28 April 2011

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

Fax: Roberta Bausch, 02 6240 3377

Dear Commissioners:

Productivity Commission Inquiry Interim Report

I am writing a second submission to you now that you have released your Interim Report. I am a person with intellectual disability and I have a sister with intellectual disability. 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. My first submission is number 389 on your website.

I am very pleased that the Productivity Commission has decided to include people with intellectual disability in the new care and support scheme. A key point of my first submission was that people with intellectual disability with low to medium support needs miss out on supports in the current service system, and this causes big problems in being able to live independently in the community. My sister has high support needs and she is able to receive more supports in her life. She should get these supports but so should I. 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.

The main points I want to make in this submission are the following:

• People with intellectual disability should live in housing in the community, the same way as other people in the community. No person with disability should ever, ever be put into nursing homes or institutions, even redeveloped institutions where you pull down one building and build another one. In this environment, you can't learn about things out in the community, how to get support, or where to get support. Institutions for people with disability should never, ever happen again, and redeveloped institutions should not be allowed either.

The government forgets about the situation of people who have lived in institutions, like me, 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.

I have spoken publicly about closing the institutions that still remain or are being built for people with more complex needs than me in a DVD for the Shut In Australia Campaign.

You can see this DVD at: http://www.youtube.com/user/ShutInAustralia#p/a/u/2/Kh3jLOo8RAY

- People with intellectual disability should be involved in every process of the new Scheme, including in decision-making and governance of the system. We are entitled to say what we want in all parts of the new system. If we need support to do this, such as a support person then we should have this as part of the system. It may be complex at first, but it will be complex for everybody who is part of the new system.
- People with intellectual disability should be involved in the assessment for supports from the beginning to the end. It should be a self-assessment process, not a process where someone else decides what you need. People with disability may need a support person of choice to assist them through the self-assessment process. Support people should be funded and resourced by the new Scheme.
- Supports need to include assistance for people with intellectual disability during life changes. For example, when my father died, I had no-one to assist me with the grief and it had a huge impact in my life. It meant that I couldn't look after myself, and this lead to a risk of losing my housing and supports. The new system needs to recognise that people need to get supports as soon as possible during events like this. What about when people die? How can you get help with that?
- The new scheme should be for all people with disability who need support. It should be fair for everybody.
- 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 to become residents or citizens of Australia.
- It is really important that the new Scheme does not put people in boxes. For example, if you have an intellectual disability and a mental illness than you get put in two boxes and services tell you to go to the other box because you don't fit in theirs. The new system must not look at creating boxes, it must look at the whole person and what they need to live a quality life like everyone else and have human rights respected in a way the person needs to have them respected.
- 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. We shouldn't be told we can't manage our packages just because we need support to assist us, such as advocates, brokers, support workers or management support services. We want to manage the funds but we want to choose who will support us with managing the funds.

The costs to support us manage our packages should be included as part of the new Scheme.

We also want to decide who is employed to support us and who we work with. We want
to be able to keep our own records even if we need assistance to do this. Who assists us
and how it would work should be our decision not the new Scheme's decision. The aim of
the new Scheme should be for people with disability to have control over their own lives,
not the service system having control over us.

I really appreciate the opportunity to tell you my views about a new Scheme for people with disability, especially people with intellectual disability. This is important because we do not get asked for our views or what we want.

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

Yours sincerely

Kim Walker