



Planning for independent living

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The biggest single concern of any parent who has a son or a daughter with a disability has to be: What will happen to my child when I am no longer here to look after them?

In early 2003 a group of parents met in response to this concern. Each had a child with a mild to moderate intellectual disability working at Waverley Industries in Nottingham, which provides supported employment. A range of issues were discussed, including:

- 1) Should the care of our son or daughter with a disability be the responsibility of our other children? Most felt that each deserved their own life.
- 2) Should the responsibility of providing for people with disabilities be left to the State Government? Some thought it should, most felt it was primarily up to us.
- 3) In questioning what plans parents had made for the future care of their children with disabilities, nearly all had made none. Some felt they wanted to wait until the child was older; or they did not want to let them leave home at all!

The following accommodation options are currently available for people with disabilities:

1. Community Residential Units – In 2003 the cost of caring for one person in a CRU was \$65,000 per year. Around that time there was a wait of more than 10 years for such accommodation. Vacancies were (and still are) scarce. In 2006 there were more than 2,500 names on DHS's register – so they changed the system. Now only those who have moved, or are about to move into independent living, can actually register at DHS. The numbers now look far better..

Interestingly, we discovered that only 20 per cent of our parents had registered their child with DHS – so the need for housing was actually far greater than the official figures indicated. Parents throughout Australia continue to care for their offspring with disabilities at home for 20, 30, 40, 50, even 60 years, thereby saving governments a staggering \$32 billion a year.

2. Nursing Homes – Whilst accommodation and support for people with disabilities is a State Government responsibility, the acute shortage of accommodation means that many young folk with a disability find themselves placed into Federally-

funded nursing homes. In 2006, 6,500 were so housed, with a further 6,000 on waiting lists. This is totally inappropriate accommodation for their needs.

3. Shared Supported Accommodation – Private operators provide the accommodation, and support is funded by DHS. Most have no vacancies, only waiting lists.
4. Residential Support Services – We learned that these organisations are not always run well, and may not be attentive to the needs of their residents.

A few of us decided to be pro-active, and start something ourselves. Hence Winaccomm (Waverley Industries Neighbourhood Accommodation) was born.

Our aim is to provide long-term accommodation and arrange ongoing support for young adults with a mild to moderate intellectual disability in the South Eastern region of Melbourne, where little exists. We particularly targeted those who were likely to be able to live relatively independently, and would not require full-time care.

Our initial steps included: Forming a Committee of Management, electing an Executive, choosing a name, agreeing on our Constitution, registering as an Incorporated Association with the Department of Consumer Affairs, and seeking recognition as a charity with the Australian Taxation Office, which indeed agreed to grant us tax exemption and donor deductibility status.

Our Committee is comprised of volunteers, all parents of a child with a disability. The Committee is now elected by the full membership at our Annual General Meeting.

Accommodation:

Our initial plan was one of member contributions to be made by parents in the form of an entry fee into a residence for their son or daughter. During a conversation with Centrelink, we discovered that this would not be possible because of their gifting rules. Parents could not give away more than \$10,000 a year, with a maximum of up to \$30,000 over a 5-year

period, or there would be a negative impact on their Centrelink Age Pension entitlement, and their child's Disability Pension. As this was central to our plans, we arranged a meeting with the relevant Federal Minister, Senator Kay Patterson. A few months later I received a phone call from her. After 20 September 2006, parents would be able to put up to \$500,000 in a Special Disability Trust, to pay for accommodation and support for their son or daughter with a disability, without it affecting either their child's Pension, or their ability to get an Aged Pension. This has been described as life-changing legislation for many people.

Winaccomm's Model is based squarely on the State Disability Plan 2002-2012. Thus we set out to "Provide more housing options for people with a disability, to give people greater choice..." Choice is the key word. Traditionally when a person with a disability moves out from the family home, they have very restricted opportunities. Winaccomm wants our members to be able to choose – who they wish to share with (compatibility is essential), the type of dwelling they wish to live in, and its location. Surveys indicate our members' desires to be near a bus route to work, and close to shops and leisure activities.

"The State Disability Plan reaffirms the rights that people with a disability have to live and participate in the life of the Victorian community, with the same rights, responsibilities and opportunities as all other citizens of Victoria." This would only be possible if our potential residents reached a certain level of independence and self-confidence. They would need to learn new skills through training. This would also reduce the number of support hours they would require once they were housed. We approached Holmesglen Institute of TAFE to ask if they would design an appropriate course for our members. They enthusiastically agreed, and in 2004, ten students enrolled in a cooking course one evening a week after work. Here they learned how to prepare and cook a range of nutritious foods, eat together, and thoroughly clean the kitchen afterwards. We are now into our fifth year. Both the cooking, and the second year course, have been a great success.

During the second year course, both communication and numeracy skills are improved, and our members learn to safely use household appliances, and gain increased competence in handling money.

Support:

Parents are not able to afford accommodation plus on-going support costs, so we approached DHS,

Eastern Metropolitan Region. We asked if DHS would help us, and finance the cost of the on-going support. Our timing was perfect, as they were just beginning a new individualised approach to assist people with disabilities. We were told to encourage those parents who had indicated their son or daughter's readiness to live independently to apply for a 'Support and Choice' package. Eleven of our members were successful in the initial round in 2004, and these funds were used to train them towards independence, by contributing to the cost of the TAFE courses, plus paying for a support worker three hours a week in the family home, to teach the recipients skills like house cleaning, laundry tasks and grocery shopping.

These packages of support hours enabled Winaccomm to house our first members in February 2005. A house was found to rent for three of our lads. It gave them the opportunity to put into practice the skills they had learned, as they did their own cooking, cleaning, laundry, banking and shopping.

Our model can be adapted by other groups, as we have made our documentation available to assist those who are interested. I have addressed a number of parent groups over the years, and sent outlines of the steps we have taken, and our constitution. Some have now formed their own associations, with the aim of housing their young adults and others with a disability. It seems self-help is the only way many people with disabilities will be appropriately housed in the future, as more and more frustrated parents form similar groups across the state.

As one of our Prime Ministers famously said – 'Life wasn't meant to be easy.' Many parents of a child with a disability can attest to that! And taking the necessary steps to secure their future is a particularly daunting task, fraught with uncertainties.

For my husband and I, it was important to have both our boys happily settled long before our demise. Having tried other types of accommodation, we have opted for the Support Worker model, where our lads live by themselves, with workers only coming in a few hours a week to guide them at times when they cook, shop and clean. This gives our sons a chance to grow and mature, to lessen their dependence on adults, learn from experience and gradually become more and more self sufficient. It also gives me, as their mother, peace of mind, knowing they are securely settled and will be well able to cope when I am no longer here.

After all, isn't that what all parents want for their children?