

A RIGHT TO MEDICAL CARE SERVICES BUT NOT DISABILITY SUPPORT SERVICES

**“How are our children going to get a home of their own,
no matter what form this takes?”**

Ruth Kyrie of Valley Carers addressed a recent meeting of the Western Region Disability Network (soon to be, "Disability Connections Victoria"), where two of the top DHS executives also addressed the meeting.

Ruth said, "I am the mother and 'manager' of my daughter, a young woman who has a moderate intellectual disability, and I am a member of Valley Carers here in the municipality of Moonee Valley.

Valley Carers is a support group for the parents and carers of people with any type of disability. We aim to help each other in a supportive environment, gathering and sharing information, establishing links with all levels of Government and Service Providers, raising awareness and promoting initiatives which will enhance the lives of the people in our care.

Although we have concerns about, after school care, facility based respite and accessible buildings, the biggest concern for all members of Valley Carers is: “How are our children going to get a home of their own, no matter what form this takes?”

A home in a safe environment, with the best essential support and one that avoids social isolation. We know that 'one size doesn't fit all' and that there needs to be a range of supported options.

We have at least 2 members who are in their seventies, with daughters in their forties and they are desperate! Others are starting to plan for the future, anguishing over not only what but how! We want to see our loved one(s) in their own home long, long before we are no longer able to look after them ourselves.

Valley Carers are ordinary people wanting ordinary things for the people in our care, people who do not have the resources to provide for themselves. We are not millionaires! We are not developers! We do not all have other family members able to "take over" and why should they?

- Is it right that a young adult has to remain at home with their parents because they can't afford and can't manage to live independently and there is a critical

shortage of suitable, supported and affordable options?

- Is it right that parents have to live restricted lives and restrict their retirement options? Or that parents resort to relinquishing their children in their desperation?

This does not happen in mainstream society and why should the 'pattern of life' be any different for people with a disability and their carers?

Recently I wrote to one of our young Councillors in regard to a comment of his, as quoted in the local newspaper, relating to a potential development. I was not presenting an opinion on the development itself, but rather providing him food for thought in relation to his remark about " how else could Gen Y get access to affordable housing". I suggested that perhaps Gen Y could remain living with their parents for the next 30 or so years until their parents died or moved into a nursing home! I believed I could hear the exclamations of horror not only from this young Councillor but also his parents! Yet this is what the parents of a person with a disability are facing.

A young adult with a disability has the right to move out of home, be settled and live their own lives and in a compassionate society, parents should be able to see their child successfully settled in their own home, with a working and appropriate support system in place, long before death! I, for one, don't want to be carted off to the Nursing Home or Crematorium, while my daughter stands bewildered at the front door of the only home she has ever known, while a stranger packs her suitcase! This doesn't mean an abrogation of responsibility on behalf of the parent(s).

Valley Carers want that home to be local, to enable a continuation of current work/recreation and friendship patterns and just as important, to enable the parents/carers to either continue in a caring/supervising capacity where possible or just to live as 'normal' families do visiting and socialising together.

We have started gathering information, writing letters to politicians about available land in this municipality and have talked briefly to a service provider about how to plan and organise a housing option that would suit our families. There is a lot more to do!

We would like to see serious, municipal based planning for people with a

disability who will need some form of supported accommodation in the immediate and long term future. It must be centred on the needs of the individual and not be profit centred or determined by the lowest common denominator. This planning for accommodation should commence well in advance of "crisis" management.

Valley Carers believe that money is not the problem. Rather, it is a question of priorities and community and political will. To that end we have endorsed the concept of a National Disability Insurance Scheme and are looking at ways of gaining community support. One idea is perhaps to have a presence at the Moonee Valley Festival in February 2010."

LISA Comment: We see Valley Carers asking, "Why can't we have care facilities in, and tailored for the local area?"

When Local Authorities are asked why they provide no facility based respite and permanent accommodation for people an with intellectual or multiple disability, as occurs in the UK and some places in Europe, they say, "State Governments have a track record of providing initial funding, and then leaving us to provide on-going funding for projects of this nature."

Families with similar concerns as those of Valley Carers, should not only consider the availability of facility based respite and permanent accommodation, but of the quality of care provided therein. It is distressing for parents to see their family member's skills and quality of life drop like a brick when they are living in a supported accommodation group home or similar.

We say, "Help us ("LISA") to encourage quality of life care, not minder care!" Elderly parents who have done it tough in caring for their family member at home, want to depart this world knowing their vulnerable family member will receive on-going quality of life care.

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