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I am the mother of Alice who is 22 and was diagnosed with Cerebral Palsy, bi-lateral hearing loss and severe intellectual delay in infancy and I welcome the opportunity to answer the following questions as part of the inquiry.

Q1. What kinds of services particularly need to be increased or created?

At the moment Alice has access to community participation for 24 hours a week. This need to be increased to a minimum of 40 hours so her parents can both work full time, like most parents in Australia do. Alice's brother only works casually so he looks after her on Thursdays but, if/when he couldn't/can't it costs \$196 for 7 hours of care, which almost equates to her full pension for the week before she turned 21 and the Labour Government finally increased pensions last year. As it is, with the cost of her taxis, her aftercare care, her clothes and other sundries, Alice meets her own expenses and saves something towards the future, but she doesn't contribute anything to the household. This would make it extremely difficult for a single parent, divorced parents or parents who would both choose to work fulltime if they could but they can't because of the needs of the child and, therefore, have a reduced income.

Alice is 22 and we are both 50. I have developed a hernia and am not supposed to lift heavy objects any more (ever! - which is totally impossible). We are divorced and share Alice's care - 50% each - week about. I don't believe that I would last long caring for Alice fulltime and I probably shouldn't be doing it at all any more. I'm fairly certain her father couldn't sustain it for very long either.

At present there are no accommodation facilities for people with high support needs in Wagga at all and no plans for any. So, if we declared ourselves unfit to care for Alice she would have to live either in the hospital or in a nursing home for the aged - completely inappropriate.

We are looking at caring for Alice forever, she is quite fit and healthy as far as we know, so we may well arrive at our seventies (if we are lucky) and have cared for Alice for forty years and had very restricted opportunities to enjoy the kinds of experiences, activities and relaxation that many people take for granted.

In brief - an increase in the number of hours of care per week and the provision of a choice to have the person accommodated in a modern, pleasant, caring facility - we're talking huge dollars Australia wide!!

2. How could the ways in which services are delivered be improved?

I have found that the ways in which services are provided have been steadily improving and that we no longer have to repeatedly fill out forms of 8,10,12 or more pages. However, that may be because Alice is older and her life is more stable. So it may be a factor that still needs improvement for carers of younger people.

Centrelink has definitely improved from annual forms requiring medical input to either 5 yearly or lifetime for people with permanent disabilities such as Alice.

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3. Are there ways of intervening early to get improved outcomes over people's lifetimes? How would this be done?

I found, even twenty years ago that there was an effective early intervention program in Wagga. I had access to the Spastic Centre in Sydney twice a year for a week so that was great. I don't know what waiting lists are like now and I'm sure that it's incredibly difficult in more remote areas.

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

I think I addressed this in my response to question 1. there is still much to be done to relieve what is unquestionably a burden on carers of people with a disability (even when you love them to death) but, in my experience, services and support have been steadily improving over the years and I think I would still rather be living in Australia, in that regard, than most other countries in the world.

5. How can a new system ensure that any good aspects of current approaches are preserved?

I would think that the most sensible way of achieving that would be to invite people who are involved in all aspects of the current system/s to have input into what is working, what is not and what is still needed.

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

More, much more, of what is gradually happening. Where the livelihood of the carers is grounded in remaining in a rural or remote area where services are not available, full accommodation and support services need to be provided in the closest centre that is large enough to do so – it's really that simple (but obviously, once again, very expensive, and people with an intellectual disability generally don't vote!)

7. How could a new system get rid of wasteful paper burdens, overlapping assessments (the 'run around') and duplication in the system?

Obviously, in the 21st century, there needs to be a secure central database that virtually eliminates the need for ever having to fill out another form!!

8. How could people with disabilities or their carers have more power to make their own decisions (and how could they appeal against decisions by others that they think are wrong)?

This one is fairly difficult because the energy, initiative, goodwill and expense that are required to establish and sustain effective and comprehensive services for people with a disability is enormous and, therefore, most often (and especially in rural and remote areas) choice about the services that are available will be very limited. Wagga is large enough so that we could make a choice between three service providers for Alice's post-school options and I thought that was enough choice (sometimes too much choice can be challenging as well).

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9. How should the amount of financial support and service entitlements of people be decided (and by whom)?

These decisions require input from carers, doctors and other health professionals, educators and, where possible (depending on the nature of the disability/ies) the person with the disability.

In terms of priority, the people and carers of people with a disability that requires constant and total care and supervision 24 hours a day should be given first priority because they are the people facing the greatest challenges and having the biggest demands made upon them. At present I think they are often put in the 'too hard basket' because of the expense involved but our society is relying to a very large extent on the goodwill and energy of many thousands of devoted (but often exhausted) carers who do not have the time, means, opportunity or education to make changes and cannot opt out because of the abiding love and respect they have for their children.

Conclusion

I'm sure Alice would not object, and I am happy for all or any part of this submission to be reproduced and examined. I am not working this year, so I would also be happy to be contacted and invited to attend meetings, conferences and symposiums, to speak on behalf of both people with a disability and carers.