that support will be individualised and self directed. SACOSS believes that this is fundamental to enable people to live full and vibrant lives as valued members of their local community.

## **Critical concerns with the national disability support system**

SACOSS's discussions with our members and other stakeholders have raised a number of concerns with the national disability system as outlined in the draft report. SACOSS believes that there are some areas of the proposed scheme that are underdeveloped, as well as some areas that need further thought and clarification.

### ***What is "severe and profound"?***

In SACOSS's original submission to the Inquiry we specifically expressed concern about its Terms of Reference, which focus on the support of people with 'severe and profound' disability. We wish to reiterate this, as there has been no expansion of these terms of reference and therefore of the scope of the proposed insurance scheme and eligibility for support provisions. Limiting access to the proposed insurance scheme for people living with a 'severe and profound' disability is problematic from two perspectives. One is definitional and the second relates to who is likely to be seen as authoritative in coming to a conclusion about whether or not one meets the definition.

For the last few decades people who live with a disability have been working to escape the controlling paradigm that has seen disability defined and almost singularly contemplated as a medical issue. Without clarification there is every chance that a trigger entitlement definition that hinges on an understanding of what is “severe and profound” is only understood narrowly and thereby results in many people who live with a significant disability that impacts on their daily life not being seen to fit this definition. Historically, this medical model approach to disability tends towards focusing attention on the capability of one’s physical bodies and can underestimate the effects of mental health and its influence on a person’s capacity. It is our belief that access should be provided based on the broad assessment of the impact of one’s disability and the additional needs that result for people, rather than a simple process of medical categorisation. SACOSS further notes that there may be some people living with psychological rather than physical forms of disability who equally need substantial and ongoing support who should also have access to the insurance scheme despite their potential exclusion from some medical and statistical categories relating to the permanence of these disabilities.

### ***What is “reasonable and necessary”?***

SACOSS supports the Draft Report’s proposal to assess the nature of a person’s disability individually, giving consideration to their particular circumstances and needs. However, the report uses the terms ‘reasonable and necessary’ in the assessment of supports eligible for funding under the scheme. There is little explanation as to how these will be assessed and by whom. SACOSS believes it is relevant to give greater definition to these terms.

### ***The problem of limiting participation to “where possible”***

Similarly, in the discussion relating to the support of a person living with disability to participate in employment, the statement is limited by the use of ‘where possible’, again with little discussion of how this will be decided. These decisions about what is ‘reasonable’, ‘necessary’ and ‘possible’ will be significant for the level of support people will receive in order to assist them to achieve full participation in the community. SACOSS believes it is preferable that we start from the assumption that everyone of working age should be supported to engage in employment rather than a starting point that limits this to “where possible”. To do otherwise is to imply that at least for some people work will never be possible and therefore limits imagination, ambition and effort likely to be directed at achieving such an outcome.

### ***Being careful to nourish the natural resources available to people***

The description of a person’s social connections and the care and support they receive from these people as ‘natural resources’ has also created some unease with our members and other stakeholders. While it is undeniably the case that family supporters and carers in a person’s life are vital and do contribute to social capital and therefore have a positive influence on life outcomes, these relationships cannot always be assumed to be a given and in fact may need a great deal of input and protection. For example, many people who have acquired a disability in later life will report that many friends and sometimes even family members drift away within a relatively short period, leaving people very bereft of supportive natural relationships. It is extremely important that any system of disability support encourages and preserves social resources, and is equally careful not to seek to exploit them.

## ***Great services will just appear to fit the new demand***

To some extent, the report also assumes following the creation of the insurance scheme, vital services of a manner, style and quality will be forthcoming via the mechanism of the market. History suggests this cannot be assumed. In part this arises from a group of customers having only a limited experience in the style and type of services available and hence having limited capacity to make really informed choices about what types of support may be needed in order to help them become valued and active members of their local community. Similarly many of the most powerful organisations operating in “the marketplace” today have histories that are entwined in the extensive segregation and congregation of people who live with a disability.

The power of a tool like an NDIS is that used wisely it can become a means to escape such histories and reinvent a future for people who live with a disability as valued and active members of our community. This won't however happen automatically and SACOSS continues to put forward the view that this will require serious investments in industry transition.

The capacity of the sector and disability support organisations as they exist today to deliver innovative, highly personalised quality services is extremely limited – not only as a result of funding but also as a result of technical knowledge and a values shift that is required to move toward a new paradigm. SACOSS argues this will require major investment and development outside of the direct investment in funding that might be available to any individual who lives with a disability. Government grants could be used to encourage industry to be innovative and to fill service gaps. The new scheme must recognise the current workforce issues in the disability sector with regard to labour supply and poor working conditions.

## ***People with a lived experience of disability should be involved in governance***

Our member organisations have also identified a significant gap with regard to the governance of the proposed disability support arrangements. Australians living with a disability must play a leadership role on the governing board of the National Disability Insurance Agency. The scheme is underpinned by the notion that people living with a disability should participate fully in the community, and as citizens that they have a voice in matters that affect them, so it is important that they are represented in leadership and governing roles in the new system.

## ***Dealing with the immediate crisis in the lack of existing support***

The four year timeframe for the piloting and roll out of the new scheme is creating some anxiety for our member groups. Given the current crisis in disability services and the significant needs that some people living with disability are experiencing now, there is a question as to how these needs can be addressed more quickly. There are also fears that changes and/or increases to State funded services will be placed on hold until the full roll out of Federal arrangements, leaving people waiting for basic needs and services.

It would be most unfortunate if the vast unmet need for support and the world for people living with a disability was simply to be put on hold as we await a new set of arrangements. While it is imperative that we are cautious to ensure any new arrangements are rolled out and implemented in an effective way, it is equally critical that people who live with a disability and their families throughout Australia are not abandoned while waiting for this process to be completed. We recognise this constitutes a major challenge, however we ask the Commission to take this up with urgency.

## **In closing**

SACOSS is supportive of and welcomes many of the changes proposed in the Disability Care and Support Draft Report. However, we would ask that consideration is made to the above concerns.