

Submission to Senate Community Reference Committee.

I am writing because I have a sister with an intellectual disability. She lives at home with me. I want to say that at all times we are cognisant with the needs of people with physical disabilities. I have never ever met a person with a physical disability who is cognisant with the needs of people with intellectual disabilities.

Firstly I would like to say the Commonwealth State Territory Disability agreement has failed us as people with disabilities (PWD). It has not taken into account the needs of Carers and the needs of people with intellectual disabilities (PWID).

~~The New Victorian Disability Legislation has discriminated against us in that it fails to give us an entitlement to services under SEC 51 of the new Act. It also fails to recognise the families of PWID. As these people often can not advocate for themselves the families who provide the 24 hour care saving the taxpayer thousands of dollars, need to be heard.~~

As families who advocate daily we have no official role and no legislation that protects us. Currently the Guardianship Board in Victoria seem to believe that a person providing 24 hour care on a carers allowance and the pension of the PWID is making some sort of a profit. They demand audits every year to ensure you are not exploiting the PWID. This is not possible on a carer's allowance and a disability pension.

Families are ostracised everywhere. The DAC of Victoria is made up of PWD that are physical and they make decisions on behalf of PWID. They have no expertise and no idea what is needed.

There is no advocacy service that represents families of PWID or their Carers. All advocacy services are geared to represent PWD who can advocate for themselves.

There is huge unmet need in Victoria and this need is constantly ignored by politicians and the CSTDA and by advocacy groups who are represented there. They do not advocate for carers or PWID or families.

This situation would be much better managed without the need for the CSTDA and direct funding as in the aged care system. Unmet need will only be addressed in Victoria when the Commonwealth Government assumes the role as in aged care.

Currently the Victorian government via the DHS dictate the size of the house PWID can live in. That is a 6 bedroom house. But in the aged care sector other options are available.

My sister could afford to buy into a retirement style village with 6 bedroom houses where there were staffing facilities. But the Victorian Government and DHS discriminate against PWID by telling them what is and what is not appropriate. All options should be available to PWID. There is a vast range of disability in this category. Gated communities would enable PWID to get out of Gaol and live in the community. Locally we have a gated community for neuro typical people. If neuro typical people can have these communities then why not PWID to get them out of Gaol?

There are a vast range of options and it is not appropriate for DHS and Victorian Government to dictate what is appropriate.

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All options are available in aged care. So why not disability? It is age discrimination to enforce these rigid housing models in Victoria.

Carers and families who provide 90% of the care are being abandoned and the only way to solve this matter is to have the Federal Government intervene to save families and carers of PWID and often physical and sensory disabilities as well.

Mental health is another area where options in housing need to be explored. There are vast numbers of people with mental health disabilities (PWMHD) living on the streets.

Housing is urgently needed and the Victorian Disability Budget is a slap in the face for families who provide the care to these people.

People with Dual disabilities (and intellectual disability and a psychiatric disability) and many intellectually disabled people fall into this category are expected to fit into main stream facilities. There are no separate facilities. My sister has a dual disability and she is intellectually 3-5. When she is forced into a main stream facility she screams with fright. She screams all night and they lock her in the lock up to keep her quiet. This reinforces her fear and makes things worse for her. She is expected to eat with strangers and in fact has only become worse in these facilities. I have had the daunting task of trying to sort this out when DHS can't cope.

Staff will not attend to the clients needs and my sister can't shower herself. She can't wash her clothes and attend to her daily living skills and staff will not help. DHS will not help. It is complete abandonment.

She would manage a lot better if she were in a psycho geriatric ward where she received nursing help.

1. We need advocacy for PWID who need their families to advocate for them.
2. We need options in housing
3. We need the Federal government to intervene as the CSTDA has failed us.
4. We need separate psychiatric facilities for the intellectually disabled.

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