

Inquiry Into Respite Services in the ACT

This submission is forwarded for your consideration from my standpoint as carer of an adult with a mental health illness and grand parent of a teenager with multiple physical and developmental disabilities. Both are included.

1. Needs of Care Recipients

- the appointment of a liaison/advocate person who fully understands the situation of the disabled person and is fully aware of the full range of assistance available from all agencies and the entitlements due . There is too much ad hoc dissemination of information, most of which has to be ferreted out by the carers themselves.
- to be treated with dignity and understanding by those providing services, especially for those with mental health issues.
- when discharged from mental health care there needs to be a supervised 'half-way' facility to ensure that the person is ready to be fully returned to the wider community.
- as a safety issue when in a respite situation to be placed with others of same sex and similar age, behaviour and personality. This has not always happened and physical violence has occurred.
- there is insufficient respite accommodation to meet the needs of a wide range of disabilities. Care recipients also need to have a break for themselves.
- to have on occasion the opportunity to be part of the wider community without feeling uncomfortable or embarrassed by others in the community.
- to have their necessary and appropriate physical needs met - furniture, equipment and hygiene.

2. Needs of Carers.

- regular respite should be available to ensure the well-being of the principal carer and their family. This may be weekend or mid-week, which equates to three whole days. A two week respite period during the Christmas or other break would enable the parents and other siblings to have a reasonable holiday some distance from their home.
- the opportunity for the principal carer to be able to work full time through the year. During school holidays the disabled child needs full-time care. This means the work has to be part-time to allow for the holidays or leave employment. There is a distinct economic price and disadvantage for these families.
- some time for in house/at home respite to meet carer's needs of shopping, house assistance and time for other siblings to attend their activities.

- on occasions have a respite provider actually take the disabled person on an outing.

3. Needs of Respite Staff

- be fully aware of the disability and trained for the situation in which they are placed - not to be asked to do things they cannot do or have no knowledge.
- a respectable wage and conditions which will entice applicants to train to join what is now an understaffed workforce.

3. Respite Care Services

- there is a need for more appropriate after-school and vacation care to meet individual needs of the disabled. What is available often does not permit the severely disabled to participate in activities because they are unsuitable or require one-to-one assistance or are at a distance from the home and collection from the centre is a problem. From experience, these children cannot be placed.
- provision of transport to attend medical and other appointments.
- too often the care provided is interrupted by changes in personnel or by them just not turning up, which has consequences for the plans of the family of the disabled person.