Productivity Commission Issues Paper: Disability Care and Support

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Submission from What Does Chris Want (WDCW)[3]

Key questions (as set out in the papers)

1. **Who should be eligible?**
    - Those with severe ABI (acquired brain impairment) who have no other means of compensation and whose disability is acquired rather than genetic, or as the process of ageing. The example we know best is set out in the attached document: '*Acquired Brain Injury (ABI): a socio-medical model for the care of young people with severe acquired brain injury'* (pp.15-16) (hereinafter referred to as '*The Model*'[4]
    - Young people currently in nursing homes (or with the prospect of admission to nursing homes) who require age-appropriate accommodation

2. **Who gets the power?**

    Power should be shared; that is, not held by one agency, e.g., who is landlord, holder of funds, and service provider for life (as in current arrangements for the Villa Maria's new house for ten people in Austin Street Alphington funded by Victorian Department of Human Services *my future my choice*). The person with the disability (or their proxy) must at all times be empowered to hold maximum control over their own future.

    An innovative partnership approach based on recent practice over several years and applying to several young people with severe ABI is outlined in *The Model* (refer No 1, above)

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[1] Dr Rosalie Hudson is the chairperson of What Does Chris Want (WDCW) a group in support of alternative accommodation for Christopher Nolan.

[2] Mrs Mary Nolan is the mother and main carer of Christopher Nolan who, at aged 41, has been in a nursing home for over 14 years. He suffered a catastrophic acquired brain injury at the age of 27 and, although he has made significant gains, he remains without sight, without speech, and with minimal almost no movement. He is totally dependent on carers for all his daily needs.

[3] WDCW is a group of 16-18 family and friends of Christopher Nolan, meeting monthly since 2004 in pursuit of our goal: to find age appropriate accommodation and support as an alternative to lifelong nursing home care.

[4] This model was published in 2008 and launched at a public meeting in December 2008 by the Hon Bill Shorten.

3. **How should the amount of financial support and service entitlements of people be decided (and by whom)?**
    - In the particular circumstances which inform our interests, the level of health care is a pivotal ingredient.
    - Detailed aspects of recurrent funding for health care need to be factored in.
    - Costs of all equipment and maintenance of same
    - Additional paid support which accounts for needs over a life time, particularly when ageing parents are no longer able to offer support

4. **What services are needed and how should they be delivered?**
    In our case, the services include disability, health, medical, allied health, slow to recover rehabilitation, and community services. They need to be delivered in an integrated manner, as set out on pp.32-42 in the document referred to in *The Model*. This means **funding** for:
    - slow stream rehabilitation which meets the client's goals
    - community access which meets the client's preferences
    - transition arrangements when moving between agencies
    - respite care (both in home and in other contexts)
    - support for holidays accompanied by appropriately qualified full time carers
    - support for home visits accompanied by relevant carers
    - care coordinator and case manager to fulfil roles set out in *The model*, p.35.
    - IT supports to maximise the person's communication
    - Research so that practice is informed by evidence
    - An appropriate physical environment which is communal rather than institutional, while delivering relevant professional care (*The Model*, p.20.)
    - The highest standards of health care, rehabilitation and disability services in accordance with relevant published standards (*The Model*, p.30).
    - 24 hr care by *clinically competent health professionals* whose vigilance can prevent unnecessary hospitalisation, particularly for the person who is unable to speak
    - Regular inservice education for all staff to ensure integrated practice of 'procedural learning' which focuses on consistency of communication, particularly for a person with no sight and no speech.

5. **How should the scheme be funded?**
    - Individual funding based on individual needs
    - Comparisons with block funding (as in Villa Maria agency noted in No 2, above) discriminate against a person with comprehensive individual package

6. **Organising and implementing a new disability policy: what are the 'nitty gritty' aspects of a scheme that will make it work practically?**

- A shared commitment to Commonwealth/State funding which crosses borders of disability and health, as indicated in the COAG agreement of 2006. A disability policy on its own does not meet the needs of highly vulnerable young people with ABI.
- An innovative, creative philosophy of care (*The Model,* pp.23-31)
- The scheme needs to include factors of long term care arrangements which include changing needs over a life time.
- An understanding of the *differences* in current disability services and *health services,* e.g., the anomaly in *standards of care*
- A recognition of the training, educational requirements to support a person with high level nursing, medical and allied health support
- Appropriate medical oversight by those who understand ABI (*The model,* p.52)
- Access to world's best practice and evidence based care for the specific client/group.
- A 'real' partnership with families so they are involved (at whatever level they desire) in all decision making and can contribute from their own experience and wisdom and knowledge of the person