

Just Better Care
Suite 6, 383 Sydney Rd
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Re: Inquiry into Disability Care and Support

Just Better Care is a provider of services for people with disability with 18 offices located throughout NSW, Queensland and ACT.

The issues that face the sector which Just Better Care will comment on are:

- Inadequate funding
- Accessibility
- Disempowerment of the person with the disability and the carer
- Lack of support to service providers
- Lack of choice and control
- Ageing carers
- Data collection
- Inappropriate placements
- Funding for the future

Inadequate funding for the individual with a disability

The shortfall in funding over the past decades has meant that people are unable to access the assistance they really need. The care has fallen onto the families who often give up their livelihoods to provide the needed care. They are everyday heroes who have not been given any option and are usually forced into providing the bulk of the care. They have saved this country a fortune in unpaid, “voluntary” care but now really need assistance.

The lack of funding has meant that people are not free to make **real choices**, whether they are the person with the disability or the carer. Real choice means to be able to say who will deliver care, when and how it will be delivered. They have been left unsupported, carrying a huge burden because some life event dealt the card of disability through genetics, birth or trauma.

Accessibility

The lack of funding has left people with disability and their carers living a second class life. Social isolation for the person with the disability and their carer is common. **Access** to the community is limited due to the expense of equipment that can support mobility such as modified motor vehicles, wheelchairs etc often being prohibitive in cost. The person with complex care needs is often not afforded a life that could be available to them due to lack of funds.

Disempowerment of the person with the disability and the carer

Carers often need to become advocates for their loved ones in a bid to try and gain some assistance. Along with providing most of the care they are faced with the need to go cap in hand to State and Federal governments and ask for help. Families are faced with competing for funds and writing endless letters of request for every little bit of assistance they require. The system totally **disempowers** the carers and the person with the disability.

Lack of support for service providers

The issue of funding is critical for service providers to successfully provide a quality person-centered service with consistent, reliable, **trained staff** that has the skills required. The main cost of service fees is the wage costs for care workers. This wage cost includes initial and ongoing training and support, vital to providing and sustaining a quality workforce. Without a skilled, trained and reliable workforce there are no support services and people with disability are left to rely upon volunteers and family who often don't exist.

The workforce needs to be a very major consideration in this commission so that we truly achieve a long term positive result. The workforce needs to be paid a fair and reasonable wage, enough to attract people into this sector and keep them there. Along with a fair wage there needs to be ongoing training and support.

Should the workforce not be supported in **remuneration**, training and career paths then we will see people with disability left neglected and unable to access a service. If the sector remains underfunded it clearly sends a message that if you have a disability you are a second class person, less important than an able bodied person. This message then transfers to the paid care worker that the value of their work is unimportant and less worthwhile than other careers.

Some programs are not financially viable for a private service provider to be involved with. This is despite them having the capability with trained staff to provide the service that is requested and required. An example of inadequate funding program would be **Lifetime Care and Support**, the MAA scheme. The low hourly flat fee set to cover services weekdays, evenings, weekends and public holidays makes it impossible for Just Better Care to be a service provider. The low fee does not allow for a fair wages for care workers, training and coordination of services.

The not-for-profit organisations (with fringe benefits capacity) that sub-contract their staff rather than employing them have been providing the service with varying levels of client satisfaction. When an organisation is underfunded and the focus is always bottom line driven, the outcomes for the service user is compromised.

Just Better Care understands the high cost to the nation in funding the service provision for people with disability but we strongly believe that every person has the **right to quality care choices** that meet their current need.

Just Better Care has also provided services for people with spinal cord injuries living together in a group home. There were originally four residents in the purpose-built house. The funding for this house has not increased over the years despite the care needs increasing for the men, who are ageing. The house now can only manage three residents.

ADHC Homecare often place work with the contracted agency with the lowest charge rate first. It seems that the quality of the service and wishes of the client have no importance; it is all price driven as they need to make the dollar stretch.

Just Better Care has seen situations where we have been providing a successful service for clients with complex care needs. At the whim of the funding body , these people have had their services transferred to another service provider, despite the desire and requests of the client and carer to leave the service with us, their original provider.

Clients need certainty that a service will happen, by reliable, known workers that are competent, and that there will be as few changes as possible so that there is consistency in their care. Clients need to be empowered to purchase their services from whomever is the best and most appropriate provider for them.

Choice and Control

These two issues of choice and control should remain with the person receiving the service, or the carer or nominated person.

They should have choice and control over:

- what service will be provided
- who the service provider will be
- when the service will be delivered and;
- where the service will be provided.

Obviously there needs to be some accountabilities around ensuring that an appropriate and agreed outcome is met.

Ageing Parents

It is a sad reflection of the lack of support provided to many families that the first time they have received any help is when the carers are elderly and unable to continue providing the care. Just Better Care has met so many families that have been placed in the direst circumstances, waiting for assistance and really needing help for themselves. We know of families who were so desperate they have left their loved one in the emergency room and walked away as they could not get access to any help.

Data Collection

We need to collect the data of how many carers/parents/siblings/family members/volunteers are providing all the care and are not in the system as yet. We need to do a complete needs analysis of the sector so we can assess current needs (both met and unmet) and future needs.

To collect this data a widespread marketing advertising proposal needs to go out into the community. Many of the full-time and part-time carers I have spoken with recently are unaware of the Productivity Commission enquiry. They would love to have their say but unless they know how to, they remain silent. I'm sure the unmet needs of the person with disability or the carer has saved the nation a fortune over the past decade but it's time to take the lid off the real cost and level of need that exists.

Inappropriate placements

Recently Just Better Care tried to find out how many persons were in Nursing Homes under the age of 65 years and it seems almost impossible to get this data, except to know there is still too many people with disability or disease that are inappropriately placed in nursing homes due to lack of alternative facilities. We have experienced such transfers with clients we have provided services to who have diseases such as MS or conditions such as Spinal Cord injury or acquired brain injury.

Funding for the future

Just Better Care's position is that the budget must adequately reflect the real cost of service provision. We would be agreeable to a levy where all Australians share the cost. Disability is not one person's problem; it belongs to the community and should be a cost burden borne by all of us. This could be similar to the Medicare levy attached to taxation. The National Disability Insurance Scheme would gain our full support. It has now been talked about for over a decade so we would hope this Commission will ensure real action is taken.