SUBMISSION TO PRODUCTIVITY COMMISSION'S
DISABILITY CARE AND SUPPORT INQUIRY

THE NEED

The need for reform in the disability sector has been well documented and well established by many reports and by the submissions that you have received to date. The treatment of Australia's disabled citizens is truly disgraceful and denies us the right to call ourselves a first-world civil society.

The circumstance of my family is typical of tens of thousands of families across Australia. We have a thirty-three year old son who has a severe intellectual disability. He is wonderful human being who brings out the best in everyone he meets. He has the functioning capacity of a three to four year old. My husband and I are coming to terms with the fact that there exists nowhere in our rich and lucky country for him go except to stay at home with us. We will go to our graves while still caring for him and he will be left to cope with trauma and upheaval after we are gone.

This is just so totally unacceptable in a country such as ours, with debate raging about the speed of the broadband connection. It is unacceptable that we who are the experts in caring for him may not be given the opportunity to pass on our wealth of expertise. It is unacceptable that we may not have the peace of mind of seeing how he will be cared for when we are not here, after we have devoted decades of our lives to his care. It is unacceptable that he and all the others like him who, by virtue of their disability, have less developed adaptive capacities than the general population, but neverthelesss are left to cope with losing everything familiar to them on the death of the last remaining parent. It is also unacceptable that we, who have worked so much harder than other parents, should be denied any semblance of a retirement experience at this stage in our lives.

Our frustration is heightened by the knowledge that this situation does not exist in other comparable countries, which have measures in place to support their disabled citizens appropriately. It is further exacerbated by the fact that a decade ago, our son was urging to us to allow him to move out of home, while now, as his adaptive behaviours diminish, he views a move with reluctance. It is no accident that in more humane societies, the transition to supported accommodation occurs between the ages of eighteen and twenty-five, which all research shows is the optimum time in life.

We have done everything that parents can do to secure supported accommodation for our son. We have filled in forms, been to countless meetings and written submissions to countless inquiries. Parents like us who take an active stance in trying to secure a future for a son or daughter with a disability are viewed as "queue-jumpers" by the disability agency, with its nebulous priority-based crisis-driven system. In reality, there are only two ways to secure an accommodation placement within the disability system: the first is for the last remaining parent to die and the second is to relinquinsh care to the state. We cannot do this to our son and so we remain prisoners of the love we have for him, victims of the "velvet violence" perpetrated upon us by successive uncaring governments.

THE DESIGN AND FUNDING

We are hoping for a scheme which is going to provide universal coverage for people who are born with a disability or who acquire a disability before the age of sixty-five. It will eventually give a legislated entitlement to services needed to meet one's potential and fulfil one's goals. It will need to be funded through increased taxation and our fellow Australians will have to accept that this is a requirement in making us the fair and egalitarian society that we claim to be. The increased taxation may be by way of income tax, such as by increasing the Medicare levy, or by an increased consumption tax on inessential items. While raising taxes is always unpopular, Australians must understand that in comparable countries, higher taxes mean pride in a good system and security, knowing that if disability befell oneself or one's family member, services are in place. In Belguim, for example, a social welfare tax of sixteen per cent is levied, on top of income tax. The equivalent in our country is the one-and-a-half per cent Medicare levy. It is our belief that fair-minded Australian citizens would tolerate a small, possibly one-per-cent, rise in the Medicare levy to obviate the risks of acquiring disability in a climate of non-provision.

We urge you strongly to design a scheme which allows individual funding and individual control of that funding. We see a system which will be centrally administered from Canberra, leaving the states out of the equation altogether. Many of the good people working in state government disability departments and agencies could be utilized in the assessment and management of the centrally governed scheme. Individualized funding will necessitate the delivery of a responsive, local and appropriate product by the service providers. Failure to do so will result in the consumers taking their funding elsewhere.

This is the key point in this submission. We see all around us waste and duplication, as government agencies and non-government providers grow ever larger bureaucracies, make services available that are not the ones needed and refuse to respond to the wishes of the consumers. At the bottom of the chain, the person with a disability and the family of the PWD find that what little funds have filtered through the many layers of management are not providing the service required.

What is not often spoken of within disability circles is just how bad some of the non-government providers really are. These providers, usually parent-initiated, have drifted far from their roots and ceased listening to their stakeholders. Instead, they have become corporatized and are in the business of dictating what may or may not be done. And so we have providers with more staff persons sitting in front of computers than interacting with disabled clients. We have tiers of management always in meetings with each other. We have fleets of company cars but none for the use of the persons with disability. We have people with a cognitive age of six or seven who are dumped "in the community" with an hour or even less of care each day. If a child of six or seven was left unattended except for an hour per day, the neighbours would ring DoCS. However, it appears that if the disability service provider does it, then that is permissible.

These providers are often the loudest in proclaiming "social inclusion" and "dignity of risk" and "person-centred planning" but in reality they are delivering abuse through neglect. There is only one yardstick by which these providers may be judged, and it is not the vision statement in the glossy brochure or the professionally -designed website. No, it is the quality and the quanity of direct care at the coal-face. There are many ethical and committed NGO's and we, the families on the ground, know who they are. With individual funding, we can direct the lives of our family members and we can vote with our feet away from unresponsive and negligent providers. For those families, and they will be in the majority, who do not wish to manage their own funds, there must be independently appointed financial managers who will liaise with families and purchase responsive and appropriate services. Never again must disability dollars be doled out to unaccountable state government departments and agencies or to unaccountable non-government service providers.

THE PEOPLE MOST IN NEED

We would have thought that this is self-evident. The most in need are surely the sons and daughters of those people who are have little time left. Start with all the carers in their nineties and those who have terminal illnesses. Work quickly to avert the tragedy that befalls the person with a disability when upon the death of the primary carer, also incurred is the loss of the only home ever known, the local community, all friends and contacts and everything familiar. Then work downwards, so that carers in their eighties and seventies and even late sixties may see their adult children settled and secure in an out-of-home setting.

It is acknowledged that there are many areas in the disability sector that need urgent attention. The growing number of children diagnosed with autism who need early intervention and the need to increase in-home support hours for people with a physical disability are two which must be high priorities. However, there can be no more urgent need than that of the ageing parent carers who have cared for a lifetime.

COSTS BENEFITS IMPACTS

The figures released by the Australian Institute of Health and Welfare are scary and enough to frighten away our elected representatives and their fiscal advisers. It is important to understand that in the AIHW view, anyone with a core dysfunction, such as sight, hearing or mobility, is classified as severely disabled. Therefore, the figures quoted are in hundreds of thousands. While these people may need some assistance, it is only people with a severe or profound intellectual disability who will need around the clock support. Supported accommodation in comparable countries is provided on the ratio of around thirty per one hundred thousand. In Australian terms, this would equate to approximately sixty-two thousand places, as opposed to the sixteen thousand we now have. This is not the total cost, of course, as people with physical and sensory disabilities and those with a mild intellectual disability will need packages of support, but not total care. The figures appear more manageable when viewed in this way.

There are many economies of scale waiting to be adopted in the disability sector. We belong to a group of local parents who have been lobbying for years to achieve supported accommodation in a cluster setting in our local community. We envision this project being far more cost effective than the discrete group home while at the same time better meeting the needs of the residents. We are as yet unsuccessful in our quest, although we continue to pursue our goal, confident that our model is one of several that will eventually be adopted throughout the country. The right to select the residential setting of choice is of prime importance, because no-one knows better than the family which is the most appropriate model for each person.

Families have the experience and the expertise when it comes to disability. They have a natural authority because they have only the very best interests of the person with a disability at heart. In the last two decades, they have been increasingly silenced, ignored and disenfranchised in all matters pertaining to disability. You need only to ask us what it is we need and the best solution will be offered. Grass roots family advocacy is essential so that we, the experts, may have a voice in planning for the future of the people we care for.

In the case of our family, it is supported accommodation that is most urgently needed. This will ideally be in our local area and with people already known to our son. It will be provided by a service that is lean, dedicated and has trained its direct care staff well. The provider will be responsive and willing to learn from us how best to care for our son. We need to have the power to direct our sons funding away from the provider if all his needs are not being met.

The benefits to us of an NDIS are obvious. We would no longer need to be home at 2.30pm every day of our lives to collect our son from his day program. We could plan for the next stage in our lives, something parents cannot currently do. We could relax and have some peace of mind, knowing that our son will be cared for when we are no longer here. Our other sons could also relax, knowing that they will not be asked to sacrifice lives and careers as we have done. The benefit to our son is also apparent: he would get to transition gradually and humanely, not in the traumatic and crisis-driven manner that we have seen so often. He will experience an independence impossible while living at home and he will enjoy the company of his peers.

The benefits to the wider community are also clear. The shame that so many people feel when they encounter people with a disability and their families will be removed. Australians are either blissfully ignorant of our plight or aware and embarrassed that there can be one group within their midst that is excluded so totally from the common good. With an NDIS, all Australians can hold their heads higher knowing that a security net is in place for one and all and that we are a fairer and kinder society. If other developed countries can do it, so can we!