

Current Situation

My husband (70) and I (77) are the sole carers of our daughter; a woman with Down syndrome aged 33.

When we die she will be alone in Australia.

Our daughter is currently renting a unit next door to us, her parents who are always available for every possible issue including preparing meals and monitoring medication

We have taken much trouble and time to ensure our daughter is familiar and comfortable in this community. All necessary facilities are familiar to her and she has learnt to access these with little or no support from us.

Our Daughter has been granted 8 hours a week support from DFC which assists with her looking after her home and some social outings.

History

For 28 years of our daughter's life we lived in a country town north of Adelaide. The very fact that she has Down syndrome was all the evidence the Education Department needed to recommend she was required to go to the Special School. Here we spent much painful energy ensuring she had an education which was appropriate to her best interest. This meant we needed to fight to keep her in the regular school with support. This was achieved and she did meet the requirement to gain a modified SACE certificate aged 19.

Her interest was in the Theatre, Opportunities for this were not catered for in the Country, so we moved to the city to allow her to follow her chosen interest.

Our new home required her to learn about a new set of rules, city and not country, however we have now enabled her to establish a life where she is familiar with all her local needs. She is able to attend many of her own needs in this community with little or no support from us her parents.

This includes Banking, Chemist, podiatrist, local shops, dentist, and optician. Familiar bus routes to work and place of education. In short we have put much effort in to helping her to learn how to survive almost independently in this new familiar situation.

Need and limitations to meeting these needs

For all our daughters acquired abilities, she remains a person with a disability dependant on a support system to survive and remain safe. Having achieved some measure of independence, she is now recognised as not having severe or multiple disabilities and as such is not considered as some one who will meet the criteria for crisis situation solution. She becomes invisible to authorities as she is a person who quietly manages her world making the minimum demand on the authorities.

That support which comes in the form of some financial assistance through DFC and 24 hours duty of care from her parents.

That support offers her a full life in the theatre as well as other possibilities of further education and experiences. Once we her parents are gone, that support will be gone

Clearly it will be to her advantage, and our piece of mind, if she could now be housed and supported in the community she has grown to know. Her transition to a future secure life without her parents would be less stressful, and therefore less costly if this could be facilitated in the near future and while we are still around to help her with the new challenges in her life.

There is no planned accommodation available in the neighbourhood and if she were suddenly to be on her own she will need to be housed in an area far from her current home without much consideration for her to be in a place of best interest to her, and she will need to begin a completely new life.

This a far more expensive project with the need for far more support than she is currently demanding.

Possible solutions

The development of supported accommodation, within the community, near enough to local facilities, in order for residence to remain relatively independent.

This could take the form of

A small group of units in the public housing sector, for example a block of four units which might be offered to four people who are reasonably able to manage with limited support. These four people although maintaining their own independence by living in their own units might learn to support each other and form a new bond/family for them to relate to. Such small communities might be jointly supported by the agencies which are currently funded to offer the same individual support.

The development of a group home in areas where there are currently none with the options of rented units being attached for those who prefer to live alone, or for that matter with a partner

It will become very destructive for people with an intellectual to be moved away from the area they have grown up in and feel secure and then sent to places so far away that all local and familiar contact is removed from their lives.

This matters very much whatever degree of disability they may have. If they have no family members they choose to go to then they must have the opportunity to remain with what has become familiar to them. It is after all the emotional life of any person that makes their world for them and to have a disability is no different. We must not put into place barriers which make people more disabled we must strive to make lives better and more enriching for them

More emphasis must be put on the importance of establishing supported accommodation facilities where people currently live, this will ensure a smoother development to a secure and fruitful life for people with disabilities.

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