

Sometimes You Get There

by Caring Parents

We have first hand experience of Department of Human Services (DHS) management practices, and their disgraceful disregard for true quality of life care. Consequently, we are delighted our family member is now in the care of an excellent Community Service Organization (CSO) service provider.

The management and staff of this service are so warm and welcoming towards residents and their families. They love to talk with residents and their families, and are very outwardly dedicated to the cause of providing real quality of life care and support, with very meaningful family contact and involvement. Staff are constantly searching for ways to engage and include residents in activities and community. A very happy place all around!

When our family member moved into this excellent service, we were immediately given their *Residential Statement* in an information folder. Subsequently, we were a very active party to developing our family member's BSP and PCP, and other health plans. All of which we were asked to approve! This service goes to extreme lengths to ensure total family involvement and satisfaction. This is in contrast to our previous experiences when our family member was in a DHS group home.

Our experiences of a DHS group home, was that of residents and their families being on the lowest rung of the ladder. The DHS service was focused on the needs of management and staff. Whereas this CSO ensures their service is all about the residents. Residents and their families are first and foremost!

Our family has a lasting memory of our initial meeting with the CSO Housing Manager. After being stuffed around for years by DHS, we were in a highly defensive mode at our first meeting with the CSO housing manager in discussing how a possible transition might go if we decided to accept the vacancy. We said to the CSO Manager, "We are not so interested in *quickly*, but would like it to be done *properly*". The manager's answer, given with enthusiasm and a smile, was, "I think we are going to get along fine, because 'properly' is what we are all about here!"

When we later said, The DHS documentation has probably labelled us as serial complainers! The CSO Manager said, "Oh no! We consider you are very good advocates for your family member!" They really do have the residents and their families always first and foremost!

There is an acknowledgment of individual needs and continued effort to meet those needs, with the result that behaviour is not the huge issue it was with our previous DHS experience, where clients just had to fit-in with staff needs. The DHS staff spent heaps of time attempting to manage inappropriate behaviours,

and never had a spare minute to provide residents with quality of life care. They even needed to employ extra special behaviour intervention staff. No one was ever happy! We tried to suggest that an occupational therapist might save them the behaviour therapist, but, who were we to know anything! We hurried out of there as quickly as possible, as the place seeped of misery!

Our experience of DHS managers is that they do not have in depth knowledge of the houses, staff, residents and their families. It is more a matter of ticking-off on the paperwork! Whereas, the service should be all about the residents and their families, not a huge bureaucratic empire.

DHS case managers have a limited budget, and often don't know the client well. This makes cutting the funds easier, but means that lots of people finish up with a few crumbs, and are left with not too much improvement in their lives, but, the case is solved on paper.

We don't imagine all these DHS managers are as heartless as they seem, and realise the government does not fund adequately. However, as a taxpayer we feel the funds would be better spent providing best practice services, rather than this delusional pretence of looking after people, and spending heaps on staff attending endless meetings to manage the huge waiting lists. In our case the more strident we were about the waiting, the more people came to the meetings (14, at one time!). Maybe for mutual support against our anger. Maybe to lull us into thinking all those people were working for us. We don't know! But what a waste of money!

Dealing with the Department of Human Services is a huge additional burden on top of the burden of caring for and supporting a person with a disability. We have had to spend hours and hours of our time explaining and re-explaining our family members complex needs. Endless, pointless meetings were required where we were usually outnumbered three or four to one by Department staff. Nothing was achieved, year after year.

We felt alienated and threatened by the bureaucratic and disinterested approach of many Department staff who mimic concern but have nothing to offer and finally don't really care. We felt dis-empowered, isolated, and often hopeless. We were often treated as 'just the parents' as if we were over-protective, with little understanding of our family member's needs.

Our current experience is a supportive one and everyone (parents/guardians included) in the organisation are valued. Our CSO Housing Manager visits the houses regularly, and is well known to all the residents. He has dinner with the residents at each house every month. He meets two residents from each house each month in his office, to ensure he hears all the gossip and knows all his residents individually. As well, he makes it well known that his door is always open to families.

LISA Comment: We know these parents went through bureaucratic hell, and used up more than their fair share of luck to get the level and quality of care for their family member which is allowing them peace of mind in their retiring years, and to be able to depart this world in peace.

Although these parents are over-the-moon with joy, they are sad for those ageing parents still caring for their family member at home, with no hope of respite but to depart this world - Leaving their vulnerable adult family member to an uncertain future!

They are also sad for those parents who have to fight daily to help ensure their family member gets even reasonable basic minder care in some group homes. And for those parents who are burnt-out fighting the endless bureaucratic battles for just a degree of reasonable common sense. And, those who are intimidated for daring to question service level and quality.

We all trust that one day common sense will prevail. As real, meaningful and accountable quality of life care is not rocket science, even for those with the highest level of need. Quality of life care is mainly "attitude", rather than "funding"!

Funding is certainly an important component which must have outcome expectations set, monitored and maintained if quality of life care, rather than minder care, is to be consistent across all services.

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