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**Submission to Inquiry into Better Support for Carers  
2008**

**From:** Jane

**Position:** Parent of a 23 year old man with multiple disabilities and medical practitioner working in disability health at the Centre for Developmental Disability Health Victoria

**The following submission addresses the following 3 key areas:**

1. Barriers to social and economic participation for carers
2. Practical measures required to better support carers
3. Strategies to assist carers to access opportunities and choices.

**Supporting adults with disabilities and their families**

I am a medical practitioner working in an academic Centre, funded by Victorian State Government, that strives to improve health outcomes for adults with developmental disabilities. I am also 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. He will need lifelong care.

I have seen how devastating – and how successful – the transition from the family home to supported accommodation with paid carers 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.