

“ETHICS AND ADVOCACY DIRECTLY EFFECT QUALITY OF LIFE”

by

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<p>“The quality of life of those living in supported accommodation, group homes, is directly proportional to the degree of ethics and advocacy”</p>

Many parents are extremely reluctant to consider any form of supported accommodation for their intellectually disabled family member, they would rather die first. Although we can appreciate their reasons, as we have witnessed service points first hand. Avoiding the issue in such a way does little for their family member’s long term well being as, unless there is a significant breakthrough in medical science, parents are not going to live for ever.

Having said this, you may rightly ask who are we. Well, our youngest son, Paul, now 25, is autistic and intellectually disabled. Our eldest son is a very well qualified accountant and corporate business manager. Extremes of range!

From an early age, Paul required intensive behaviour intervention, at a time when being a parent of a disabled child was extremely isolating, with little physical help or material guidance. Most of our behaviour intervention programs and ideas came from the USA. Thank goodness things have changed now!

Having put in the hard yards with every difficult behaviour in the book, and most that were not, to bring Paul to a level where he was reasonable to live with, we decided, reluctantly, that we were getting no younger to provide twenty four hour care. Mum needed some life of her own before it was too late, we wanted to be around, and able, to encourage the best support service for our son, and Paul needed to be young enough to accept living away from Mum and Dad.

All good theory; the practice, somewhat different! It took four years of lobbying the state government controlled supported accommodation

central allocation system before being made an offer. Although we could refuse the offer if we considered it unsuitable, the inference was, “Take it or leave it, there is little choice!” Well, we agonised at great length, finally deciding to get a foot in the door, as changes would be easier from the inside of the system. Wrong! Another great theory blown! The system’s “Entry, Exit and Relocation” policy sounds great, but there are few vacancies!

So having finally perpetrated the system and ascertained the degree of limited choice, we decided to actively encourage the service provision, at the service point, to work as is intended according to the service providers documented policies, standards, procedures and guidelines. After all, providing quality care for people is not rocket science – Mums and hospital nurses have been doing it for centuries! Wrong! Another theory blown!

When we questioned the service provider’s procedures, we were told that, as mere parents, we did not know what we were talking about. So, with Heather no longer having to provide twenty four hour care for Paul, she did a full time, 12 month, college course to become qualified (as an IDSO-1) to work directly at the service point of supported accommodation services. Well, Heather worked extensively over four years for both government and non government service providers.

Despite that as parents the system, conveniently, considered we knew nothing, Heather’s findings were little different from our previous suspicions and observations. It was however nice to experience the process first hand, to learn the administrative procedures and how. in most cases. residents receive minimal interactive and developmental care, or active support. Although it was refreshing to observe group homes where the residents were considered and treated by direct care staff as their second family, it was disappointing to see this was mainly reliant on the integrity of the direct care staff, rather than good service provider management.

In conclusion, our findings from both direct inside observation, and as a service user, the quality of life for residents of supported accommodation is directly dependent on both “Ethics and Advocacy”.

Most parents with a family member living in supported accommodation spend much time chasing quality of life issues, such as whether their son or daughter is having good meals, is well and appropriately dressed, how much time they spend doing nothing, etc, etc, They being extremely concerned about what will happen or, more importantly not happen when they are no longer around.

Service ethics compound the problem for parents, especially where their family member has high support needs, and the supported accommodation is isolated in the community with minimum staff supervision and minimum visitation by service provider management to ensure adherence to service level and quality policies.

- Tony & Heather are Plenary Guardians and Administrators.
- Lifestyle In Supported Accommodation (LISA) is a small, unfunded, parent lobby group.
- The largest direct service provider in Victoria is the Department of Human Services.
- Details on “Active Support” can be found in an article entitled “Evaluation of the Dissemination of Active Support in Staffed Community Residences” by Edwin Jones, David Felce, Kathy Lowe, and Clare Bowley of the University of Wales College of Medicine.