Organising and implementing a new disability policy

What are your views about the ‘nitty gritty’ aspects of a scheme that will make it work practically?

The most important aspect of any new scheme involving people with Disabilities is for the government to understand a few practical realities that seem to have been overlooked in the past.

1. The overall cost of living for someone with a disability and their family is substantially more than for a person without disabilities.

2. The degree to which someone with a disability, and their carer can contribute to the community through work, social engagement, sport etc will be affected by these additional costs, as well as other factors.

3. Funding for respite support must be **BUILT IN** to any event or occasion where carers are asked to attend.

   Recent Carer Consultations around Australia were supposed to give carers an opportunity to participate in forming new strategies. However, funding was **not** provided for the provision of support workers to care for the person they usually cared for during the consultation process! This meant many carers could not participate, and highlighted the depth of the government’s ignorance of even the most basic needs of people with disabilities and their Carers.

4. The flexibility to ‘bank’ a larger number of hours of ISP support so that people with disabilities and their families can go on a holiday, or take a short term break from support for any reason without it affecting their funding, is essential.

5. Services need to be able to offer a wider range of activities and experiences for their customers. Most service providers (in Tasmania) seem to offer a narrow range based on white, middle class values and interests, and seem unable to look beyond the local community for activities.

6. The practical assistance a person with a disability and/or their family may need could be almost anything, depending on their location, age, disability, circumstances, work, interests etc. As such, the funding provided should be flexible enough that it can allow a

far wider range of service options.

What services are needed and how should they be delivered?

What kinds of services particularly need to be increased or created?

Services that are far more flexible in their ability to cope with the way consumers want to live their lives. Eg At present hours and days of support are “locked in” and difficult to change because of staffing issues.

A more flexible system would allow consumers and their families to live more normal lives, with the support enhancing their lives, not running their lives.

I believe nothing will substantially change for the better until the Government ensures that service delivery for consumers and Carer’s needs mesh.

One way of improving this would be by the introduction of Multidisciplinary Day Centres, where consumers can receive in house service provision, activities, job training, personal support etc whilst, at the other end of the centre Carers and families can attend their own activities, wellbeing courses, Carer training sessions, employment options etc.

In some cases, these could be located adjacent to existing rehab facilities, Job network providers etc.

In other cases, especially larger regional centres, accommodation should be included as part of the centre, so more remote consumers and their carers/families can attend the centre for blocks of time at regular intervals.

A mobile services for the far remote areas could be created to operate in two ways:

1. Mobile units (semi truck type) can travel to remote townships and communities. They

would offer a range of prebooked services for consumers and their families for a specific period of time. Assistance with the cost of nearby accommodation could be attached (similar to the Patient's Accommodation Scheme).

2. For the far remote consumer, I suggest a program where trained staff and/or volunteers contract to provide individual services for a specified period, eg 4 – 6 weeks at the home of the consumer. Properly trained volunteers could assist here, receiving costs and accommodation in exchange for specified hours of provision of services such as respite, education, physio program (devised by professional physiotherapist) etc.

   The VISE program offers a similar structure for assistance to remote families and takes advantage of the many grey nomads travelling in Australia, who represent an enormous pool of experience and labour that could be tapped.

Transport is another area where we struggle. We desperately need access to appropriate free transport to get my husband to programs, respite etc. This scheme needs to be available in regional areas too.

Again, a volunteer program, similar to the Red Cross Transport scheme may be appropriate for many people and less costly to set up and run.

How could the ways in which services are delivered — including their coordination, costs, timeliness and innovation — be improved?

See above

Plus -

I really believe a "one person" case worker approach would work best. This simplifies the number of agencies and departments an applicant and their family must liase with, and allows the case worker time to come to know the situation well enough to be able to more accurately assist and assess needs, and make appropriate responses.

We all know what a complex, interconnected and non transparent patchwork this area has become over the years. . A far more transparent, understandable and consistent approach is urgently needed so consumers and their families can knowledgably and confidently navigate through the process of assessment, funding and service application etc.

How could a new scheme encourage the full participation by people with disability and their carers in the community and work?

Obviously this will vary enormously with the individual needs of each consumer, however, I would offer the following thoughts:

One of the main obstacles to employment for people receiving Disability Support from Centrelink, is the current Centrelink legislation around earnings, and Health Care Cards.

Recognising the additional costs associated with disability, and changing the ratio of pension reduction to income earned would assist carers and people with a disability to actually benefit from work For many people, additional costs, because of the disability, incurred in working, make it unviable.

However, I believe the most urgently needed change is in the rules around Health Care Cards. If we accept that (speaking broadly) people with a disability incur additional expenses because of their disability, then that cost needs to be recognised by changing the legislation to allow people with a Disability, and their carer (or family member who contributes to the costs of the person with a disability) to keep their Health Care Card for as long as their income is below a defined threshold, rather than for a specified time.

Eg A person without a disability may be able to manage without a Health Care Card when their income reaches $50,000pa because they are healthy and would not need to access medical services frequently, can catch public transport etc. A person with a disability may need that threshold to be $85,000pa or more.

If this inequity were addressed, I believe more people on Disability Payment would be able to afford to work, at least part time.

Expanding the current Day program schemes to include longer hours, and programs more suited to particular types of disability eg ABI, might make these more desirable options, allowing Carers to work part time.

What should be done in rural and remote areas where it is harder to get services?

See above