

Disability Care and Support Inquiry
Productivity Commission
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Re: Issues Paper, Disability Care and Support Inquiry

We write in response to the May 2010 Issues Paper in relation to disability care and support.

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 Issues Paper as well as issues raised in the submission made by the ACOSS on behalf of the COSS network. SACOSS contributed to and supports the COSS network submission. This submission is designed to supplement that national COSS submission and deals mainly with the framework of the Productivity Commission Inquiry and the process of change.

Terms of Reference and the framework for a system

SACOSS believes that fundamental to any system of long term disability care and support are the assumptions and framework which underpin it. Before we begin designing systems to deliver specific services and supports, we need to decide whether or not, as governments and as leaders in our community, we sincerely want to ensure that people who live with a disability belong at the valued core of community life?

If, as a community, we are agreed that people living with disabilities should be at the centre of community life, and that they should be supported to access all "the good things in life", then it follows that the supports we make available to them must be both sufficient and delivered in a way that ensures this happens.

There are many starting points for such an approach, whether it be from the very beginning of life, ensuring young parents are supported to think optimistically about

the future that awaits their child, or in the emergency waiting room soon after a critical road accident likely to leave someone with disabilities. First and foremost, however, it must begin within our community. The practical and physical barriers to participation must be minimised, venues and community facilities made accessible, housing universally built to facilitate ease of living for people living with disabilities, our schools made welcoming, and community groups supported to embrace and include people with disabilities in all aspects of their activities.

People who live with a disability inherently have the very same needs as all other community members. However, sadly, many, if not most, will also have had a wide range life experiences which have seen them rejected by other community members, congregated and segregated as a group, and subjected to a range of practices that would rarely be accepted for other members of the community. These types of experiences are reflected in many of the individual submissions to the Productivity Commission Inquiry.

The opportunities made available to many, if not most, people who live with a disability will typically be limited not just as a result of the impact of their disability but more by the way our community reacts to and supports them. This implies that in addition to any needs for personal support and assistance that might flow from the person's disability, access to the good things in life will be limited by our community's willingness to engage with, welcome, and support people's participation as valued citizens.

When the community does engage positively, participation of people with disabilities is possible and valued. One of our members provided an example of this with the Scottish piper (bagpipe) community in Adelaide being able to fully embrace people with Asperger's syndrome. Apparently many people with Asperger's are excellent pipe players, but rather than seeing the way forward as establishing disability-specific bands or groups, the Scottish piper community has embraced those people by listening to what they need and attempting to accommodate that. In some instances mentors help people with Asperger's navigate cultural norms and point out inappropriate behaviour, knowing that this may not be clear to the person. The beginning point for this engagement was seeing the person with Asperger's as a whole human being and listening to work out what they needed to function in the community. This was community-level action rather than a service provision, and was based on the assumption that the best place for the person with a disability is in the broad community.

The harrowing stories in many of the submissions to the Inquiry suggest these examples may not be the majority, and that there is still a long way to go in making the changes necessary in the broader community. Those changes are as much a part of "disability care and support" as any disability-specific services, and any scheme for delivering those more specific services needs to be put into this broader context or else it will simply continue the marginalisation of those with disabilities – at great cost to both them and the broader community. In that sense, a social insurance scheme should be seen as a potentially useful mechanism, but not the whole part (or even the centre) of a system of disability care and support.

Furthermore, we are concerned that the Terms of Reference for the Productivity Commission Inquiry focus on people with severe and profound disability – and only those whose disability is not acquired as part of the natural process of ageing. In addition to the issues raised in the COSS submission around ageing, we suggest that the focus on "severe and profound disability" is also problematic. Such a focus is underpinned by a medical model of disability that focuses attention on the physical

bodies and sometimes (though not always) the mental capacity of those with disabilities, rather than on the rights and lived experiences of people. The model does not take into account social and environmental factors and the fact that there is a dis/ability continuum across the whole population.

The critique of the medicalised model is important because that model creates a bias toward institutional treatment and “care”, rather than, as noted above, a system that enables and empowers people with disabilities to live in the broad community, with access to all the rights and experiences of life commonly expected by and for other members of the population. As the NSW Disability Discrimination Legal Centre’s submission to this Inquiry notes, this is not just an aspiration: it is a legal responsibility pursuant to Australia’s obligations under the UN Convention on the Rights of Persons with Disabilities.

Lessons from Previous System Changes

None of the above is to suggest that better systems of service provision are not required by those living with disabilities – indeed, as noted above, such services are required to enable people to live fully in the community. However, whatever recommendations the Productivity Commission finally makes in relation to the funding and provision of those services, it will be important to learn lessons from past attempts to change the system.

Over the last four decades there have been repeated inquiries, reports and investigations internationally, nationally and in almost every state and territory that have continually recorded the problematic nature of institutional programmes and services. These reports note the deep de-personalisation that often accompanies service structures which require the congregation and segregation of people who have a disability. It was this understanding that underpinned the federal government’s determination in the 1980s to introduce a new framework for the support of people who live with a disability, ultimately enacted in the Disability Services Act 1986 and supported in each of the states and territories by enabling legislation. The framework for future support services was established by the objectives of the Act, which laid out inspirational goals for the way in which funded services were to operate in future.

This development was greeted with excitement by many people, and led to the development of a new generation of community based organisations, often led by people with a disability and/or family members (typically parents) concerned for the future welfare of a son/daughter living with a disability. Typically these were small initiatives, sometimes sponsored by larger more traditional services.

There was some effort to build the capacity of traditional organisations in the sector to move toward changes that would see support services become more personalised and focused on helping people belong to their local community. There was also some effort to ensure community members and community groups got some assistance to re-conceptualise their role in opening up opportunities for the participation of people who live with a disability. Equally some effort went towards ensuring neighbourhood schools took up the challenge of including children who lived with a disability.

At the same time, however, almost from the outset there was widespread fear-mongering from some parties about the increased vulnerability that might flow from providing support that would lead people toward active lives embedded and employed alongside other community members in their local communities.

With the benefit of hindsight it is possible to see that the investment made in supporting reform of service and support arrangements was insufficient. A greater investment was 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.

The failure to make these changes resulted from a combination factors including:

- sincere limitations due to the amount of funding available to support reform of existing services and to promote development of new service entities;
- a lack of understanding about the complexity of such a change process;
- institutional reactions to demands for change, including the fact that those with the most entrenched traditional service models often also had the most resources to resist change;
- failures to institute proper audits, and sanctions on services that failed to demonstrate movement towards the new objectives;
- limitations in ensuring other parts of government and community services reformed their own practices so as to include the interests of people who have a disability;
- insufficient investments in new styles of support services that could convincingly demonstrate how to ensure people could get better support in their local community; and
- a lack of sustained leadership ensuring the interests of people who live with a disability were afforded deepest regard.

SACOSS contends that any scheme that looks to play a helpful role in the lives of people who have a disability must take full account of this history and be founded on the learning that flows from this.

We thank the Commission for your consideration of this submission and look forward to seeing and commenting on the draft report when it is released.

Please do not hesitate to contact me on (08) 8305 4222 or email ross@sacoss.org.au if you have any questions regarding this submission.

Yours,

A handwritten signature in black ink, appearing to read 'Ross Womersley', written in a cursive style.

Ross Womersley
Executive Director
South Australian Council of Social Service