

Productivity Commission Inquiry into

Long term care and support of people with a disability

Submission from

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1. Background:

My submission is based upon two main sets of experiences which include:

a) My role as a sole carer for my son Peter who is forty five years of age and has an intellectual disability and autism. Peter requires daily support for all his personal care. In 2007 Peter was diagnosed with inoperable heart disease, breathing is difficult and angina attacks are common. As a result Peter has lost most of the confidence he previously had and has become more dependent.

Peter attended a (so called) special school until he was eighteen and then worked in a (so called) sheltered workshop. He was employed for eleven years as a retail assistant through the Commonwealth Employment Support program. Peter became unemployed when his shop closed and during the last two years his employment support agency has found him just one work trial which was unsuccessful. For two years Peter has had no regular day activity.

b) I am sixty nine years of age and have been retired for more than five years. I was employed in the field of disability for twenty years - was a volunteer for people with an intellectual disability for ten years – and was employed in the addictions field for nine years where I worked with many clients who had a disability. My most recent employment was: 10.5 yrs as a Local Area Coordinator for Disability Services Commission in Western Australia.

2. Who should be eligible: Who should be in the new scheme and how could they be practically and reliably identified? Which groups are most in need of support and help? What could be done to reduce unfairness so that people with similar levels of need get similar levels of support?

2.1 Who should be eligible?

The United Nations definition of disability is relevant as it identifies limitations according to the interaction between a person's physical and sensory features and the society in which they live, however the influence of secondary limiting conditions such as other disabilities and health issues should also be recognised. A distinction should be made between people who have been

diagnosed with a permanent disability and those whose diagnosis is unclear. Assessment should be based upon need to function at a level that Australian society accepts as being basic to everyone's needs.

2.2 Identifies:

a) Descriptive words such as severely and profoundly disabled do not best represent the people for which they are intended. These words are used subjectively and mean different things to different people and therefore should not be used to identify levels of entitlement to funding, services or other supports.

b) The assessing authority should not be the funder. Assessment outcomes could be identified by an appropriate code which would indicate an annual dollar figure. Both the person with the disability and their family carer could receive individualised relevant cards. Assessment and entitlement should have a flexible process that enables easy adjustments to changing circumstances regarding health, disability, the impact of aging, as well as changing carer needs.

c) Reassessments should only occur at certain milestones such as looking for work, seeking alternative accommodation, impacting health issues, ageing, and other significant changes to needs. Reassessment could occur at the request of the person with the disability or their advocate or routinely, as aforementioned, by the system.

2.3 Groups of people most in need include:

a) In brief: People who would benefit from early intervention therapies including people with a congenital disability as well as those immediately post trauma/surgery; people with an intellectual disability who have no regular and reliable day options; people with an intellectual disability requiring daily care and support, are over the age of forty, living with a family carer and needing alternative appropriate accommodation; carers over the age of fifty who require regular and reliable out of home respite for their sons and daughters that is appropriate, small, family friendly and flexible to ensure minimal disruption to their sons and daughters routines and will protect the carer from burn-out and a debilitating lifestyle.

b) Adults over the age of forty years who require daily care and support and need alternative accommodation from their family carer who is over the age of sixty years. Alternative accommodation in support of both the person with the disability and the carer would benefit not only they and their families, but also society in general through the avoidance of inevitable costly outcomes of adverse health conditions. A suitable option to address this need could offer these carers an 'aged retirement plan' to

relieve them from their caring role. This would give the carer hope and motivation knowing that retirement is eventually possible and would go some way to answer the question 'What happens to my son/daughter when I am gone'. However unless alternative care and support arrangements for their son or daughter is suitable, many carers may not choose this option.

c) Carers over the age of fifty years should be entitled to regular and reliable out of home respite for their sons and daughters who have a disability. At least six flexible weeks per year is needed to achieve satisfying and productive support. The respite option must meet the requirements of the individual or the experience of the person with the disability would be unsatisfying and stressful and the carer may be left to deal with dysfunctional behaviours as a result of the bad experience; the result being of no benefit to the carer or the individual with the disability.

2.4. Unfairness results from subjective assessment tools; inflexibility of a system; subjective interpretation or reporting skills of individuals; a competitive marketplace where the few get much and the tired and weary get little. The system and its related forums require equal recognition for people with an intellectual disability and people with other disabilities.

Compensation needs to be considered to address potential fraudulent or negligent behaviours of fund managers and consideration given to address potential economic crisis that unfairly deplete either the individuals entitlement or the scheme in general.

3. Who gets the Power? How could people with disabilities and their carers have more power to make their own decisions and how could they appeal against those decisions?

a) The myth about direct consumer funding: this does not always equate to choice. With direct consumer funding families often need to engage a service provider to provide the care and manage their funding which ultimately means, there is less choice. Or if a family carer or the individual endeavours to personally manage their funding they will need a commitment equivalent to a lengthy part-time job to find, engage and supervise care and support as well as be accountable for income and expenditure. Even then, through scarcity of supply care and support can be unreliable or very expensive when purchasing from a care agency. This on top of an already large caring role, or other stressors of living with a disability, often brings more pain than gain.

b) The power of personal decision making is influenced by information and knowledge. As the Inquiry suggests, a Coordinator would be most helpful to assist the person with the disability and their carers/significant other to make informed decisions. The Western Australian model of Local Area Coordination is far from perfect, but has many good aspects which are worth building upon.

c) Education programs: To further support the power of best decision making I recommend the introduction of regular information programs targeted at families but available to all interested persons to inform on a range of significant topics including understanding particular disabilities and how they may manifest; research and development reports and their expected influences; legal, social and environmental issues and systemic issues. These education programs could be offered monthly perhaps on a Saturday to give best opportunity to attend and should include opportunities for attendees to make valued connections.

d) The principle of entitlement would empower people, rather than hand outs based upon subjective assessment. However without adequate service provision and an ability to access it, entitlement or social right, is a misnomer. Flexibility in using proposed new entitlements would enable carers to address their ever changing needs.

e) An appeal mechanism and a complaints mechanism should be a vital component of the new Scheme; however a legal complaints system should be only one of many less invasive mechanisms for addressing appeals and complaints.

4. What services are needed and how should they be delivered? What kinds of services need to be increased or created? Improved timeliness and innovation? Early intervention for improved outcomes? Full participation of people with disabilities and their carers in the community and work?

4.1. The increase of and creation of new services include:

a) Out of home respite services: Many people like my son need to be happily accommodated in an out of home respite option that is small, homely, has minimal staff changes and takes personal interest in tenants and ensures they have continuity with their regular activities. If Peter and I had access to this style of respite on a regular and reliable basis such as six weeks per year it would be most helpful and highly valued. "Friends of Respite" is a service in Kalamunda operating in this way.

Private out of home respite operators need to be encouraged, trained, supported and accredited to provide a financially viable business that gives satisfaction to them as well as their tenants and their carers.

Current options include large, impersonal unhappy settings which I would not choose for Peter; or in-home support where I need to vacate my home so several formal carers could visit Peter daily and attempt to address his needs. In the past I have used this option with help from my other son and daughter, but due to our changing needs this option is no longer suitable.

b) Alternatives to employment programs: Designed for people who could work but are unable to find employment. Alternatives could include:

- Supported Voluntary Work. I recommend the Commonwealth Supported Employment program be inclusive of supported voluntary work as a valid alternative for people who require and request it. Voluntary workers should not replace paid workers. I suggest there is a harm minimisation principle here, which is: it is far better for people to be productively and happily engaged in work for no financial reward, than to be staying at home, losing their work ethic and adversely affecting their health and well being.

- Adult education programs for people with an intellectual disability. I recommend on-going learning as a valid alternative to employment, just as it is for all of us. Topics should not be exclusive to vocation skills and should be meaningful and varied with an aim to inform, motivate, stimulate and build confidence.

- Sport and recreation: Community inclusion for people with an intellectual disability should include a variety of opportunities that respect and values difference. For too long bureaucracy has held the view that they would determine how people with an intellectual disability were included into community programs – this worked well for several decades whilst the option of inclusion was practiced and became much valued, but now it is time to broaden support by financially enabling people with an intellectual disability to assemble together as a rightful choice alongside other highly valued inclusion programs.

The Ministry of Sport and Recreation could assume a major role in providing practical support for people with an intellectual disability to participate in community sport and recreation through innovative ideas which engage volunteers from the community to act as facilitators.

c) Accommodation and housing options need to be much broader than they currently are. Many individual housing options have delivered loneliness and boredom for the person with the disability, especially those with an intellectual disability. These experiences can become very debilitating and often leads to depression or anxiety and later a dependence upon medication to deal with symptoms. State Housing Depts should support new initiatives or increased opportunities for people who pay rent and could include: small shared housing and care options; co-operative housing; small group cluster homes.

d) Age driven entitlement to more appropriate housing and care options for people aged over forty who require daily support and still live with their family carer, to an appropriate alternative housing option that does not unfairly disadvantage their care needs and their associated lifestyle. This will support carers to plan an alternative lifestyle for a time when they can take 'retirement' from their caring role.

5. Funding: How should a new scheme be financed? How can it be ensured that there is enough money to deliver the services that are needed and provide greater certainty about adequate care in the future?

5.1 The proposed National Disability Insurance Scheme has a lot of validity, but is not necessarily the answer to all care and support needs. Individual funding without the necessary support services just shifts the responsibility to the person with the disability or their carer: however factors which may be relevant to a NDIS are:

- Payment into a proposed scheme should be universal for people earning over the minimum equivalent of a Government pension
- Full entitlement as determined by assessment should be available regardless of when a person enters the scheme.
- Allocation of funds should be on an annual basis and adjusted annually as necessary. Allocation should be made direct to the funding manager formal or informal.
- Residual individual funding entitlement to be invested in some way, perhaps similar to superannuation and allocated pensions but safeguarded by Government.
- Built in cost of living increases at a realistic value.

6. Organising and implementing a new disability policy: The roles of service providers, people with disabilities, their carers and the current eight government departments; what workers are needed, how to recruit and what training requirements?

6.1 In the advent of a National Disability Support Scheme - I envisage:

- Money collected from income earners via a taxation system which implies the Federal Govt would collect the money and issue to State Govt.
- State Govt would conduct assessments and allocations to cater for local conditions.
- State Govt would be responsible for the accreditation of financial managers.
- State Govt to be responsibility for informing and supporting consumers and for facilitating best practice in using their entitlement.
- State Govt would engage Coordinators to be the link between relevant State Govt responsibilities and consumers rights and responsibilities.
- State Govt Coordinators roles would include: information dissemination, unbiased brokerage advice, personal and systemic advocacy, mentoring and other relevant supports. Effective Coordinators would need analytical skills be lateral thinkers, and have counselling and relationship building skills.

6.2 Organising and implementing a new disability policy: Federal Govt responsibility: communicating directly with the general community and as the funding source. State Govt's for organising, implementing and linking the Scheme to consumers.

WA Disability Services Commission could use proposed new responsibilities for the Scheme to separate their current role as authority for people living with intellectual disability and autism from their current broader roles for people living with all disabilities and enable them to focus on the new Scheme.

The people of WA need a specialist authority for those living with intellectual disability and autism. Currently WA Disability Services Commission is presumed to be that authority however, I don't think DSC can justify that claim. Services have generally been outsourced, depleted or ceased, research and development is a mystery and their consultation process is narrow and selective. For many Western Australians living with intellectual disability, their Local Area Coordinator is their only contact with so called specialist services.

6.3 A role for State Government: To facilitate and enable the availability of accredited service provision through effective marketing, valid incentives, training, accreditation and monitoring of service provider's practices against standards. I am aware there is a current reluctance by State Govts to act upon adverse monitoring findings or other reports, for fear of losing service providers from a system already short supplied.

Governments should be more pro-active in pursuing relevant means for identifying why things are as they are, how can they be addressed adequately, who needs to address them, what constitutes best practices and what are minimal acceptable standards.

6.4 The role of people with disabilities and their carers: a) To endeavour to live happily and productively within society by attaining their greatest potential; b) to inform society of their needs and help society to help them overcome their difficulties. Difficulties are compounded when society seeks not to understand and so people with disabilities and their families become devalued with negative consequences occurring; c) advocates, particularly family advocates need a higher profile that includes recognition of relevant reputes as the knowledgeable link between service providers and the best outcome for people with decision making disabilities. State Govt Coordinators at a local level could be central to ensuring people with disabilities and their advocates are able to best fulfil their roles and achieve satisfying outcomes.

6.5 What workers would be needed in a new scheme?

Coordinators: The current Local Area Coordination program in Western Australia could be restructured to a flatter level and redesigned to address consumer needs in relation to the proposed new Scheme. These Coordinators should have a pivotal role and could be the source to reflect consumer' interests, concerns, and recommendations to the Scheme's planners and policy makers. The building of trust, the generosity of productive time and creditability in addressing consumer needs would be valued assets and for this they need a wise degree of flexibility and autonomy. The Scheme's Coordinators should not be the Scheme's assessors or gate-keepers.

7. What other ideas do I have?

7.1 Confidentiality regarding personal issues is a valued principle. Currently under the guise of accountability too much personal information is available on-line to a variety of staff: this unnecessarily strips a person of their privacy, sets up an environment of mistrust, suppresses a person's dignity and confines a person to a welfare model where all people involved believe they have a need to know. I acknowledge the need for staff to be accountable for their working practice, but this can be done by sharing minimal statistical data.

7.2 Ageing: A person born with a disability and reaches retirement age should have a choice between services in the aged system or in the disability system.

Thank you for the opportunity to contribute.

Lorna Carroll
Carer.