Personal Response to questions posed by the enquiry

My personal situation is that I am the mother of a 20 year-old young man who has severe intellectual impairment and autism. He has difficult behaviour and requires a great deal of care. I have recently given him into the care of the State Gvt.

1. **Who should be in the new scheme and how could they be practically and reliably identified?**

Anybody who needs a carer as currently assessed by Centrelink could be included in the scheme. There could be a sliding scale of how many carer hours per week the disabled person needs to decide how much support the disabled person would be given.

2. **Which groups are most in need of additional help and support?**

I do not think that additional support should be given to "groups" who are identified statistically. Disabled people should be assessed by individual need and not according to which "group" they belong to. If additional support is given to people because they belong to this or that group, then anyone outside the group misses out and the system would be unfair.

3. **What could be done about reducing unfairness, so that people with similar levels of need get similar levels of support?**

I think that first we need a system that is run by the Federal government so that people will not have different support in different states. I think that no disability funding should be given to the states and that all the money be distributed directly by the Federal Gvt.

We also must have some system of entitlement so that people do not have to beg. If a person's situation is established then they ought to have the right to receive certain supports because of that situation. The current system (I live in Qld so am aware of what happens here) allows disability Qld to give support according to priority which they decide themselves. No-one currently has any entitlement to support beyond basic food and housing for homeless disabled people who cannot look after themselves.

Centrelink are masters of the art of drawing up tables and sliding scales and allocating points to determine how people in similar situations get similar levels of support. Something similar could be done for disability support.

4. **How could people with disabilities or their carers have more power to make decisions, and how could they appeal against decisions by others they think are wrong?**

Establishing entitlement would be the first step in giving people control. If the funding belonged to the person they could then decide how it would be spent. An appeal's tribunal could be established where people could put their case.

5. **See my answer in Q3**
6. **What kinds of services need to be increased or created?**

Every current service needs to be increased especially training in work skills. There needs to be more attention to work skills training and not just the living skills training which is mostly what is available at the moment.

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

As per Q 6 more training in work skills is needed for disabled people. For carers we need an extension of the current childcare arrangements so that carers can go out and earn some money. Childcare should be renamed as Personcare and be available for anyone who is a carer with appropriate rates depending on how much care is needed.

12. How could a new system get rid of wasteful paper burdens, overlapping assessments and duplication in the system?

The current system where community or church groups establish facilities for particular people or in particular areas and seek funding for their “cause” leads to a lot of overlapping and “run around” for disabled people and their carers. If we go back 50 years or so something similar used to be the case for disabled people seeking education. The situation was changed when the Qld Gvt accepted responsibility for the education of all children and took responsibility for the schools which community groups had already established. If the Federal Gvt takes responsibility for all disabled people’s support and we have a system of entitlement then all the multitudinous community groups will not need to have lots of different assessments and forms and duplication.

13. How can it be ensured that there is enough money to deliver the services that are needed and provide greater certainty about care in the future?

First we must do our best to keep our country prosperous because a poor country will not have money for disability. We also need to persuade the Australian population that disabled people are worth spending money on. It is the mindset which makes the difference. We always have enough money for the things we value.

The National Disability Insurance Scheme would be a useful way to fund disability support just as Medicare is a useful way to fund healthcare.

Thank you.

Joan Lammas