

family

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Abstract

An information paper (one of a series) by the Department of Community Services and Health which clarifies and explains that class of services defined in the Disability Services Act as 'Respite Care Services'. It provides a description and explanation of the target group, key features and various approaches. **Keyword:** Respite

Respite Care Services

INTRODUCTION

This information paper clarifies and explains that class of services defined in the Disability Services Act 1986 (DSA) as Respite Care Services. In doing so, it reflects the provisions of the Act in three important areas:

- the definitions for each class of service type (sections 7 and 9);
- the objects of the Act (section 3); and
- the Principles and Objectives (gazetted under section 5).

The paper is intended to be descriptive, and not prescriptive, of the features and aspects that need to be considered in the development of service delivery models under each service type. As such, they build upon the descriptions of the new service types, which were distributed previously by the Department.

The revised descriptions provide more detail about the key features of each class of service, which are considered essential to achieving positive consumer outcomes for people with disabilities. These key features are derived from the Principles and objectives and the objects of the Act and encourage diversity and flexibility of service provision within the legislative boundaries laid down for each service type.

This paper is one in a series which aims to explain aspects of a complex piece of legislation in a way which will be meaningful to a wide audience, including people with disabilities, their families and/or advocates, service providers and the general public. Other papers are available from your State Office of the Department of Community Services and Health on the other eligible service types provided for under the Act.

RESPITE CARE SERVICES

1. INTRODUCTION

This paper provides guidance to potential service providers on the eligible class of service defined in Sections 7 and 9 of the Disability Services Act 1986 as "respite care services".

Organisations providing prescribed services may wish to refer to this paper, if appropriate, to assist with their transition plan development. Separate information is available on the process of the realignment of prescribed services to conform with the eligible service types and the Principles and Objectives of the Act. Organisations should also refer to the paper on accommodation support services, as much of it is relevant to respite care.

2. DEFINITION

The Disability Services Act defines respite care services as “services for relief or assistance, for a limited period of time and whether on a planned or unplanned basis, to -

- (a) families of, and other persons who provide care for or assistance to, persons with disabilities living in the community; or
- (b) persons with disabilities living in the community”

(Section 7 Disability Services Act 1986)

The long-term care and support needs of many people with disabilities depend predominantly on the resources of their families and unpaid carers. The stability and viability of these care arrangements can be affected or threatened by short term events such as illness or by the unrelenting pressure on the carer, or on the person who cares for themselves.

The primary aim of respite care services is to make available to individuals and long term carers, on a short term basis, relief from or assistance with their caring responsibilities in order to maintain the long term viability of the usual care arrangements in the community. This assistance may include skills training for the family carer.

Respite care services can address the full range of support and assistance normally provided to an individual by his/her family or regular carer, including personal care and support with activities of daily living, maintenance of regular routines in the community (e.g. school, recreation).

Respite care services can also contribute to the quality of life and development of the individual person with a disability by providing opportunities for new, age-appropriate experiences and relationships or by offering particular kinds of support or training which would otherwise be beyond the resources of the regular carer, plus associated developmental activities to promote greater competence and independence in the individual or skills acquisition for the family/carer to support the regular caring relationship. . However, these would usually be a secondary consideration of a respite care service.

The range of services necessary to achieve these outcomes are as diverse as the needs and lifestyle aspirations of people with disabilities, and as varied as the respite needs of their carers. Generally, respite care services for people with disabilities will:

- support existing care arrangements with the family or unpaid carer in ways, which enhance, maintain or prolong their stability and capacity.
- be provided in regular, community based settings, including the individual's own home or non-institutional alternative accommodation.
- involve substitution for or supplementation of usual support arrangements, which may be organised on a planned basis (to meet goals of the individual or carer including prevention of institutionalisation) or in response to an emergency situation.
- be short term and time limited in duration.

3. TARGET GROUP

Respite services are particularly directed to individuals with disabilities (and their families or those in caring arrangements with them) whose long term support arrangements are or would be at risk without access to short term relief.

Priority is given to people with intensive support needs and those who would otherwise be at high risk of requiring long term placements in a more restrictive living environment than their present one, particularly an institutional setting such as a nursing home or hostel.

The target group does not extend to elderly people (who would be more appropriately assisted under RACC or through Residential Programs). It includes people who care for themselves.

Respite care services can only provide relief or assistance in cases where the normal long term care arrangement or relationship is essentially of a private and unpaid nature. Accordingly, services would not normally be provided for people resident in nursing homes or hostels, or in group homes where staff provide significant levels of support and care to residents.

4. OUTCOMES

A wide range of positive outcomes will arise from the provision of respite care. These outcomes will vary according to the circumstances and objectives of each respite placement, but they will tend to give an indication of the overall effectiveness of the service.

Outcomes may include:

- the continuation of existing care arrangements
- improved family interactions
- changed perceptions of developmental possibilities

Broad performance indicators could include:

- numbers of persons receiving respite care
- total, maximum, minimum and mean hours of respite received
- settings in which respite occurred (own house, host family, respite house)
- frequency of use of the service by eligible families
- type of respite provided (regular, pre-arranged, crisis)
- degree of client and family involvement in control of service
- decreased demand for longer term accommodation support

5. KEY FEATURES

In order to be eligible for funding, proposed services need to further the objects of the Disability Services Act and the gazetted Principles and objectives.

Without limiting the generality of that requirement, the following aspects are seen as key features for respite care services.

Tailored for individual needs

- respite services should be tailored to meet the individual- needs and goals of the people with disabilities (and their carers) receiving those services and have sufficient flexibility to respond to changing clients, and their changing needs over time. This involves ensuring that people with disabilities and their advocates likely to use a given service are involved in the planning and operation of that service; that services are fitted to people rather than people being fitted to pre-conceived services, and that congregate respite care is not provided unless users of the service themselves make that choice and also choose these with whom they are to associate.

- services should aim to provide as broad a range of choices as is practicable. This could include such aspects as service settings (client's home, host family, respite house etc), an appropriate balance between planned and unplanned respite, frequency and duration of respite, and times of the day or days of the week.
- regular weekday activities (e.g. during business hours most days of the week) whilst often having a respite value for families and carers, are more appropriately provided through vocational services or a vocational alternative. (Principles, 1, 3, Objectives 4,13).

Meeting community norms, providing least restrictive alternatives

- services should achieve living and service delivery arrangements that are the same as or as close as possible to general community norms and patterns, that are appropriate to the age and cultural background of their users and that involve the least restriction to their rights and opportunities.

This involves people with disabilities preferably being supported in their own homes or where that is not appropriate, respite care being made available:

- in ordinary dwellings
 - in household units of normal domestic composition and dimensions
 - in residential neighbourhoods
 - under arrangements which follow the usual patterns and practices of everyday life, and
 - which involve the minimum feasible restriction of their independence.
- (Principles 1, 2, 4, 6, Objectives 2, 5, 10, 14).

Maximising participation and integration

services should maximise the physical and social integration of people with disabilities in the general community. This involves respite care being provided in ordinary dwellings, with occupancy on a scale and under arrangements the same as or as close as possible to ordinary domestic arrangements in situations in which people with disabilities are in the minority in the street or neighbourhood.

It also involves maximising the extent to which the service users use, or continue to use, ordinary community facilities and services provided for the population at large and minimise segregated or specialised arrangements, particularly those provided on-site. The maintenance of pre-existing involvements is particularly important in respite care. (Objectives 1, 2, 3, 7, 8, 10).

Avoiding undue control by an organisation

services should ensure that no service organisation exercises control over all or most aspects of a person's life. Undue control may arise from a combination of co-location and management arrangements.

Respite services may be operated by organisations which also provide other services to people in the same target group. While co-location of services per se is not prevented under the DSA, the particular nature of respite care services means that respite should not be provided in the same physical location as long-term accommodation support, administration, employment or other services. (Principles 2, 4, 6, 7 Objectives 1, 2, 7, 8, 10, 12)

Enhancing client control, independence

services should ensure that they maximise control, independence and autonomy on the part of users. This involves such matters as potential users (and their carers) being involved in the planning, design and day-to-day operation of the service including staff selection, resident selection, setting and varying daily routines and household activities. This involvement will include the ability to choose (or reject) a given carer.

The role of staff should be enabling rather than doing and the presence of staff in people's lives should be at a minimum level consistent with fostering the independence and autonomy of service users. (Principles 1, 2, 3, 4, 5, 6, 7 objectives 8, 9, 10, 11, 12, 13).

Enhancing dignity, privacy

- services should enhance the dignity, privacy and human worth of their users. As examples, where respite is provided in the person's own home, staff should recognise their visitor or employee status. Where provided in host family homes, users should be regarded as invited guests. In specialist respite care houses, it involves recognition by staff that the house is not their property, and that their role is one of employees and assistants, rather than controllers.

Where overnight respite care is provided, users should generally have their own room (unless they choose to share).

Information about service users should be treated in confidence. Particular attention should be paid to dignity and privacy in regard to eating, bathing, toileting etc. (Principles 1, 2, 3, 4 Objectives 2, 6, 8, 10, 14).

Achieving positive outcomes

services should produce a range of positive outcomes for people with disabilities (and their carers) such as maintaining and enhancing the caring arrangements, enhancing quality of life, providing relief from or support with care responsibilities and increasing (or at least maintaining) their participation and integration in the community. Particular attention should be paid to planned respite to reduce the pressure on carers and forestall, so far as practicable, recourse to crisis respite caused by breakdown in caring arrangements. (Principles 3, 6 Objectives 1, 2, 6, 7, 10).

Equal opportunity

services should give particular attention to meeting the needs of individuals who experience a double disadvantage as a result of their sex, ethnic origin or Aboriginality (Objective 5).

Other key features of a practical nature include:

Boundaries with other programs

organisations may be involved in the direct provision of respite care services (e.g. by employing care staff, operating a respite house etc) or take on an exclusively co-ordinating role (including referral, booking, networking with service providers and community).

- services should develop policies and practices, which distinguish, respite care from other accommodation services. Practical but sympathetic limits should be set on the duration of individual respite instances and/or an aggregation of such instances. As a guide, time spent in continuous respite care should not exceed one month, and over a 12-month period should not exceed a total of six months.

- respite should not be used as a trial or transition to long term supported accommodation or institutional care.
- generic services such as the Home and Community Care (HACC) Program should be utilised to the maximum extent possible, with the respite care services meeting only those needs outside of or over and above those covered by that Program. Any service or facility, which is commonly available in the community, should not be duplicated within a respite service unless it is customarily provided in ordinary households.

services should fit in with other generic and specialised services in their geographical area and should not duplicate existing services (Objective 3).

Services for Children

services for children should normally be provided or sponsored by State/Territory governments and should involve children living in their own or a substitute family situation with non-disabled children.

Financial Arrangements and Considerations

- services should be cost-effective within the funding levels of the Disability Services Program.
- support will not normally be provided with capital or recurrent costs associated with transportation unless there is no other appropriate way for users to access the service or community facilities.
- where out-of-home respite care is required, maximum use should be made of existing housing stock to secure accommodation options e.g. public housing, private rental stock, housing co-operative. Duplication of existing options or use of purpose-built "disability" housing should only be considered as a last resort when all other options have been fully investigated.
- options that lend themselves readily to adaptation or change in response to the changing needs of service users are preferred. For example, in-home respite is likely to be more flexible than facility-based respite. Where establishment of a respite care house is required, rental options would generally be preferred to purchase options so that organisations and individuals are not locked into a particular model of service delivery. This needs to be balanced against the need to ensure on-going availability of respite care in a region.
- Client families toward the costs of respite care should make a contribution. As a guide, a contribution of \$1 per hour to a maximum of \$10 per 24 hours of respite should be sought. In circumstances of economic disadvantage the client contribution can be waived.

6. APPROACHES

The most successful approaches to the provision of respite care are those which are tailored to the needs of specific individuals likely to use the service, and which have the flexibility to deal with unusual needs, and to change as needs change.

Without limiting possible service models, respite care can be provided through:

- the provision of support to people in their own homes, giving relief to carers through taking on the personal care tasks morally performed by them

- a network of "host families", matched to the age, interests and cultural background of the person with a disability and their carer, who voluntarily provide both general casual support (on a family to family basis) as well as short periods of respite care in the host home.
- formal respite care facilities, located in an ordinary house in the community, where periods of respite care are provided to a small group of people with disabilities. This model, while acceptable, is not favoured as the model of first choice.

Given the expectation that respite services will be flexible and respond to real needs, it is difficult to propose restrictions on the timing of respite care. It should be recognised, however, that respite is not intended as a substitute day-service, live-in recreation service, independent living training service or emergency long-term accommodation.

Again without limiting possibilities, the timing of respite care may be:

- regular weekday, evening or weekend care
- pre-arranged week, weekend or holiday period respite
- crisis care, with the flexibility to meet urgent needs.