2008
Personal submission 1
to the Inquiry into Supported Accommodation for Victorians with a
Disability
Dr Jane Tracy

I am a medical practitioner working in the disability sector and the mother of a young man with cerebral palsy, intellectual disability and epilepsy. My son is a happy outgoing chap who communicates with gestures, facial expressions and vocalisations – but no speech. His needs for support, in relation to personal care, mobility, communication and advocacy, mean he will need lifelong care.

My personal and professional experiences with families of adults with disabilities have again and again demonstrated how devastating or how successful the transition from the family home to supported accommodation can be. The worst scenario is when parents care for their son or daughter at home for as long as they can. They love their son or daughter and fear for his/her safety, health and wellbeing. They may perceive advocating for a place in supported accommodation as rejecting their son/daughter, or relinquishing their responsibilities. They may fear handing hand day to day care over to disability services. The tragic inevitability is that at some stage become too ill to care. Their son/daughter has then lost their lifeline (the parent), their home, their normal day activity and their friends. Long term housing for people with disabilities is scarce and people in this situation are often moved to short term facilities until a permanent place is found.
Understandably these grieving, lonely, frightened people, many with limited communication ability, may express their distress through their behaviour (self injury, property damage, assault). They may then be taken then to doctors for medication (to ‘settle them down’) when the answer is clearly not medical.

The best scenario is when the young adult moves out of home to a supported accommodation setting with the support of their parents. The transition can be planned and parents involved in smoothing the process, informing staff about what their son/daughter does and doesn’t like; how they express pleasure, pain or illness; who their friends are and what daily routines they currently enjoy. The young person can be proud of their new home – after all they have moved out just as their siblings have! The parents can stay involved but have the ability to move into their retirement years having time for themselves, time for their partners and other family members, and time to contribute to their communities.

I see a solution as providing young people with disabilities an opportunity to move out of the family home into a their own home (supported accommodation or other) – at a developmentally appropriate age – say between 25 and 35 - as a matter of right. It would be a normal transition, a rite of passage, something of which to be proud. The young person would be moving out at a similar time to their siblings and aged peers and their parents are likely to be well enough to support the transition.
There are enormous cost implications – but there are even greater personal, social and economic costs of continuing to do what we have done in the past.

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I am writing to support the introduction of a National Disability Insurance Scheme as one possible contributing mechanism of funding the accommodation needs of people with disabilities within our community.

I am a medical practitioner working in the disability field as part of an academic unit set up to improve health outcomes for adults with developmental disabilities in our (Victorian) community.

People of all ages - from conception to old age - can experience a developmental difference or injury to the brain - that leads to impairments in function in either cognitive, motor, social or sensory domains. People with significant impairments will need personal care and support, aids and equipment and appropriate healthcare provision - regardless of whether their underlying neurological impairment resulted from a developmental abnormality, an infection in the womb, a near drowning of a toddler, a fall of a skylarking teen or an adult involved in an accident in the workplace or car crash. The causes may be different - but the outcome for the person - and their subsequent need for lifelong care and support – are the same.

Currently the primary responsibility for the coordination and provision of day to day care usually relies on unpaid family carers. People with disabilities (despite the dramatic health inequities and disparities they still experience) are living longer than ever before and are outliving their parents and carers. Parents of children and young adults with disabilities are part of the paid workforce and therefore have limited ability to be available to provide the full time care required of previous generations. Their expectations too have changed. They believe their sons and daughters have a right to take their place in the community without their parents constantly at their side, and the parents themselves believe they have a right to participate in and contribute to work and community in the same way as their age peers – roles often made difficult or impossible while being a primary carer.

People with disabilities need early intervention programs, therapy, aids, equipment, home modifications, holidays, meaningful day activities, ongoing educational and skill development opportunities, social and recreational opportunities, personal care assistance, transport … and, often, shared supported accommodation.

Disability is a part of life. We are all vulnerable. Some babies are born with disabilities – the reproductive risk we all take when we have children – others acquire disability in their childhood or adult years. The heart and soul of a society is reflected in how it cares for its vulnerable members. People with disabilities need the support of those of us who are (perhaps temporarily!) able.
The fully-funded universal National Disability Insurance Scheme proposed at the recent 2020 summit provides a model for funding care — in a similar way to the current Victorian third party insurance and work-cover schemes. All Australian tax payers would contribute to such a scheme — making the per capita payment relatively small, and people with disabilities and their carers would have the respect and dignity inherent in being able to make choices about how they live their lives.

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