Submission No. 1211
(Inq into better support for carers)
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BETTER SUPPORT FOR SENIOR CARERS

Submission

By Beverley and Steve

As a Hostel Owner/Operator for 5 years, I wish to offer my opinion and comments on the above subject. Due to the on-going extreme stress and pressure, plus the lack of support and co-operation, caused by various departments in all 3 levels of government, we were forced to close our hostel (on my doctor's orders) – however my husband and I (also seniors) still care for 3 senior male residents with mental disabilities in our home. We do this work because **we care** – we are not related in any way to our residents – they have no families.

There is a definite need for co-operation, understanding and support from government departments, e.g. DSQ, Centrelink, Public Trust, and Adult Guardian. Things were made so difficult for us, that we actually felt that we weren't wanted. We chose to do this work, enjoy it, and are good at it, (because we feel it is a 'calling in life'), yet we have had a constant struggle since day 1. The hardest part of our work was, and still is, dealing with red tape – not caring for our residents. Particularly, in a country area, a common sense approach is required.

1. Legislation:

I doubt that the person or persons who wrote the legislation have ever had any contact, or spent any time with a person with a mental disability. Plus the public servants who use the legislation to regulate are more interested in the 'bricks and mortar', and do not appreciate that the residents are happy, healthy, and living in a loving home situation. There desperately needs to be some flexibility in the execution of the legislation. It needs to be a guide only.

Our Hostel (Hidden Valley Hostel) was registered and accredited as Level 3, for 7 permanent male residents with mental disabilities, classed as 'low-care'. I can understand that a larger hostel may need to run like an institution, but surely smaller homes do not need the over-regulation that currently exists. Common sense and logic seem to play no part in the decision making. The feedback from the Justice Dept Community Visitor and occasional 'official' visitor (regarding the care we provided) was always extremely positive.

In our experience, the rules and regulations of the Qld Fire Safety Dept, the local Council, and the Qld Government all differed. Which ones were we supposed to follow? E.g. Re: size of bedrooms. The Fire Safety Inspector passed our hostel with flying colours, the Council was indecisive, and the Government demanded that we remove a bedroom wall, (causing lack of privacy) because one bedroom was 100mm too narrow. It was still a comfortable bedroom, and the 2 residents had privacy and were happy.

The Council Health Inspector demanded that we line the resident's dining room walls with plasterboard (it was tongue and groove – our home is an old Queenslander in a country setting) in case some dust fell into the meals. I explained that some of our resident's are unable to use toilet paper (hence, we do a lot of extra cleaning). On his next visit, he demanded that we also line the ceiling. When he came to inspect later, his comment was "Oh, did I ask you to do that?" He also requested another sink in the kitchen (as well as the double bowl sink) for hand washing.

1. Why does a family home need a licensed kitchen?
2. Why is it necessary for a separate toilet (not in the bathroom)?
3. What is the difference between our home and any home with 7 children?
4. The registration of medication administration is understandable is larger places, but a time waster (when the medication for only 3 residents, arrived from the Chemist in Webster Packs).
5. The registration of meals provided was a waste of our valuable time, and proved nothing. (If we weren't decent enough to provide good meals – we certainly wouldn't be honest enough to register them !!)

Once again, flexibility is required. It is a loving family home – not an institution! Surely, the spot checks from the Community Visitor from the Justice Department were adequate.

The Council demanded that we remove a perfectly good septic system, (that had been adequate for 10 people in the past) and replace it with an Aqua Nova treatment system - at a cost of $14,000 – which has caused so much trouble during the last 4 years. At one stage, it was overflowing raw sewerage under the kitchen window, the installer blamed the designer, and the Council offered no assistance whatever. It turned out that the medication required by the residents was the cause of the problem. The designer, the installer, and the Council were aware that our residents suffered mental disabilities with behavioural problems requiring medication. Plus, the Council demanded that after washing dishes, sterilizing the dishes in bleach was necessary – however bleach was one of the things that could not go into the Aqua Nova.

I must state at this point that I had no problem with the fire regulations, as the safety of all our residents was, and still is, a priority.

The government must realize that we are all unique human beings, and do not (and were never meant to) fit into boxes (to be ticked). Once again flexibility and common sense are

required. **Our residents are disabled – not stupid.**
1. Query by the government auditors "Should the soap powder be left in the laundry"????
2. As we do all the washing, what difference does it make what size washing machine we have? Why is that regulated?
Regulation required that our residents (who cannot read or write, and some were non-vocal) are to be provided with 48 hours written notice before we enter their bedrooms.

(i) they can't read
(ii) there are no doors, as constant supervision was required.
(iii) there was more than one resident who was incontinent and all the bedding needed to be changed daily?

We were often reminded that the resident's had rights and choices – but where is the fine line between their choices and our duty of care? E.g.:-
1. If a resident wanted to walk out of the gate and onto the road – it was his right (we were not allowed to stop him), yet if he was hit by a truck, it was our duty of care that was lacking.
2. Our carers (during courses) were taught that if a resident wanted to wander off in a shopping centre – this was his right.
3. As part of our Fire Management Plan, we are required to do a yearly check to ensure no extra people have moved in without our knowledge. Where's the common sense in that?

Where is the flexibility or common sense in the legislation for small hostels? If a resident passed away at the hostel, our first phone call had to be to the police, as it was classed as a 'death in custody'. This is not common sense to me. Caring for anyone with a disability 24/7 is similar to caring for a new baby. The physical and emotional load is heavy enough, without the mental stress caused by over-regulation. The government even demanded 30 days notice of closure (even though we had arranged alternative accommodation for the departing residents); otherwise we would be fined $7,500.00.

2. ***Medical***

I have been advised that during medical training to become a doctor, there is a very limited amount of time spent on dealing with the disabled. In fact, this section of the course does not even require a pass. This definitely needs to change! Doctors must learn to listen and trust the carer. In the past, we have been treated with contempt by doctors. We know our residents, and a simple change in routine or behaviour can have a meaning, particularly when the resident in non-vocal.

Doctors need to believe us when we say that a person with a mental disability has a very high pain threshold, and when they show pain – there IS definitely something wrong.

1. On one occasion, we were told by a locum doctor that "He couldn't have gall stones, he would be doubled up in pain", when an x-ray had already proved otherwise. Although this resident was Category 1 with the Caboolture Hospital, it still took numerous phone calls and over 12 months to get him treated. When I explored the option of private medical care, Public Trust Office said his money should be saved for later life. This resident has Down's Syndrome and is 52. Surely, his health is the most important thing.

2. On another occasion, after explaining that a particular resident was terrified (because of abuse in his past) and would require sedation to be examined, the nurse still showed him the needle (for his approval) which terrified him even more, and then he needed to be held down by 4 people and became even more distressed. We knew he was ill, because of different behaviour, yet the doctor didn't believe us, because the resident didn't display enough pain.

3. Why are we subject to political correctness – (e.g. "person with a disability" not a "disabled person"), when the Caboolture Hospital has M/R (meaning mentally retarded) written in black pen on the front of a resident's file?

3. ***Centrelink***

Why does any slight change in circumstance require a totally new claim, when the carer is the same and the resident is the same? Filling out new 32 page claim forms, providing new ID, completing a treating doctors report, (all so time consuming), and then the wait for payment is unacceptable. Every phone call to Centrelink provides a different answer.

Then to have a Centrelink Customer Service Officer say, regarding the Carer Allowance: "It is only a miserable $50 a week anyway" is just so insulting. The fact is that the Carer Payment and Carer Allowance average out to $1.32 an hour per resident. That is the amount of government support we receive for a 24/7 difficult job. Currently, there is a carer who has waited over 2 months for approval of a Carer Allowance, due to the disorganization of Centrelink. Meanwhile – care of residents and expenses still continue.

The payment to us from Public Trust (from the residents pension) of $264.00 per week covers all food, lodgings and personal care (i.e. washing, ironing, cooking, cleaning, bathing, shaving, toileting, driving to appointments, emotional support, medical support during the night, finance handling, etc. etc. not to mention total supervision 24/7) – and yet Centrelink even questions this. Where else, could one rent a furnished house for this amount, even without the personal care necessary for the disability? Why is it that we were required to meet standards for accreditation and registration for 7 residents with mental disabilities, yet my husband and I can only claim **1** carer payment each?

For ID purposes, (required by Centrelink every claim), our residents only have pension cards, Medicare cards, and bank statements. Centrelink don't understand that due to their disability, they don't have a drivers licence, mobile phone bill, or electricity account, or rate notice. Plus, Centrelink still require an original birth certificate – a certified copy isn't acceptable.

4. ***Public Trust***

I required a birth certificate for a resident recently, for ID purposes for Centrelink. I was told by the Public Trust Officer that it was an unnecessary expense for his client. Yet, Centrelink will only accept an original birth certificate – which is held by the Public Trust Officer who was reluctant to release it.

The Public Trust Office deposits $60.00 per week in the resident's bank account. This is supposed to cover all outings, toiletries, clothing, haircuts, and any spending money on outings. To buy any new clothing, we are supposed to go to the nearest town (20 klms away), obtain a quote, return home and fax it to the PT for approval, and then return to the shop to purchase the item.

To organize a holiday for the residents is a mammoth effort. In 5 years, they have only had 2 holidays due to the ridiculous amount of red tape required. I send the PT a quote (which can only be an estimate); the accommodation cannot be booked until we have the PT approval. The accommodation place cannot take a booking until they receive a deposit. Then the PT requires an itemized account of the spending. Prior to the holiday, we can only estimate.

The last holiday took 6 weeks to get organized by the PT (and had to be postponed once, much to the disappointment of the residents). Finally, approval was granted 3 days before the date of the holiday.

In their wisdom, the PT deposited:-
1. carer money into one account,
2. insisted on paying the real estate agent by cheque in the mail, 5 days before the planned date,
3. travel, food and spending money into another account.

This meant that the full time carer plus residents had to visit 3 banks to withdraw the money. Common sense should dictate that the total amount is deposited into the carers account, and then PT can receive all receipts at the end of the holiday.

5 ***Disability Services Queensland***

When my husband and I bought this property and took over the running of the hostel, we were told by Disability Services that there was a waiting list for accommodation. So after meeting all the requirements for accreditation and registration (at a cost to us of over $100,000.00), we had a vacancy for over 3 years. During that time, we even offered respite care – which was not utilized, due to lack of support from government departments – even though there is a great need in the community.

I would like to add that now that the hostel is closed, the money we invested is lost.

There is a case manager for each resident who is **supposed** to visit on a regular basis. This case manager is **supposed** to provide support in the way of transport to appointments, parent's visits, etc. but is of the opinion that the distance is too great. So, we have to do it. I was often told by the Community Visitor that we did too much: "You are not their parents" – but if we didn't do it – who would?

Even when we closed the hostel, the DSQ case manager still wanted a meeting to discuss protocol and procedures. As we had arranged accommodation for all the departing residents – we strongly declined the offer. Now, as just carers (not hostel operators), we were told that we were entitled to 1 week's respite 4 times a year. I explained that respite would be very much appreciated. The reply: "Just wait for a month till I get back from holidays." We've had 1 week's holiday in 5 years.

A carer (our previous hostel manager) who took our 2 departing residents into her home (also providing 24/7 care) and the 2 residents, were recently ill with vomiting and diarrhoea. A DSQ staff officer visited, and said 'if you chose to be an individual organization, you can't expect us to help.' I thought that the job of DSQ was to support residents and the people who care for them.

6. ***Adult Guardian***

As some of our residents were without family, the Adult Guardian was their decision maker. If a resident was ill, we were supposed to get approval from the AG to have them treated in a hospital. (Too bad if it happened during the night or on a week-end.) We were told that all hospitals have a decision maker – we never found one hospital aware of this.

The AG was very attentive when trying to find a home for a new troublesome resident. We agreed to try. However, when that resident became violent, it took the AG 4 days to find alternative arrangements. During this time, either my husband or I had to remain awake all night for supervision purposes. The comment from the AG – "our thoughts will be with you" – which I felt was very condescending.

After we closed the hostel, the AG was advised and sent a staff member to visit the new accommodation of their client and was confident that the resident was well cared for and happy. Then, I received a phone call from the AG to state that they hadn't approved the move, and they would prefer that the resident live in an accredited hostel (to be protected by the legislation) instead of living in a loving home where he was settled and loved the carer and the carer loved him. He has responded even more now, with noticeable behavioural improvement.

It's ironic that the resident that was attacked by the newcomer (refer paragraph 2 of this section) and required protection for 4 days, is now the one that the AG is supposedly so concerned about. It's a pity that they weren't so concerned about him, during our 4 days of frantic phone calls for assistance.

7. ***Insurance***

The annual insurance premium for our home and contents (when it was classed as a hostel) was $3800.00 – yet, now with only 3 residents, the premium is approx $600.00. Even though the insurance company was aware of our situation, the questions we were asked included:

1. Do any of the residents undertake skydiving, scuba diving, abseiling, mountain climbing, etc?

2. What are the disabilities of the residents? I felt that this question was discriminatory, and refused to answer.

We were not an adventure park, but a normal loving family home. Where is the common sense? This is another reason why people (who are good carers) chose not to do this job.

Conclusion:

The things that would be of most benefit to carers would be:

1. Having one department with one case manager (with authority to make common sense decisions) per hostel or resident (aged or with a disability) – who could liaise with other departments on our behalf, and provide guidance and assistance with the mountains of paperwork. Consequently, when I needed assistance, I would be always talking to the same person who understands our situation – rather than (at present) talking to a different person every phone call and explaining the situation over and over again, which is very draining and frustrating particularly when I receive differing answers. Plus, in my experience, there are many more capable (and willing) carers who enjoy this type of life/work, but do not want to cope with the 'Bureaucratic Handbook of Meaningless Verbiage.

2. The legislation needs to be changed to suit differing situations. E.g. Currently, there is no legislation or protection if one is caring for 3 residents – which could lead to possible abuse (with the wrong type of carer).

   Residential Services Accreditation covers 4 or more residents, and in my opinion, it should be as follows:
   a. A home with 1 – 5 residents requires a more flexible, common sense approach,
   b. A hostel with 6 – 10 residents requires a more moderate approach,
   c. The full legislation would suit an institution type hostel with more than 10 residents..

Signed: Beverley & Steve Dated: 11/06/08