Submission to the Productivity Commission re the need for a National Disability Care and Support Scheme.

I am the father of a 19 years old son with Low-Functioning Autism with associated complex needs and epilepsy. Declan is a well natured young man who is much loved by his family and friends. He attends Black Mountain Special School in Canberra from which he is due to graduate in December. Although he has progressed steadily from year to year, due to the great efforts of the teachers and support workers, he has very limited skills. He has little meaningful language and awareness of safety issues outside the home. He is toilet-timed rather than toilet trained and is prone to accidents unless prompted which also necessitates him wearing a ‘pull-up’ to bed. He is a tall and strong young man who needs help with all facets of personal care. His size prevents his mother from assisting him with the majority of tasks for a sustained period of time. This is a major issue when I need to go away on business. Declan also functions best with routine, including good planning in advance and clear communication of activities occurring the following day. Although he appears to have a high pain threshold he has limited ability to express the presence of pain. He requires a general anaesthetic for such simple procedures as teeth-filling or cleaning, necessitating extra vigilance and careful planning.

I am not sending this submission to the Commission to vent my spleen at the inadequacies and lack of vision of the current system. We all know it has serious issues, is economically unsustainable and is poorly placed to support and protect the rights of a very vulnerable group of people.

The current system is crisis driven rather than well-planned. It is not whole-of-life focused and deals in segmented periods, of the life of a person with a disability, with very little continuity and communication between government departments, service providers and carers. Examples of this are the transition from school to post-school options, creation of employment opportunities and planning and transition to long-term accommodation.

Why does the general population not demonstrate incredible anger and disbelief at the current situation? They would expect (and rightly so) a soldier returning from Iraq or Afganistan, with an injury resulting in life-long disability, to have access to the best care and accommodation possible. Why do we not demand the same for people with a disability from birth or due to a catastrophic occurrence in their life? Is it because the general population somehow assume they are being looked after by the system or do we not value their lives, which have been severely disadvantaged, through no fault of their own, as much as the returning serviceman or woman? I feel that the Commission has a responsibility, as part of it’s recommendations, to ensure that the Australian people are clearly informed of the appalling plight of people with a disability and their carers and what needs to happen to rectify the situation. Such an awareness campaign will benefit the social fabric of the nation and support recognition of the value of people with a disability and their carers to the nation.

The Current System:

- Depersonalises the individual with a disability. It categorises them as a client in a Service Provider focused system which effectively disenfranchises them.
- It is onerous for families to access services. They must apply for hours or funding (e.g. ISPs) and then navigate a disjointed system.
- It is wasteful, with families often being referred and having to 'tell their story' many times.
- The lack of guaranteed funding or continuity of funding mean service providers often do not know, well in advance, what demand there will be for programs from year to year. This can result in a lack of innovation and program development, often with adverse impact on the client (e.g. families find themselves with allocated hours and no suitable programs or available places).
- It is very rigid in it's 'streaming' structure. Prior to graduating from school an assessment is made on whether the person with a disability is suitable for employment training programs or not. If not, the programs they are generally streamed into do not have a focus on developing the skills required to, at a later stage, cross over to employment training programs.
- Has a clear government view that support within the family structure is the preferred model, while failing to underpin it with adequate support funding, resources and health and aging planning. This can result in substantial hidden costs in such areas as carer's health, medication and hospitalisation costs, family breakdowns, sibling emotional and social issues and eventually crises management.
- Allows the government to abrogate responsibility by playing the 'guilt card' on families.
- Has a woeful lack of long-term accommodation places.
- Has a narrow focus in relation to long-term accommodation models which can result in inappropriate placement and care.

A Long Term Disability Care and Support Scheme must:

- Be simple

    1. Reduce paperwork and disjointed co-ordination.
    2. Single reference point for qualification criteria for services, their availability and appropriate accredited service providers.

- Cater for all levels of disability.
- Have a strict audited accreditation system for service providers.
- Increase support (programs and respite) for the family as a whole if we wish to keep a person with a disability in the family home for longer.
- Recognise that ALL members, within a family of a person with a disability, deserve enjoyable, meaningful lives with an opportunity to achieve their full potential.
- Take a holistic approach to support of the 'total family need' including the availability, or lack thereof, of a supportive extended family structure.
- Not expect siblings to take over responsibility once parents or carer's can't cope.

- Take a ‘whole of life’ approach to care and support.
- Approach long-term accommodation on a far more pro-active, planned basis (timing / structure / co-tenants) and not wait for a crisis to occur. A good transition program is essential – emergency relocation can be extremely stressful on an individual and other family members.
- Take a more holistic approach to accommodation models, with greater vision and options, that focuses on the health, wellbeing, community inclusion, potential and value of a person with a disability.

Potential Funding and Administration Models:

- Formalised assessment structure based on total care and support need. This should include assessment and categorization of the total care need of the person with a disability and the family as a whole. This would allow guaranteed minimum automatic ‘flow-down’ funding to support the care needs of the person with the disability while being flexible enough, in it’s assessment structure, to provide additional funding to support the identifiable needs of the family.
- Should be a Federal system with support through the States and Territories.
- It should use an existing administration structure, such as Medicare or Centrelink, rather than creating a new one, due to required linkages with other sectors (e.g. Health, Aged-Care).
- It should be a collaborative rather than adversarial system. If the person with a disability is to remain in the family structure, for the maximum possible time, the needs of the family are of paramount importance.
- Upon assessment, funding should be directed to the individual or their carer rather than service providers.

    1. The family decides the best way to utilise funding, in a system which must be outcome based and have appropriate accountability.
    2. The system should be flexible:

        - Total carer / client control with availability of appropriate training to assist with such things as budgets, compulsory reporting requirements etc.
        - Case-management for less-capable carers (e.g. due to age, language skills etc) with NO loss of net hours or $$$s.

    3. Allocation of funding directly to the client should increase competition among service providers. It may also help generate a collaborative approach, between service providers, in order to produce economies of scale from both a service provision and economic viewpoint.

- Although the cost of such a system will be high initially, the costs will decrease over time due to indirect inputs into other revenue streams. These include getting carers back into the workforce, potentially helping to address skills shortages, while increasing tax and superannuation contributions. There should also be a reduced draw on the welfare benefits purse, while improved physical and mental health of carers should also help ease health demands and costs.

- A lot of potential funding is already caught up in existing insurance schemes (e.g. Motor Vehicle, Professional Indemnity, Workers Compensation etc.) which might be freed up to support ‘cost-of-care only’ under a new scheme.
- There is scope for more creative funding options, such as tax deductibility for items and services not covered by an NDIS but which deliver demonstrated outcomes. The level of deductibility could be means-tested with reduced benefit the further up the tax- bands one goes.
- Innovation through collective funding.
  The current system is not conducive for people with disabilities and/or their carers to get together, using collective funding, with a goal to develop a custom-made program with demonstrable outcomes (e.g. a Social Enterprise).

  Potential Beneficial Outcomes:

  1. Develop and improve skills.
  2. Maintain and develop friendship groups.
  3. Viable long-term project offering ‘job’ security.
  4. Create links to and gain support of skilled volunteer group(individual and corporate).
  5. Links with the community (individual and small business).
  6. Increased social integration and acceptance within the local community.
  7. Changed community perceptions of people with a disability.
  8. Meaningful and enjoyable activities.
  9. Family pride and involvement.

Conclusion:

The Commission has a unique opportunity to completely change Government policy in relation to people with disabilities and their carers. Bold recommendations can result in outcomes which are beneficial for ALL Australians. People with disabilities are not victims and should not be viewed as such. We take responsibility and embrace the challenge. We just need better support mechanisms to help us achieve for our loved ones what is their right, as indicated in ‘A Policy Framework for People with Disability in the ACT – Strategic Priorities 2009-14 Consultation Paper’ …… “All people with disabilities achieve what they want to achieve, live how they choose to live and be valued as full and equal members of the community”.

Thank you for your time in reading this submission.
Patrick White