



**SACOSS Submission to the Senate Community Affairs
Committee Inquiry into the National Disability Insurance
Scheme Bill 2012**

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Executive Summary and Recommendations

SACOSS welcomes the advent of the National Disability Insurance Scheme as a positive step forward for people with disabilities. It agrees with the government's assessment that the current system is "inadequate and indefensible" and welcomes the move to a system which seeks to give people real choice and control over their affairs. However, SACOSS is concerned to ensure that the NDIS is not seen as a panacea or an end in itself. It is a tool to improve the lives of those with a disability and their carers, and it needs to be seen in the context of a broader agenda to realise the rights and aspirations of those with a disability. Accordingly, SACOSS is making a number of recommendations to place the Act in the broader context, including by adding a preamble and amending the objects and principles of the Act. It will also recommend strengthening the recognition in the Act of the Convention on the Rights of People with Disabilities (CRPD).

While SACOSS supports the overall intent of the Act, there are a range of particular issues with the draft legislation that have been identified in consultations on the Act as causing concern or requiring further elaboration. Accordingly, SACOSS makes recommendations on the need to monitor the impact on services not covered by the legislation, access to early intervention and support; the purchasing of services (including the costs of service brokerage and the potential conflicts of interest); the evaluation of outcomes for individuals; gaps in the review processes within the Act; the governance arrangements; and for the mandatory review of the performance of the Act overall.

There are 14 specific recommendations which are in bold italic in the body of our submission, and are as follows:

1. That consistency with the CRPD be added as a General Principle Guiding Actions Under the Act in Section 4;
2. That a preamble be included stating the vision for the Act and its place in the broader recognition of and supports for the rights of people with disabilities;
3. That an additional clause be added at s3(3) stating that in giving effect to the objects of the Act, regard is to be had to "(c) any other national strategy agreed by COAG in relation to people with disabilities";
4. That a further principle be added at s4(15) stating that the Ministerial Council, the Minister, the Board, the CEO and any other person or body that is to perform functions and exercise powers under this Act must have regard to "(c) any national strategy agreed to by COAG in relation to people with disabilities";
5. That there needs to be clarification about the process for establishing eligibility for early intervention support;
6. That the requirement to be a registered service provider be relaxed;
7. That s5, "General principles guiding actions of people who may do acts or things on behalf of others", should reference the need to encourage choice and consideration of different sources of support i.e. from public, private, non-government or informal community networks.

8. That the legislation should state a principle that the cost of brokerage services will be minimised so as to ensure the funding allocations are designed to maximise the benefit flowing to the individual participant;
9. That “the Agency” be removed as one of the potential managers of funding supports under ss42 and 43(4),(5), or that an independent brokerage agency be mandated;
10. That a clause be inserted after s43(1) either prohibiting any agency, organisation or individual who is managing the funding for supports from also providing supports to that participant, or alternatively and at a minimum, requiring the disclosure to the participant of any financial or other relationship between the person managing the funding for supports and the support providers;
11. That the sections relating to participants’ plans be revised to state that supports included in a participant’s plan need to be described in relation to a specific purpose/purposes and in a such a way that the achievement of the purpose can be evaluated, and that periodic evaluations of the outcomes of plans are required;
12. That gaps in the review provisions be addressed at a minimum by inserting s197 and s44 into the specific sections into s99 Reviewable Decisions, but more desirably by amending s99 to make all decisions of the CEO, including the refusal to make a decision, a reviewable decision;
13. That the following words be inserted at the end of s127(6) “and that at least 2 members are people with a lived experience of disability either as carers or as a person with a disability.”; and,
14. That s208(3) be amended with the addition of the following words at the end of the sentence:
“and must include:
 - a. An evaluation of the extent to which the objects of the Act are being met; and,
 - b. An evaluation of the impact of the NDIS on disability support services operating outside of the legislation.”

In addition to these recommendations, SACOSS emphasises the need to adequately fund the NDIS.

SACOSS would be happy to provide further comment and evidence to the Senate Committee about its concerns and recommendations.

Introduction

SACOSS welcomes the opportunity to provide a submission to the Senate Standing Committee on Community Affairs inquiry into the *National Disability Insurance Scheme Bill 2012* (NDIS). 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, and has a strong membership base representing a broad range of interests in the social services arena. SACOSS' 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. As part of this submission consultation was undertaken with SACOSS member organisations and drew on previous policy work in this area. SACOSS is aware of and supports submissions made by interstate colleagues in the New South Wales Council of Social Service.

Overall, SACOSS is very supportive of the new scheme and its focus on improving the ability of people with a disability to exercise choice and control in the planning and delivery of their supports. However, there are some concerns about the way the NDIS is viewed and how it fits in the broader context of support for people with disabilities. Accordingly, SACOSS wishes to make a number of recommendations to ensure that the NDIS legislation better reflects this broader context. Having done that, this submission also highlights a number of specific issues raised in the consultation with SACOSS members which need to be addressed.

Framework and Context

Prime Minister Gillard's (2012) National Disability Insurance Scheme Second Reading Speech made clear statements regarding the intent of the draft NDIS legislation, including that for more than 400,000 people who live with significant and permanent disability in Australia, the current system is "inadequate and indefensible". SACOSS agrees with this assessment. The Prime Minister stated that if passed, the NDIS legislation "will build a new system from the ground up" bringing to an end "the tragedy of services denied or delayed" and fostering "innovative services that are delivered and coordinated by local people" (Gillard, 2012). As will be evident below, SACOSS has some concerns about over-reach and over-expectation for the NDIS, and particularly where Section 3(1)(g) gives the NDIS responsibility for building community awareness about disability and encouraging research. However, SACOSS definitely supports the fundamental goal of the scheme to "give people real choice and control over these supports, including the ability to manage their own funding if they wish" (Gillard, 2012).

SACOSS' starting point is a commitment to recognise, respect and protect the rights of people with disability. This is consistent with the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and it is pleasing to see that the NDIS incorporates many principles of the CRPD. In particular, the NDIS restructure of the funding process in a way which recognises the autonomy of people with disability is consistent with the CRPD Preamble, which recognises:

“the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices,”;

and considers that,

“persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them”.

While SACOSS supports these principles and the NDIS funding model which is consistent with them, it is of concern that the explicit statements regarding the CRPD in NDIS legislation are minimalist. Section 3(1)(h) is a constitutional enabling statement which simply says that the Act will give effect to certain provisions of the CRPD. While this is true, we believe the Act should go further to ensure that when implemented all aspects of the NDIS are consistent with and uphold the CRPD. Accordingly, ***SACOSS recommends that consistency with the CRPD be added as a General Principle Guiding Actions under the Act in Section 4.***

Such an amendment would ensure that the autonomy of people with disability to make key decisions which affect their lives is not merely a consequence of the NDIS, but is a clear and unambiguous purpose. It would also ensure that the NDIS is consistent with the commitment to the CRPD emphasised in the National Disability Strategy (NDS) which treats human rights as imperative: “People with disability must be afforded the same rights as all other Australians. ... People with disability are citizens with rights, not objects of charity” (Commonwealth of Australia, 2011, p.16).

Additionally, SACOSS recognises that while the NDIS is a step forward in ensuring that people with disability in Australia are provided with scope to exercise their autonomy in transacting with service providers, the realisation of the rights and aspirations of people with disability is not limited to the processes governing client-service relationships. The National Disability Strategy recognises that, for people with disability, barriers to engaging and participating fully in community, social and economic life relate not only to individual support needs but can and do result from external and environmental factors. Such barriers include inaccessible public and private buildings, lack of access to protection for their rights, disincentives to employment, a lack of capacity among education providers to offer inclusive high quality programs, and the lack of capacity across all health service providers to meet the needs of people with a disability (Commonwealth of Australia, 2011). It is important to recognise that without significant attention and funds to address *all* of these needs, individual funding for the support needs of people with a disability will not in itself enable equitable participation in our community.

Consequently, it is important that the NDIS is not seen, explicitly or implicitly, as an end in itself for achieving the wider goals of the National Disability Reform Strategy. This is particularly relevant where one of the Objects of the proposed Act at s3(1)(g) is to “raise community awareness of the issues that affect the social and economic participation of people with disability, and facilitate greater community inclusion of people with disability”. Much of this role falls outside the ambit of the NDIS and the scheme cannot and should not be expected to achieve this goal. The current financial allocation is such that it would be impossible to meet all of the National Disability Reform Strategy’s objectives within the NDIS budget. However, substantial publicity surrounding the NDIS, coupled with a lack of clear contextual positioning of the NDIS legislation within the larger Disability Strategy, may

potentially see the vital larger goals of the National Disability Strategy relegated to a less significant position. Or they may simply fail to be realised through a lack of adequate funding.

SACOSS therefore suggests that the NDIS legislation should give context to the role of the NDIS within the broader and more far reaching goals for the inclusion of people with a disability in all aspects of community life. Accordingly, **SACOSS recommends the inclusion of a preamble stating the vision for the Act and its place in the broader recognition of and supports for the rights of people with disabilities.**

SACOSS further **recommends that an additional clause be added at s3(3) stating that in giving effect to the objects of the Act, regard is to be had to “(c) any other national strategy agreed by COAG in relation to people with disabilities.”**

In addition, we **recommend that a further principle be added at s4(15) stating that the Ministerial Council, the Minister, the Board, the CEO and any other person or body that is to perform functions and exercise powers under this Act must have regard to “(c) any national strategy agreed to by COAG in relation to people with disabilities”.**

In the current context, these changes to the legislation would lead to the need to recognise the National Disability Reform Strategy and work within the UN CRPD and the *Disability Services Act 1986* (Cth).

Specific Issues

As noted above, this submission arises following consultation by SACOSS with key South Australian stakeholders and interested parties. Taking part in the consultation process were representatives from service providers, disability advocates, consumer peaks and South Australian state politics. In the absence of the NDIS Rules (due to be released in March 2013), close consideration of the operation of the scheme is not possible. However, the following are the key areas of concern drawn from participants during the consultation or from SACOSS' subsequent analysis of the draft legislation.

Age eligibility

In relation to eligibility for the NDIS, the draft Bill distinguishes between disability acquired before and after the age of 65. NDIS eligibility is limited to individuals with a disability who are under 65 years of age. A person aged 65 years and older in receipt of funding under the scheme can, however, voluntarily choose to instead access services from the aged care sector. SACOSS supports a system where people with a severe and permanent disability are given such a choice, but is concerned that support under the NDIS will not be available for those over 65 so that those people will not have the same choice.

Impact on services for those not eligible

In line with the issues raised above in relation to the general framework and the NDIS not being seen to be the totality of disability support, anxiety was also expressed during the consultation process about the potential threat to services currently being provided to people who may not be eligible for the NDIS. SACOSS and the members it represents are eager to know how services will be maintained for individuals who are not eligible for the NDIS. Anxiety and concern on this point is especially acute given the recent South Australian experience of state government funding cuts related to changed involvement of the Federal

government in health funding. The “McCann Review” (2012) recommended cutting a number of preventative health initiatives on the grounds that the roles would be taken on by federally-funded Medicare Locals, although these services are not in place and will not be able to fill that role in the immediate future) (SACOSS, 2013). SACOSS would obviously object to a similar scenario being played out if there were cuts to state-funded disability services. On the other hand, concerns were also raised in consultations about potential duplication of services, with the existing Disability SA case management services likely to be similar to the agency referral and brokerage role.

While it is difficult to legislate against adverse impacts on services provided by agencies outside of the sphere of the NDIS, **there should be systems in place to monitor and evaluate any such negative effects**. These should form part of the Review of the Act, and a specific recommendation about this is made in the section below dealing with the Review.

Access to early intervention support

As a general principle in a wide range of areas, SACOSS supports early intervention as being a best-outcome-for-client and a most cost-effective approach. However, there is a concern about the exclusion of some individuals from early intervention services under the legislation because of the difficulty in predicting the extent of future gain from intervention to prevent deterioration as required under per s25(b) and 27(1)(d). Again, the issues here are difficult to comment on in the absence of the Scheme rules, but there was particular concern from SACOSS stakeholders that any eligibility process should not be primarily reliant on a GP as they may not have the capacity to make that judgement. Accordingly, **there needs to be clarification about the process for establishing eligibility for early intervention support**.

Purchasing services

The requirement under s33(6) that funding for supports can only be to “registered providers of supports” may significantly reduce the ability to provide individual, cost effective and innovative services. For example, a suitable locally-based individual service provider may be able to provide services to one person with a disability but may not wish or be able to register as an “approved provider”. **SACOSS strongly recommends that the requirement to be a registered service provider be relaxed**. This would enable the pilot to provide an opportunity to test the efficacy of such local and individual service solutions.

SACOSS consultations also revealed a particular concern in relation to programs dependent on block funding. The change from block funding to arrears in individual client payments may mean that smaller organisations which lack the capital reserves are unable to participate in service provision under the NDIS. This would potentially limit choice and innovation.

SACOSS recommends that s5, “General principles guiding actions of people who may do acts or things on behalf of others”, should reference the need to encourage choice and consideration of different sources of support i.e. from public, private, non-government or informal community networks.

Cost of service brokerage

Concern was expressed about the proportion of funds that may be allocated to “middle-man” service brokerage and planning rather than to direct services or benefits to the individual participant. At the present time, it is unknown how funding will be allocated and whether

these costs will come from the same stream of funding available for direct services. If this is to be the case, the **legislation should state a principle that the cost of brokerage services will be minimised so as to ensure the funding allocations are designed to maximise the benefit flowing to the individual participant.**

Conflict of interest

SACOSS is concerned that there may be inherent conflicts with the Agency's role as both a budgetary regulator and a service broker for individuals. There may also be conflicts of interests for non-government organisations which are service providers but also take on brokerage roles. The management of funding for supports should be by the participant and/or an independent third party which does not have an interest in the rationing of funding.

SACOSS recommends removing "the Agency" as one of the potential managers of funding supports under ss42 and 43(4),(5). Another option for separating the regulatory, budgeting and plan management functions might be through the use of an independent brokerage agency.

In addition, **SACOSS recommends that a clause be inserted after s43(1) either prohibiting any agency, organisation or individual who is managing the funding for supports from also providing supports to that participant, or alternatively and at a minimum, requiring the disclosure to the participant of any financial or other relationship between the person managing the funding for supports and the support providers.**

Evaluation of outcomes for individuals

SACOSS is concerned that the bill does not provide process for periodic evaluation and review of participants' plans. Without such process, there is a substantial risk that participants' plans may not meet the stated goals and may continue unmonitored and unchanged. The legislation should also provide minimum requirements and specific outcomes that should be included within the plan.

Part 2 Participants Plans Division 2 attempts to ensure that the participant is central to the planning process. In order for participants to effectively engage with the plan and to ensure value for money, the plans need to be measurable. This will require considerable skill on the part of plan developers to ensure the plan accurately reflects a participant's goals and aspirations, is understood by the participant, and progress towards the stated goals and aspirations can be evaluated/measured.

It is also the case that in this section of the legislation, guidelines are established specifying that general supports must be included in the participant's plan. As set out in s33(3), a support included in the plan may be "described generally" or in relation to a specified purpose. While this may allow for some useful flexibility, there is a danger that supports being "described generally" could result in plans where funding supports do not have a clear purpose. This could be to the detriment of the participant and does not promote accountability of the agency. **SACOSS recommends that these sections be revised to state that supports included in a participant's plan need to be described in relation to a specific purpose/purposes and in such a way that the achievement of the purpose can be evaluated, and that periodic evaluations of the outcomes of plans are required.**

Gaps in the review process

The legislation in its current form provides a review process for some but not all decisions made under the NDIS. SACOSS submits that all decisions, including refusal to make a decision, should be subject to internal review. This is important in light of s103, which only permits applications to the Administrative Appeals Tribunal in respect of a *decision* made by an internal reviewer. In particular, two standout sections of the bill should be subject to review but are missing from s99 Reviewable Decisions: ss197 and 44.

In relation to s197, while it is reasonable to give the CEO discretion not to make a decision if a request or application is not in the required form, the “decision” not to make a decision should be reviewable. It is conceivable, for example, that a person is unable to include all information or documents in making an access request (s19). The “decision” not to make a decision on the access request in this situation should be able to be reviewed. Further, there should be a requirement to inform the applicant of what they have failed to comply with.

In relation to s44, the legislation places strong emphasis and importance on giving effect to the participants’ wishes, including in relation to management of funding. However, when a decision is made under s44 to refuse a plan management request, that decision is not reviewable and there is no requirement for reasons to be given. This is inconsistent with the principles underlying the legislation and the clear rights of the participant to manage their own plan.

SACOSS recommends that these gaps in the review provisions be addressed at a minimum by inserting s197 and s44 into the specific sections into s99 Reviewable Decisions, but more desirably by amending s99 to make all decisions of the CEO, including the refusal to make a decision, a reviewable decision.

Governance

The legislation establishes a Board and an Advisory Council and SACOSS supports the requirement that at least 4 members of the Advisory Council are people with disability who have skills, experience or knowledge relating to disability services. However, the draft legislation does not contain any requirement for the Board to have representation from people with a lived experience of disability. As decisions made by the Board may have implications for participants and people with a disability generally, adequate representation on the Board is also necessary.

SACOSS recommends that the following words be inserted at the end of s127(6) “and that at least 2 members are people with a lived experience of disability either as carers or as a person with a disability.”

Review of the Act

Section 208 of the bill provides for a review of the operation of the Act commencing on the second anniversary of its commencement. SACOSS welcomes this provision, but believes that the terms of the review are not adequately spelt out in the legislation. At a minimum the review should evaluate whether the objects of the Act are being achieved, and we have noted above the need to evaluate the impact of the NDIS on disability support services outside the NDIS.

SACOSS recommends that s208(3) be amended with the addition of the following words at the end of the sentence:

“and must include:

- (a) an evaluation of the extent to which the objects of the Act are being met; and**
- (b) an evaluation of the impact of the NDIS on disability support services operating outside of the legislation.”**

The budget & funding allocation

There are two related issues of concern in regard to budget and funding allocations being adequate to achieve the stated objects of the NDIS. Firstly at the individual level, funding allocations on the basis of “reasonable needs” and a “reasonable budget allocation” are vital in any consideration of the scheme’s ability to meet identified needs and aspirations. The budget for an individual will need to be determined with consideration of the environment within which they live, the mainstream supports available and the “reasonable” costs of support. These may be highly variable even between individuals with similar diagnosis and functional needs. *It is assumed, although not confirmed in the draft legislation,* that funding will be allocated after appropriate identification and assessment of participant needs and aspirations and will be adequate to meet those needs.

Secondly, the ability to meet individual needs adequately will wholly depend on the budget for the entire NDIS scheme. Rationing of resources is the current experience of people with a disability and the extent to which this takes place under the new scheme may well determine its fundamental difference from the current “inadequate and indefensible” disability services system. Individual choice is impossible without adequate resources.

Although perhaps beyond the ambit of the wording of the legislation, SACOSS cannot make a submission on the NDIS without emphasising the need for adequate funding for the scheme.

Conclusion

SACOSS commends the government in developing the National Disability Insurance Scheme as being a significant advance on existing models of service delivery to people with disability in Australia. In so far as the NDIS is designed to respect the rights and aspirations of people with disability as independent and autonomous individuals, this is an important and worthy scheme. However, there are some areas in the draft legislation which SACOSS believes require strengthening if the NDIS is to achieve its goals as established in the Objects of the Act, and in accordance with the principles upon which it is based.

These points were elaborated above with recommendations made for ways to strengthen the legislation so that the NDIS does indeed multiply and enhance the choices available to people with disability. The importance of properly contextualising the NDIS has been emphasised – it is a tool to realise the aspirations and needs of people with disabilities, not an end in itself or the entirety of the supports required. This goes beyond the legislation and the NDIS, but SACOSS has made recommendations to incorporate recognition of this broader context into the legislation.

SACOSS would be happy to provide further evidence to the Senate Committee in relation to any issue raised in relation to this submission and looks forward to the Committee’s recommendations and an amended bill.

References

Gillard, Julia (2012) "National Disability Insurance Scheme Bill 2012 Second Reading Speech", *Hansard*, Australian Commonwealth House of Representatives. Thursday 29 November, 2012.

Commonwealth of Australia (2011) *National Disability Strategy 2010-2020*.
<http://www.fahcsia.gov.au/sites/default/files/documents/05_2012/national_disability_strategy_2010_2020.pdf>

McCann, W. (2012) *Review of Non Hospital Health Services*, Government of South Australia, Adelaide.

SACOSS (2013) *Submission to the Review of Non Hospital Health Service by Warren McCann*, South Australian Council of Social Services, Adelaide.