BUREAUCRATIC POWER OVER PEOPLE
versus
COMMON SENSE QUALITY OF LIFE CARE

At a hearing of the Guardianship List at the Victorian Civil and Administrative Tribunal (VCAT), the 20th for my son since late 1988. The Tribunal demonstrated just how powerless my son and I are against an introvert bureaucratic process based on legislation originally intended to ensure a quality of life for those disadvantaged by disability.

I am an elderly and long time widow in declining health. My only son suffers
hypoglycaemia, and now Prader-Willi Syndrome (PWS), mild intellectual disability and has also lymphoedema, cellulitis and osteoporosis. The latter being caused by his astronomical excessive weight problem.

My son's excessive weight is as a direct result of living in a supported accommodation group home, where the Department of Human Services (DHS) is the service provider, since I had to accept I was getting no younger to provide continuous care for him.

Shortly after my son moved into the group home, the DHS applied, under the Guardianship and Administration Act, for a "Health Guardian" from the Office of the Public Advocate (OPA) to be appointed for my son, as the DHS considered I knew nothing about caring for him, was not advising them correctly and I was too strict with his diet.

The actions of this bureaucratic process has resulted in my son being continuously and excessively over weight, with numerous health problems as a result of the questionable action, and inaction of the health guardian (person), the group home staff, the service provider management and the medical persons to whom he has been directed to attend by the health guardian (person). Consequently, he remains far too much overweight for quality of life and longevity.

The group home, all female staff, have totally lost (if they ever had) his cooperation in doing that which is necessary to maintain a healthy weight. With the health guardian (person) considering their role as, “Not a friend, but a substitute decision maker!” The care process is consequently opting out of its care responsibility by now saying, “It’s the ‘client’s choice’ if he keeps to his exercise as well as a strict diet!”

My guardianship was removed from me in 1994, and given to a person at the Office of the Public Advocate (OPA). Since the bureaucrats took over, my son’s weight has escalated from 55Kg whilst he was in my care to over 90Kg in theirs. They can’t get his weight down because they locked in bureaucratic due process, and locked out of common sense.

These bureaucrats believe that because they have read all about it, they have the practical experience. Yet allowing his weight to escalate with the lymphoedema, cellulites and osteoporosis setting in, is certainly reducing his longevity. The bureaucrats the, DHS and the OPA cannot reduce my son’s weight as I can over just one week end.

Frequently I see on television, the State Government spending big dollars to tell the general population how they should look after their health, and exercise to keep a healthy weight. Yet, those who have an intellectual or multiple disability are ignored – they are not considered real people when they live in group homes where the government is the direct service provider.

There is, therefore, a real need for the NDIS to help give people with a disability and their families a choice of service provider.

In Victoria, the Department of Human Services has total control of all services which take any government funding, and this is almost all. The DHS allocates all group home placements statewide, both its own direct care group home services and non-government group home services.

Despite they pay rent, the residents of DHS group homes are denied residential tenancy rights and access to their support funding. So they have no ability to choose their service provider, their staff or their service contract.

If there was choice, I would encourage my son to move from his present DHS group home immediately.

(Mrs) N-B. McNamara
Victoria