

Kim Walker

Submission to Productivity Commission 2010

16 August 2010

Inquiry into Disability Care and Support
Productivity Commission
GPO Box 1428, Canberra City ACT 2601

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Dear Commissioners:

Productivity Commission Inquiry into Long Term Disability Care and Support

I am a person with intellectual disability. I have a sister with intellectual disability, who has more complex needs than I have. I am a member of People with Disability Australia (PWD) and the NSW Council for Intellectual Disability (NSW CID). I have been on the Board of both PWD and NSW CID.

I have worked in the disability sector as an educator for people with intellectual disability for 17½ years. I have also been on many Federal and NSW State Government committees advising on issues for people with disability.

In my younger years, I did not live at home with my parents as they were told by doctors to put me in an institution because nothing would become of me. Both my parents were migrants and didn't have any family to support them in Australia, and they felt that the doctors knew best.

Main Points:

- The new scheme should be for all people with disability who need support. It should be fair for everybody.
- People with disability need to have different kinds of supports, and these supports will be different during their lifetime depending on their situation. People with disability shouldn't be denied support, they are entitled to it.
- A new scheme or system should be properly funded so that everyone can get the supports they need.
- The funding should go directly to people with disability, including people with intellectual disability. Some people with disability, including people with intellectual disability may need support to manage these funds, such as brokerage or management support services.
- People with disability need to decide what supports they need and control their own funding and supports. They may need assistance to do this, such as assistance from advocates, support workers, brokers etc, but the aim should be self-determination by the person with disability.

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- All people with disability should be treated equally in the new scheme or system; and funding should be allocated on an equal basis according to need.
- Funding and supports should empower and support the person with disability to get out in the community and belong.
- Support and funding needs to be flexible so that it can address the person's situation throughout their life.
- Funding and supports should move with the person so that they can live anywhere in Australia and not have to be on another system's waiting list, or receive different and worse kinds of support.
- The new scheme or system needs to ensure there is strong and independent advocacy to support people with disability and protect their rights.
- There needs to be clear processes and safeguards for people using the system and this includes complaints and appeals processes separate from the administration of the scheme or system.
- Children with disability and their families need to be provided with all the supports they need to ensure that children with disability can grow up with their families and know they belong, are loved and that they are not a burden on society.
- The Government needs to support the new scheme by providing community awareness around the rights of people with disability, around the value and dignity of people with disability, so that the community can understand that having a disability is not a bad thing and the community will accept people with disability.

Who should be the focus of the new scheme?

The new scheme should be for all people with disability who need support. It should be fair for everybody.

It cannot just be for people called 'severe and profound'. For example, my sister currently gets support from the disability service system because she has greater support needs than me. I am seen as having low to medium support needs and the disability service system doesn't provide support to me because I am not a priority.

There are very few services for people with low to medium support needs. I have worked so hard in my life to not have support, and this means that I haven't been able to deal with issues that would help me belong and participate in the community and make me feel good about myself:

- I lived with people with the same disability since I was three in an institution. In the institution, I always mixed with people with intellectual disability – in school, at mealtimes, at bedtime, and social events – so I never learnt how to mix and socialize with others, including other people with different kinds of disability.

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- I now live in the community on my own. People with intellectual disability who have low support needs often stay home a lot; they don't get out in the community like everyone else. If they have lived in institutions, it is hard for us to know how to link in with the community and how they can link with us. It's hard to know how to make and keep friends.

The government forgets about the situation of people who lived in institutions, and people who do not live with their parents. Many of us live on our own and have support needs that come from being put in an institution. The government was wrong to put us in institutions and they should give us support now to assist us to live fully and participate in the community, to belong, to have friends and to feel good about ourselves. It doesn't matter if you are viewed as 'severe and profound' or as having 'low to medium' support needs. We all need supports throughout our lives and this support will change with our situations.

I believe that I would be in a different situation now, if there was system that allowed me to have control and make decisions about the support I need in my life.

I also believe that the new scheme or system should include groups from the start that might fall through gaps, especially:

- people with disability who still live in institutions and boarding houses;
- people with disability who are in gaol or juvenile detention centres;
- refugees and new migrants waiting for residency or citizenship status.

What should a new scheme cover?

The new scheme should cover everything you need in your life at the time you need it.

I should have had support in my life when I left the institution to learn live in the community independently. I had to work hard not to need support because there wasn't any for me. Now I find it hard to look for support because I have learnt to do without it even when I need it.

The government had negative views about 'disability' and decided to put people in institutions, which I think is cruel and they were wrong. I wasn't allowed to be part of a family, go to school, to work in the community or learn how to socialize in the community. I think the Government has a responsibility to make sure that the new scheme provides assistance for people with disability to deal with the grief and loss involved in the system they forced us into. People with disability didn't get a choice in this or support in dealing with this, but it can bring up really deep feelings and it can make you feel unloved and as though you don't have any self-worth.

I had a family for 3 years, then I lost them. I found my parents when I was 40 years old, but then they died. I had my father in my life for almost 7 years and my mother for 5 years. When they died, I found it very difficult to cope and to look after myself, and it got to the point where I could have lost my housing. It was only at this point of crisis that I was able to get support

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from the disability service system to assist with cooking, shopping, personal hygiene and paying bills. This assistance is very important but I should be able to get this before I have a crisis. I should also be able to get extra support like counseling for my grief and loss relating to the death of my parents.

The new scheme should enable me to control when I need support and the support I get so that when I have extra support needs I can get it. The new scheme also needs to ensure that supports are available like counseling services that have expertise in working with people with intellectual disability. It should enable me to get assistance in making decisions about the support I need and assisting me to understand the available supports and to feel comfortable with these supports in my life.

The new scheme should not provide any support for people to live in institutions. Everyone has a right to live in their own home with the right support so that they can live in the community like everyone else. There should be no institutions at all. I am concerned that the NSW Government is still saying that people with disability, because they have high medical and complex health needs, or because of their behaviour or because they are older, need to live in institutional facilities. The new scheme should ensure that this is not supported because it will create the same problems and difficulties for more and more people with disability. This is degrading and against their basic human rights.

How should the scheme be governed?

People with disability and representative organisations should be involved in all levels of governance in a new scheme.

People with disability and representative organisations should have control over any new system of care and support for people with disability. They are the ones that will benefit from the new scheme and they should control it – ‘nothing about us, without us’.

Some people with disability, including some people with intellectual disability will need support to be fully participating in their role on the governance body for the new scheme, and this should be provided. People with intellectual disability should always be on the governance body.

How should the new scheme be implemented?

The new scheme should be implemented in a way that ensures that the human rights of people with disability are carried out. This means that there should be strong and independent advocacy support and other safeguards and structures so that people with disability are supported to make good decisions and understand what the scheme does and what it means for people. This will include providing information in a way that a person can understand like pictures, posters, role plays and stories and information in Easy English.

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The new scheme should ensure that there are no people with disability who fall through the gaps in the different service systems. It should ensure that people with disability are supported so that they don't come into contact with the justice system or have to go to prison; and it should never support a person to be placed in an institution.

Concluding Points

This is the very first time people with disability have been asked to provide their views on their support needs, how support can work and what we want. I really appreciate this opportunity.

I would be available, with support to provide more information around this submission.

Yours sincerely

Kim Walker
