

My name is Samantha, I am 25 years old and I live in Melbourne's Outer East. My disability is Dystonia which affects me physically, as well as my speech. To get around, I use an electric wheelchair and use a Lightwriter to communicate.

I would like to comment on some of the issues I am having with supports:

- **Long waits to get the equipment I need - everything happens way too slowly!**

One of the worst examples of this is - it took over 2 years from when it became pretty clear I needed a motorized wheelchair to when I finally got one, and then yet longer to get transport training. This held me back unnecessarily from gaining independence and impacted on my self-confidence. I missed out on many opportunities to take part in the community, including doing some valuable volunteering.

- **My parents are still the main ones who provide on-going support for me – I would like to have the support I need to be able to be more independent from them.**

I had to rely on support from my parents intensely growing up and this put great deal of unfair strain and some extent trauma on my family and myself. Though I am able to do a lot more for myself now, I still would like and need to be a lot more independent from them. I need more support to enable me to get through my education and have a social life, as well as support for getting a job and to move out of my family's home.

- **My family have to pay for lots of extra things related to my disability**

My family has to pay for a lot of the supports I need. This should not be the case! If able-bodied people don't have to pay the costs for a disability why should we?

My suggestions about how a new scheme could make things fairer:

- **There should not be any means or assets testing for people with disabilities to get supports under the scheme.**

It would continue to make things very unfair if anything we manage to earn just disappears into our disability needs. It would also discourage us from becoming a

valuable part of the workforce. Again if able-bodied people don't have to pay the costs for a disability why should we?

- **There should be more supports under the scheme for young people with disabilities who are studying.**

All Uni and TAFE support needs to be universal, so wherever we go to learn we can be sure of the same level of support. It's hard enough choosing and getting to know a new learning institution without having to worry about support we are going to get there.

- **I think the new scheme should be about people with disabilities getting the supports they need, as individuals, to be more independent.**

We all need to have a life independent from our families. There should be more supports under the scheme for areas like education, socializing (especially attendant support), getting a job and moving out of home.

- **I think young people with disabilities should have a right to choose who supports them.**

People who provide us with personal care are helping us with very personal things and becoming part of our personal life. It's so important that we can choose and trust who's working with us to have any quality of life. In general, it's important to have support workers who are open-minded and good communicators.

- **I think a new scheme should also offer some supports for carers.**

Having to care for a person with a disability, especially over a long period of time, impacts on carers too. They should be able to get counseling, extra health checks, respite holidays, whatever they need as a result of being a long term care-giver. Ultimately there should not be one major care giver day in day out, year in year out, it isn't fair on either carers or carees.