PRODUCTIVITY COMMISSION

Disability Care and Support

Introduction

Thank you for the opportunity to comment on this important matter.

Credentials

My knowledge of disability matters comes from three sources – 30 years as the parent of a severely handicapped child; 18 years professional employment in policy and planning in the disability area for the WA State Government; and an aggregate of some 30 years on Boards and/or Chairman of disability-related non-government agencies.

General Comments

The Issues Paper is excellent, and gives a comprehensive account of the many issues involved. This instils confidence that the matter is being addressed by knowledgeable and competent people.

The range of combinations and permutations of the issues is great, and while there are many ways of achieving a suitable outcome, it should be noted that there are very many more ways of getting it wrong, than there are of getting it right.

There is an implied assumption in the Issues Paper that the current system is stuffed. I would argue that the current system in Western Australia, which has evolved over many years with major stake-holder input, is a pretty good system. No doubt there are areas where it can be improved, but the single major flaw in the current system is that there is not enough to go around. If that was the only thing fixed, the other matters would soon sort themselves out and settle down.

My submission is not intended to be a comprehensive response to all the issues raised, nor does it propose an ideal system. Instead, it will focus on three key aspects:-

- Key underlying principles which should form the basis of the system
- Elements of the existing system that should be retained
- Elements of the existing system that should be fixed.

Finally, there are two key questions that plague the mind of primary carers; “How can I get through today?” and “Who will care when I’m gone?” These two fundamental questions should underpin the deliberations of this Inquiry.

Underlying Principles

I wish to suggest some key underlying principles or features, with their supporting rationale, in order to provide some fixed points around which a structure can be designed. This would leave ample scope for various combinations and permutations in the design of a scheme.

Stability and Certainty

Minimise disruption and maximise stability and certainty. People with disabilities and their kith and kin are often vulnerable and fragile. Technical changes which just tinker around the edges without substantial benefit are more trouble than they are worth.

Eligibility

Eligibility should be the same as for the Disability Support Pension. Criteria for the Disability Support Pension have been clearly established for many years, are well known, and are subject to verification by Commonwealth Medical Officers. Different eligibility criteria would add unnecessary complications, duplication, and would be likely to result in unintended consequences.

Sliding Scale

The level of funding should be based on a sliding scale related to the severity of the disability. The World Health Organisation ***Classification of Impairments, Disability and Handicaps*** has clearly defined criteria for levels of disability which have been adopted internationally. These could be used for a sliding scale.

Scope

The scheme should include those with mental health related disabilities.

Overlaps not Gaps

Where disability, mental health and aged care intersect, there should be overlaps rather than gaps between these domains.

Basic Social Unit

The kith and kin primary carer should be included in the basic social unit for people with disabilities, particularly when there is a cognitive disability whether it is related to intellectual, psychiatric, or ageing.

Individual vs Service Funding

Funding should be linked to the individual, not to service providers. Control and choice should remain with the person with a disability

Funding

Funding should come from the community at large, as every Australian citizen is at risk of being touched by disability, whether by birth, accident, or ageing. Expanding the Health Levy to a Health and Disability Levy seems an eminently sensible way to go.

Feathered Implementation

Given the scale and complexity of the task at hand, the proposed scheme should not be restricted to that which is feasible in the short to medium term, but should map out the route ahead with staged implementation to keep it manageable and affordable

Elements to Retain

Individual Focus

Meeting individual needs and aspirations was an important conceptual shift from the systems and programs approach of the past.

Empowerment
Empowering individuals and their primary carers was an important element in restoring dignity and respect for those with disabilities.

Early Intervention
The focus on early intervention to ameliorate the impact of disability is a wise investment. For example, teaching a child to be toilet trained not only builds confidence and independence in the child, but also helps ease the burden of care for the primary carer.

Research
Research on all aspects of disability, causes, cures, prevention, therapies, technologies, aids and appliances, helping carers care, etc are all useful avenues to explore, and the findings should be more widely publicised and incorporated in service delivery. R&D needs more encouragement and support.

Elements to Fix

Enough to go around
This is the greatest bane in the disability sector, and the root of most if not all the subsequent problems.

Partnership, not Master/Servant
The dynamics within the disability field have changed for the worse. The well of good-will between the levels of Government and with NGO's has been poisoned by weasel words and betrayal. Things like "efficiency dividend" imply extra funding, but mean the opposite; "increased service choice" imply more options, but mean the shortfall is redistributed; "accountability" implies professional standards, but means more paper work; "deinstitutionalisation" implies better services, but means kith and kin are left to pick up the pieces; to mention but a few of the examples. Working together as partners in providing a service, has been replaced with a master/servant mind-set, running a business. Finance, funding and efficiency have replaced helping, caring and well-being as the fundamental drivers.

People, not Paper
The current focus on acquittal and accountability has resulted in undue emphasis being placed on filling out forms, rather than helping people. Some estimates are that one-quarter to one-third of resources are taken up by administration. This should be kept in perspective at around 10%. In addition to the obvious effect this has, it also has a much more pernicious effect in changing the tenor and tone of services by driving out the "people oriented" staff while attracting and promoting "paper oriented" staff. This is the opposite of what should be occurring.

Help, not Hinder
Many of the current processes are inordinately convoluted and complicated, and are beyond the comprehension and ability for the average person to navigate, particularly if they are in shock from a newly diagnosed or recently acquired disability (or the primary carer).

Overlaps not Gaps
The current system has numerous artificial boundaries between different diagnostic, age and area of responsibility. This is compounded when people with multiple disabilities seek help

from agencies which see their own role as “border protection”. There should be overlaps, not gaps; and cooperation not boundary riding, between domains.

Thank you for the opportunity to comment. I would be happy to clarify or expand on any of the matters raised, and would welcome the opportunity to give evidence at the public hearing to be held in WA. I wish you God-speed in this important task.

Charlie Rook OAM

2 July 2010