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Some reflections on community life in the Blue Mountains

for people with developmental disabilities

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Abstract

This account describes how two parents realised they had held the mistaken belief that love for their daughter with high support needs meant protection. They watched with trepidation while their daughter moved from institutional type accommodation to a supported house in an upper Blue Mountains community and then observed how at last she was able to establish an identity and begin making choices for herself. **Keywords: Families, Education, School age**

SOME REFLECTIONS ON COMMUNITY LIFE THE BLUE MOUNTAINS FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

These remarks represent the feelings and thoughts of the parents of a person with a severe developmental disability who moved into supported community accommodation after living at Rainbow Lodge for over 20 years. The purpose of this statement is to offer some positive hope to parents who still face transition for their disabled sons or daughters.

When we first learned of the proposed demise of Rainbow Lodge in 1989 we were as devastated by this news as any parent could have been. We fought hard to have this decision reversed. We consulted politicians, government departments, parents of disabled people who had already moved out of institutions; a word that did not come easily at the time, and managers and staff of community houses.

It was a long hard road over which we would not like to travel again, but the journey has been rewarding. During that initial period of 6 or 8 months we were able to visit some of the newly established community based accommodation services. We met people with higher levels of disability than any of the residents of Rainbow Lodge. We were also given an opportunity to inspect the institutions in which these people had previously lived.

We began with cautious optimism and continually asked ourselves the question, "Why should we trust people on matters about which we are not yet qualified to pass a valid opinion?" We looked, listened and asked questions. Our attitudes began to change as we became more and more impressed by the new system. Although we encountered some devastatingly unrealistic philosophies of "experts" along the way our overall progression could be described as optimistic and enthusiastic. Knowledge gave us strength. Throughout this difficult period, officers of what was then the Department of Community Services & Health, now the Department of Health, Housing and Community Services, were both compassionate and supportive. Without their help and guidance we may have faltered.

Although Rainbow Lodge had been implementing many of the Principles and Objectives of the Disability Services Act for a number of years, it was applied only in the case of mildly disabled residents.

It is now a little over 12 months since four of the more severely disabled residents of Rainbow Lodge moved into supported community

based accommodation in the Sutherland Shire, and 6 months since eight more resident with severe disabilities moved into two houses in the Upper Blue Mountains.

We had no doubt at the outset that the new system would be of enormous benefit to people with relatively low support needs. At Rainbow Lodge these people had always been selected to participate in community based activities, while the more severely disabled residents remained behind in the protected environment of Rainbow Lodge.

Our severely disabled daughter now lives in one of the houses on the Upper Blue Mountains. There is absolutely no doubt that the quality of her life has been enriched by the change of environment. The list of new experiences which she has enjoyed and marvelled at is too long to include. Transition has opened a new world for her that for all practical purposes never existed within the protected environment of Rainbow Lodge. She is beginning to establish an identity and is doing things which we never believed would be possible. She is exhibiting more independence and making choices for herself. She is becoming an individual.

The past year has been an exciting time for her parents who take great pride in her new achievements.

In the past we held the mistaken belief that love for our disabled daughter meant protection. Love is much more broadly based than this; a lesson we had to learn. Protection of those dearest to our hearts is just one aspect of love.

It is our view that the keynote to success for a community based accommodation service is unashamed honesty between residents, staff, parents, co-ordinators, and service providers. In any discussion, the positive achievements as well as those aspects of the service which are in need of modification should be included. None of us has all the answers. However, if we resolve to work together on the identification of problems and communicate our thoughts about short term and long term goals and outcomes for our disabled sons and daughters we can look forward with confidence to a richer life for them and a service which aspires to excellence.

Our text for the future is CEEING IS BELIEVING. This includes Courage, Compassion, Communication, Confidence, Co-operation, and Co-ordination.

Two Born Again parents whose identity is irrelevant.