

Disability and Care Inquiry

**Dear Commissioners** 

I am pleased to take part in the consultative process that will have I hope a profound and positive benefit to Australians with a disability.

My contribution comes from 3 perspectives, which of a Carer for an aging parent with complex needs a Disability Support Worker in Tasmania and a new business operator seeking to establish a business that serves the expressed needs of a person with a disability and their family.

I have worked in the community sector in Tasmania for the past 25 years in various capacities, Youth Services Coordinator, Local Enterprise Facilitator and various Community Development roles. For the past 10 years I have been employed as a Disability Support Worker for various services in Tasmania.

The role of Carer is undervalued; I can speak from personal experience where I have on 3 separate occasions been required in this role, once for 5 years with a former spouse, my mother from ill health through to palliative care and currently with a father with complex needs. I can speak of the isolation that Carers feel, the financial sacrifices they make the complexity of care and the expectations that you can fix anything. The physical and mental health of those in the Carers role is little researched, understood or responded to.

As a Disability Support Worker I often heard concerns, complaints and frustration at Disability Service Organisations and their dismissal of both the individual and families. With consent of the family I raised these issues with service managers only to be told not to buy into clients issues.. As a worker I saw it as my role to empower people as a means of creating greater independence, not a view shared by some service managers. There are good services however my major issue with services is that they promote an image of a person that serves their needs and is a disservice to people with disabilities. The "poor disabled thing" image is perpetuated in fundraising exercises with appeals to help those that can't help themselves. There is no benefit for a person with a disability, they have no say or input into where the funds raised on their behalf are allocated. In any transaction with another person we can either validate or invalidate their worth, we can empower or disempower, we can reflect their value or devalue by dismissing their insights.

It is not that I am against Disability Services but I feel and fear that the focus and resources needs to be on the individual and not a service. I must confess a vested interest in individuals and their families being the focus of reform in disability support. I believe that my business ILS will be part of a new wave of Person Centered services. These services, if the individual and their families are the service designers, monitors and evaluators will promote lifestyle changes that are socially productive.

My business took part in the FaHCSIA consultation that led to the SHUT OUT publication and in that submission I advocated Direct Funding to Individuals over funding services. I advocate this to the Productivity Commission. Customers with funds will themselves reform the services sector. This has been in operation in the USA and UK for over 2 decades in the USA and approaching 2 decades in the UK. Instead of passive service recipients the person with a disability will be the driver of the service and will only pay for the service that meet their specific needs and wants.

Person Centered Planning and Person Centered Services are the benchmark of best practice and mandated in law in many states in the USA. PCP is mandated in the UK under the Valuing People legislation.

The highest priority has to be removing the myth that a person with a disability in incompetent and incapable. It can never be productive to leave people languishing in Day services day in day out, it is a waste of life for them and a waste of resources for Australia. This is not a situation that a person with a disability has any control over; in fact they have little control over anything. A vast amount of information is available on PCP and funding individuals, the KPMG review of contemporary approaches in Victoria makes a good resource.

I appeal to the Commission and Commissioners to research both Person Centered Planning and Individual Budgets in order to reform how Australians with a disability are treated. There is no doubt in my mind having worked alongside a person with disability that the current system suppresses the individual's productivity. Social Policy relating to Australians with a disability can support best when it liberates their skills and abilities and assists them to add to the social capital of Australia.

With an aging population and a reasonable proportion of these in a Carer role there is a grave concern over who will take over once they can no longer provide primary care. Adequately prepared, well informed and empowered people will meet this change far better than those who remain passive service receivers. The one service suits all style of support should be history by now, but it's not because consumers/customers do not have the means to provide pressure for change.

In Australia we have taken people out of large institutions and confined them to smaller ones, it looks better but the ideology is much the same, people are still grouped in disability same environments and all treated alike. People with disabilities are as diverse in personalities, their interests and views as the rest of Australia. Speaking for ILS it is the building of informal networks not formal services that needs to be the focus, relationships built on mutual shared interests, social, sports, and engaging in real Australia not one conceived on perceived needs.

In taking part in surveys and consultations and the resulting recommendations I remain certain that given the opportunity and resources people and their families can determine the services needed and live more productive lives.

I thank the Commission for the opportunity to be part of this consultation; I await the outcome with great interest.

Yours Sincerely

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