

To the Productivity Commission into

We are writing a personal submission because Assaad, my husband has Multiple Sclerosis which has gradually deprived him of many faculties, not the least of which are his mobility, his bladder and bowel function as well as generalised fatigue.

Assaad and I are writing this submission to testify about the high quality of services we have received in Western Australia and emphasize that the major need that WA has is to have access to additional funds and not to replace the existing infrastructure that works really well.

The LAC (Local Area Coordination) program run by the Disability Services Commission in WA has been our life saver in so many different ways, providing us with: Information, support, advocacy to enable us access the general community, family time out to recharge our batteries, application to receive further support from the Commission as well as non government organisations.

One of the most essential features of this support was that we had a longstanding dedicated person(s) who could help us plan for the future, draw on our natural existing resources, put us in contact with other families/carers who were experiencing similar challenges and respect and take our cultural difference into consideration, enabling us to make choices that were 'right for our family'.. We speak two different languages at home other than English as we each have a different mother tongue and fully understand each other's.

We have also received very timely and valuable support through the MS (Multiple Sclerosis) Society of WA who has provided information, varying levels of support, both in home and in outreach facilities to enable my husband retain the maximum of his abilities.

We have had to fight long and hard to obtain some support, but we believe that this is due to lack of funding. We highly value the skills of the staff we have been in touch with and strongly recommend that any recommendation from the Commission builds on existing supports. To start a new system from scratch would represent a huge loss of 'know how' as well as very precious formal and informal relationships that no amount of money could replace. It takes a lot of energy to retell one's own story and to start again, and it would be very difficult for us to start again, and again.

We understand that the new proposed system only proposes initial case management and we strongly object to this. The key factor enabling us to feel confident that someone who knows the system is walking alongside us on our journey is essential and to remove it will create additional stress and difficulties. We value the long term relationships that LAC offers us and would feel very concerned to loose this.

There is a desperate need for additional funds in all areas, mostly to fund more CAP applications, but also for accessing home modifications, appropriate equipment and the like.

In short, we welcome the perspective of much needed additional funds, with the ability to be individualised and promote individual choice and be culturally appropriate, but we would like to see this happen using the existing infrastructure in WA, in order to preserve the formal and informal relationships that are priceless. The system is very cost effective at present and adding another bureaucratic and remote layer of administration will only take away much needed funds from a service that is in desperate need of more funds.

Kind Regards,

A&R Salamé