

Family and Community Development Committee.

Having closed the institutions the institutional behaviours of the DHS staff have carried over into the CRU (Community House) model. The house where my sister lived (which was a DHS house) was an extension of the experience she had at Janefield (J) commonly referred to as an institution although it was not an old Victorian style institution.

At this congregate care facility (J) my sister had her teeth brushed. At the CRU staff would not brush her teeth. They insisted she should be independent and brush her teeth. But she was unable to do this and in the 9 years she lived there she had 8 teeth removed.

At (J) my sister was able to use her own soap. But at the CRU she had to use communal soap on tap.

At (J) my sister was able to go for a walk independently and walk across to the sheltered workshop. But at the CRU she was confined to the house and the door was locked three ways so clients could not work out how to open the door. She was a prisoner in the house.

Even the French doors were replaced with doors with slit windows which were more like prison doors.

Residents were middle aged women and families had asked for all female staff. But the DHS refused all female staff saying they had an equal opportunity policy. So male staff were employed! What rights did the clients have? Even prisoners can choose the sex of their staff. Male staff were not registered with any registering authority.

My sister was afraid of the shower and needed a bath. But DHS altered the bathroom and so my sister was unable to use the bath because it was the type used with a hoist. It was deep with wide sides and my sister is short and could not use it. I was unable to get anyone including the Ombudsman and Community Visitors to view the bath.

My sister was drilled to say she was having a bath when in fact she was having a shower. She was also coached to say she wanted to live at this CRU when in fact she wanted to come home. She was too scared to stand up for herself. This is a type of mental abuse.

I took her to Church at 9 am and staff complained it was too early. So we started going to the 11am service. Then staff said this was too late. I was speaking to the house supervisor about my distress and said "Well I can't take her to Church at all." The house supervisor replied "Well that's your decision." This is a type of

brainwashing where you are blamed for something someone else has done. This is a common tactic of the DHS staff.

My sister had an incontinence allowance (CAS allowance). The house supervisor used my sister's CAS allowance to buy laundry products for the whole house and soap on tap for the whole house, antiseptic cream for all the ladies, and dressings for all the ladies and gloves for staff. I was always buying undies because they wore out in the bleach the house purchased for the whole house with my sister's allowance. The CAS allowance should have been paying for the undies.

Whenever my sister went out she accessed the community with the ladies from the house. She went to the same day program (despite the fact it did not suit her) because it was convenient because of transport.

She went to the same evening class despite the fact I paid to get another program for her. Staff would not allow her to go for three months until I made a complaint.

This CRU was the worst type of institution anyone could have. Most families put up with these CRU's because they can't cope with their person at home. They are told if they don't like the CRU they can take the person home. There is no alternative. Many of these families pay \$100 a month out of their own pockets to keep the person in the CRU. Simply because families have placed a loved one does not mean they relinquish their loved one.

Medical treatment in a CRU is often obtained without the consent of the family but with the consent of the DHS. One family in Gippsland objected to their young daughter have a hysterectomy but they were overruled by the DHS and Office of the Public Advocate. After the surgery the DHS had the audacity to expect the parents to provide convalescence because they said they could not do this at the CRU!!! I had to constantly fight to be involved with my sister's medical treatment.

My sister has a dual disability. So when she got sick at this CRU they rang the police and she was admitted to a local psychiatric hospital. She was in with other people who were "normal". But my sister needs assistance with her daily living skills and staff refused to provide this assistance. I had to go in to shower her. The CRU sent staff but the DHS would not allow them to shower my sister.

We need separate facilities for people with dual disabilities.

My sister was scared of the other patients. She was forced into the lockup every night because she would not stop screaming. All this for a person with an intellectual age of 3-5 years! The facility made her worse.

The stress it caused her family was horrific. Now that my sister is home she has had her medication halved and there is no sign of psychiatric illness. But a bureaucrat at the DHS decided my sister was best living in her CRU. And a bureaucrat at the Office of the public Advocate agreed. They came with the police and seized my sister off me under the guise that I was unwell when in fact I was perfectly well and DHS documentation proves this. They did everything in their power to force my sister to live at the CRU when they knew we were both unhappy about this.

Half of the disability budget is used on the 4,000 odd people who are in CRU's. The other half of the budget is used to provide all other services to the 92% of people with disabilities who live at home.

Many people with intellectual disabilities have ended up in SRS style accommodation. Often they do not have assistance with their daily living skills when they need assistance. They are often cared for by unqualified medical people and they do not get timely medical attention because of this.

I am unable to mention the names of the two cases I am referring to. But there are many more like them.

Many parents with the daily responsibility of caring for people with an intellectual disability are unable to get guardianship. The Guardianship Board are seen to have an anti family agenda. There are some bad families but the majority of the 92% who live with their families are good families. As above, they can force surgery on our loved ones. Under the new Disability Legislation they can force medication on our loved ones.

There must be alternatives to the CRU. Village style communities and cluster developments should be allowed. There is nothing wrong with congregate care. We allow it for over 65's and we allow it for all holiday resorts and hotels. We should allow them for people with disabilities who may want a holiday while the parents are having respite. This model has been refused for respite in Victoria. We could have farms with horses, a swimming pool, rivers, boats and an oval for sports etc.

But successive governments have refused these alternatives in favour of the 5 bed institutional CRU. Does the size of the roof make any difference or is it the relationships inside?

The 92% who live at home have nothing and the waiting list gets longer because there are no alternatives and no innovative models being built on. There are models available but they are in the private sector. For example Waldreus Lodge in Wantirna. Why can't governments look at the success of this facility?

The new way, chiefly because CRU's are too expensive; are packages. But packages will not work because the money is given to Service Providers who take in some cases 70% of the package in case management and administration. This leaves the family who provide the 24 hour care with insufficient funds to provide any quality of care and leaves the family drained with poor resources for ground level care.

This is overcome with the family governance model where a service provider acts as a broker only for a percentage of the package and the family run the package or case manage it themselves. This family governance model has worked for over 10 years but is not promoted by the DHS. DHS promote the service providers who are interested in propensitating their jobs. Why are bureaucrats and government so anti family motivated?

The 1985 steering committee into Social Security Costs said that governments should promote families to reduce their burden, but no notice has been taken of this. Governments do not value social capital. In fact they work against it.

Families know what they need. They know when they need respite and they should be the drivers of their packages. So if packages are the way of the future then Family Governance should be promoted.

It is a worrying trend for governments to say people with disabilities should live at home all their lives.

Advocacy is a sad issue because people with disabilities who have good communication skills or are normal except for a physical disability tend to speak on behalf of all people with disabilities. They often advocate the closure of institutions in favour of CRU's which has been the government line and they are also funded by governments and promote the government line. There is a conflict of interest here. People with no communication skills have no say because of this vocal minority. This vocal minority never ever think of the family who are providing 24 hour care. They are completely selfish in their own desires for themselves. No congregate care is their favoured line! And government listen to them and pay them to be like this!!! There has never been a full time carer from a family on any Disability Advisory Body or in any other body. VALID do not represent the majority who can't speak and are left in the family home all their lives sometimes with no services at all. They have refused one person I know who asked them to advocate cluster housing for their daughter. They told the mother this sort of accommodation was not supported by VALID. It is not supported by any other government funded advocacy group either.

Many parents lose their own lives in the daily struggle of 24 hour care and they should be able to retire. Many die not knowing what will happen to their loved one when they die. This is completely unacceptable in our society. These parents have saved the Federal Government \$100,000 per year by providing

home care. Yet they can't die in peace. They are not valued and they are told what is appropriate for their loved one by bureaucrats who really have no idea. It is an area where the rights of the person with the disability and the rights of the family are abused. It is a Human Rights issue. Their Human Rights are always breached by bureaucrats and governments. We are already in a humanitarian crisis.

Families should have the automatic right of Guardianship where the child does not reach intellectual maturity and this is so in other countries and works well.

The Federal Government need to fund disability and they need to provide 108 beds for every 1,000 people with a disability. That is benchmark funding in aged care and that is what is required in disability.

No more passing the buck. Rights for families who provide all the care, the right to retire knowing there is a place and freedom from government abuse.

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