

SUBMISSION TO LEGISLATIVE ASSEMBLY STANDING COMMITTEE ON
HEALTH, COMMUNITY AND SOCIAL SERVICES

ON ITS INQUIRY INTO RESPITE CARE SERVICES IN THE ACT

We make this submission as the parents of a Down Syndrome lady who have used respite services in the ACT for 7 or 8 years. We are aged 81 and 79 and our daughter is 38. In her student years we were actively involved in the Koomarri (now Black Mountain) School Board and P & C.

Currently we are involved in St Margaret's Uniting Church Aged and Disability Committee, sponsor of the Stepping Stones For Life project, and are one of the Focus families referred to in that committee's submission .

Our daughter has always lived with us and is more fortunate than many others in having part-time work (13 hrs/week), as well as a wide circle of friends and relatives. Never the less we find it very helpful to us and to her, that she is able to spend one week, every 7 or 8 weeks, at Eleoura, the northside Respite house of DisabilityACT. She has received funding this year, for the first time, under the "Quality of Life Grants" which enables her to be taken swimming for 2 hours each Thursday afternoon. This is helpful and appreciated.

From our own experiences and those of other families who we know well, most of whom are in much worse circumstances than we are, we offer the following comments and opinions;

1. The provision of respite is one of the most useful things governments can do to alleviate pressures on carers, who are often elderly parents in need of care themselves.
2. Respite not only takes pressure off carers, but it helps the person being cared for to broaden their horizons, form new friendships and develop more independence.
3. Every person is an individual with unique combinations of abilities and disabilities, who need solutions tailored to their particular needs. One-size-fits-all solutions only go so far.
4. Demands on staff are heavy; physically, mentally and emotionally. Therefore they should be;
 - a. trained adequately for the tasks they are expected to do;
 - b. supervised properly, especially in their early years;
 - c. paid a salary commensurate with their responsibilities;
 - d. not expected to shoulder too much responsibility in their early years;
 - e. rewarded for seniority, experience and wisdom;
5. In regard to accommodated respite, several options should be available e.g.
 - a. group house, as at present at Eleoura, catering for 6 - 8 people;
 - . for people with mild to moderate disabilities
 - b. small house for one or possibly two who are similar
 - . for people with behavioural problems or high needs
 - c. co-located 5 or 6 bedsitters with communal kitchen, dining and living rooms
 - . for people contemplating more independent living

6. In regard to day respite, we believe the key word is 'flexibility', flexibility in regard to what, when and how it is provided.

a. to help the person and carers in the home to carry out normal living tasks e.g. feeding, bathing, toileting, dressing;

b. to take the person being cared for out of the home e.g. to and from work, shopping, to a sports fixture, to swimming classes, to the movies, for a walk in the park, to visit a friend ... the list is endless.

7. We have had little experience with non-government providers but the experience of Stepping Stones For Life (non-government) working closely with Disability ACT (government) has shown us the value of co-operative efforts. As a matter of principle then, we would support the development of services, including respite services, run by non-government agencies and funded by government. We believe this model has the potential to be more flexible, efficient and economical.

8. In regard to unmet needs, we would refer to families caring for people, young and old, with very high needs. We know of one family which is desperate: Young parents trying to work, raise a family of several children and care for a girl who is virtually unable to do anything for herself. How many families are left to battle through, virtually on their own, until a long-term solution is found? We believe a national audit should be carried out of all people with disabilities to identify those in most need, and action taken immediately to alleviate their situation.

9. Finally, we make the obvious point; no less relevant for being obvious. Underlying all needs of the disability sector, including respite care, is the need for adequate funding. Neither government nor non-government agencies can do what should be done without the resources. A groundswell of public opinion is needed to persuade governments of all persuasions to lift their game and redirect funds to where they are needed most i.e. assisting the most vulnerable people in our society

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