

Social Inclusion Blueprint for Disability Reform
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Re: Discussion Paper - Activating Citizenship: A Social Inclusion Approach for Disability in South Australia

We write in response to the July 2010 Discussion Paper in relation to the Board's mandate to develop a blueprint for the reform of support available to people who live with a disability, as well as to their families and carers.

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 Discussion Paper and welcomes the opportunity to contribute to a process for reform. SACOSS agrees with the premise of the paper – that fundamentally this is a discussion about citizenship and our community's willingness to actively treat people who live with a disability as citizens and valued members of our community. SACOSS notes that this South Australian discussion is taking place against a backdrop of the Productivity Commission Inquiry into a national system of long term care and support for people who live with a disability.

SACOSS also notes that this reform process takes place in a context where there is enormous disenchantment and even anger from people who live with a disability and their families many of whom have felt abandoned and alienated by government and the community. There is no doubt that for the great majority of people the current support system is lurching from crisis to crisis plagued by both a lack of resources and often times a lack of vision. Moreover, the system is currently located in a community which still has to be challenged in almost every life domain, to open up the doors of participation and possibility to people who have live with a disability.

Terms of Reference and the framework for a system

SACOSS believes that fundamental to the reform of the systems that support people with a disability 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 repeatedly reflected in the stories told by people who live with a disability and the people who care for and surround them. These experiences are also reflected in vast majority of individual submissions made to the Productivity Commission’s national 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 outlined in reports and submissions made to countless previous inquiries suggest these examples may not be the majority, and that there is still a long way to go in making the changes necessary to ensure people who live with a disability are welcomed as valued and valuable members of the broader community. Those changes are as vital to reforming “our system of 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. SACOSS contends that this would be at great cost to both people who live with a disability and our broader community.

In that sense, mechanisms such as a social insurance scheme or indeed individualised funding frameworks should only ever be seen as potentially useful mechanisms, but not the whole part (or even the centre) of a system that leads to, nurtures, and promotes, the active inclusion of people who live with a disability.

We are also concerned that the definition of disability as framed by the South Australian Disability Services Act (1993) 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. We agree with the discussion papers suggestion that such a framework for defining disability does not take into account social and environmental factors or acknowledge 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. SACOSS notes that 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 Social Inclusion Board 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 reform process that looks to contribute to ensuring people who live with a disability are embraced and actively welcomed as citizens must take full account of this history and be founded on the learning that flows from this.

SACOSS also contends that reform needs to take place at all junctures of our community. A key starting place is in our child care and schooling system. It is here where we have most opportunity to positively and negatively shape attitudes to disability.

Historically, our failure as a community to ensure children who live with a disability are welcomed and actively included alongside all other children in their local neighbourhood child care services and schools has set a tone – not just for those children who have a disability and the people who love and support them, but for all those other children and adults who have been taught that those children are fundamentally different from all the others and therefore need different forms of nurturing and support.

SACOSS contends that potentially the strongest opportunity we ever have as a community to reform the way in which people who live with a disability are perceived and treated, starts here. It demands outstanding modelling that demonstrates welcome and how to ensure genuine inclusion to an ever emerging generation and the families who surround them.

At the very same time we must also be working at an overarching level to assist the broader community to embrace people by building a framework for equality based on the United Nations Convention on the Rights of Persons with a Disability. We need to work to enhance the basic accessibility of all elements of community life and this must be underpinned by strong advocacy and active community development. This capacity to include then needs to extend out from education into all other elements of community life be that health care, housing, transport, work and recreation.

Last but by no means least, we must build a system of providing personal support to people who require this on a day-to-day basis, which is highly personalised; which gives these people as much authority and control over these resources as is possible; and which also provides them with the expert guidance they might need so as to ensure the support they receive constantly works to embed them in the life of their local community.

Of course, SACOSS acknowledges that none of this will be possible without a major commitment on the part of government and community organisations. We cannot ever underestimate the investment in community development and sector capacity building that is required in both the disability sector and the community more broadly.

There are still far too few excellent examples of how people are and have been well supported to enjoy all that our community has to offer.

There are still far too few people well placed to lead the kind of change required.

There are still far too few services properly engineered to provide people with support that is highly personalised and empowering.

There are still far too few people that see it is their own individual responsibility as citizens, to embrace and include people who live with a disability.

There are still far too many government, private sector and community organisations who recognise that they too have a basic responsibility to ensure that the services they provide are welcoming and inclusive of people who live with a disability.

There is indeed a need for major reform that crosses all these domains!

In closing, we sincerely thank the Social Inclusion Board for the opportunity to contribute this submission. We look forward to seeing and reflecting on the blueprint when released, and to supporting the deeper reform of services and our community, so as to ensure people who live with a disability and the people who care for them are able to lead rich a contributing lives as valued members of our community.

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', with a large, stylized flourish at the end.

Ross Womersley
Executive Director
South Australian Council of Social Service