PERSONAL RESPONSE – I am happy for this response to be made public

In relation to a NDIS I submit the following points for consideration.

1. Need for a National Disability Insurance Scheme

Since the formalization of disability services in the 1980s, **funding** for specialist disability services has been inadequate. The inadequate funding base has led to state disability agencies putting more and more of their resources into rationing. The agencies themselves are not necessarily in need of overhaul – but the funding model certainly is.

Relying on State and Commonwealth governments to provide funds within the budget cycle has resulted in a high level of unmet demand. Unless we do something different there will be no change. A new approach is essential. A NDIS collected in a similar way to Medicare must be tried.

2. People with Intellectual Disability/Cognitive Impairment

The Productivity Commission needs to understand that people who have impaired cognitive capacity¹ are highly vulnerable and their unique needs must be acknowledged in any new system.

3. Eligibility and Definitions

Using definitional terms like 'severe <u>and</u> profound' in relation to describing the eligible population is fraught. 'Severe' describes a 'sometimes' need for assistance in core activities whereas 'profound' describes an 'always' need for assistance in core activities. Also, a focus on core activity limitations (communication, self-care and mobility) can obscure the needs of some people with cognitive impairment. Better definitional wording is found in the Western Australian Disability Services Act 1993, 3 (d):

- (i) a substantially reduced capacity of the person for communication, social interaction learning or mobility; and
- (ii) a need for continuing support services.

Not all people who receive a Disability Support Pension will require high cost, ongoing specialist disability supports like accommodation or respite. Some only require limited term income support while others will also seek and need support to secure employment.

4. Incremental Growth – Don't throw the baby out with the bath water

Schemes currently in place such as compensation for motor vehicle crash victims should be left alone in the short term, to be integrated into the national system down the track. At that time the adversarial, court-oriented system currently used by the Insurance Commission should be abandoned. A need is a need regardless of apportionment of blame.

 $^{^1}$ AIHW unmet demand data shows that 85% of unmet demand for accommodation and respite relates to people with an intellectual disability. (AIHW Disability in Australia: Intellectual Disability -Information Bulletin No.67 - 2008 - p5)

Immediate attention in the new model should go to those people who receive their catastrophic injuries outside of the motor vehicle scope. For example, in WA someone with paraplegia resulting from a MV accident receives compensation whereas the same level of injury from a surfing accident does not.

In the same vein, existing state disability agencies currently administering specialist disability service funding should continue to administer existing funding arrangements. As well, in the short to medium term new funding applications should be administered by these agencies. Once a NDIS is operating new applications may still be best administered by these agencies. As in 1. above, it has been the inadequate funding base that has resulted in state disability agencies having to put more and more focus on rationing. The agencies themselves are not necessarily in need of overhaul – but the funding model certainly is.

A high priority should be given to working with data that relates to actual people who have applied for funding, been deemed eligible but have not been funded because of chronic funding shortfalls.

About me

I am the parent of two children with disabilities: my son (37) has intellectual disability and autism and my daughter (31) has paraplegia. My son needs ongoing support in every aspect of his life. On the other hand, my daughter is a high achieving individual who has married, had a child and enjoys a rewarding job. These achievements are made possible by initially having had access to the DSP, by securing funds through the Insurance Commission to construct an accessible home, purchase a wheelchair and modify a car. Living in a community that is improving its overall accessibility and having access to specialist healthcare have also played a major part in her independence.

While my daughter has been well served by receiving a once only payment via Insurance Commission compensation this model would not suit my son's need. He has a lifelong dependence on support 24 hours a day. The current system suits him well. His agencies of choice (accommodation and day activities) receive ongoing funding from the Disability Services Commission.

Di Shepherd

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