Respite program guidelines (disability)

Operated and funded services under the disability services program

Ageing, Disability and Home Care
Department of Family and Community Services
Contents

1 About the respite program guidelines 1
  1.1 Services these guidelines apply to 2
  1.2 Updating the guidelines and feedback from service providers 2

2 Overview of respite 3
  2.1 Definition 3
  2.2 The role of respite 3

3 Responding to a growing need for respite 5
  3.1 Flexibility and choice 6
  3.2 Providing respite services that meet changing needs 6
  3.3 Older carers 8

4 Principles 9

5 Eligibility and priority of access 10

6 Service types 11
  6.1 Own home (MDS 4.01) 11
  6.2 Host family (MDS 4.03) 11
  6.3 Peer support (MDS 4.03) 11
  6.4 Flexible (MDS 4.04) 11
  6.4.1 Teen Time – After school and vacation support 12
  6.4.2 Respite camps 12
  6.4.3 Families Solutions Program 13
  6.5 Centre-based (MDS 4.02) 13
7 Funding

7.1 Flexible respite

7.1.1 Teen Time – After school and vacation support

7.1.2 Respite camps

7.1.3 Families Solutions Program

7.2 Centre-based respite

7.2.1 Use of ADHC properties for centre-based respite

8 Operational service requirements

8.1 Intake, assessment and allocation

8.2 Respite plans

8.3 Planned and emergency respite

8.4 Fees

8.5 Complaints and disputes

8.7 Volunteers

8.8 Hours of operation

8.8.1 Children and young people

8.8.2 Adults

9 Service monitoring

10 Legislation and policy

11 Working in partnership
1 About the respite program guidelines

The Respite program guidelines (disability) (the guidelines) provide the framework for respite service delivery for Ageing, Disability and Home Care, Department of Human Services (ADHC) operated and funded disability respite services. The guidelines have been developed by ADHC to support ADHC and non-government providers in delivering respite services in NSW. These guidelines will also be used by ADHC staff involved in the performance monitoring and reporting of respite services.

These guidelines provide an outline of respite services, the role of respite services within the disability service environment and the principles and values that should guide service delivery. They provide information about ADHC’s expectations for the provision of respite services by ADHC Regional and funded providers, while also enabling providers to deliver services in ways that respond to the needs of respite users and local conditions. The guidelines reflect the NSW Government’s commitment under *Stronger Together: A new direction for disability services in NSW: 2006-2016* to expand existing respite services and build a more flexible and responsive disability respite service system.

These guidelines are not intended to provide detailed operational guidance but should be considered within the existing policy framework as set out in the funding agreement and the description of funded service or the service description schedule.

Copies of these guidelines and the documents referred to in the guidelines may be obtained from ADHC’s website at www.adhc.nsw.gov.au
1.1 Services these guidelines apply to

These guidelines apply to:

- all ADHC-operated respite services under the National Disability Agreement; and
- all non government operated respite services for people with a disability funded under an ADHC funding agreement including respite services transferred to ADHC from the Australian Government through the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) under the Disability Assistance Program (DAP).
- all government operated respite services for people with a disability in receipt of ADHC funding.

The guidelines do not apply to:

- respite services provided under the Home and Community Care (HACC) Program
- respite provided through other funding sources e.g. Australian Government respite services including those funded through the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), Department of Veteran Affairs or the Department of Health and Ageing.

1.2 Updating the guidelines and feedback from service providers

Comments or suggested improvements to these guidelines can be emailed to respite@dadhc.nsw.gov.au
2 Overview of respite

2.1 Definition

Respite services provide planned short term, time-limited breaks for families and other unpaid carers of children, young people and adults with a disability with the intention that families/carers resume care at the end of the respite period. They are services that assume the caring role during the period of respite.

Respite should be a positive experience for both the carer and the person with a disability with services providing positive and meaningful experiences for the person with a disability at the same time as giving the carer a break from their usual care-giving role.

2.2 The role of respite

ADHC understands the importance of strengthening family relationships and provides and funds many support services to strengthen these relationships. For many people with a disability, their families and carers provide the best opportunities to assist them in building a life within their local community. Respite plays an important role as one of the range of support services for people with a disability living in the community and their families and carers¹. Respite is one of a suite of services which supports families by providing short term breaks to the carer and other family members from care giving responsibilities.

Respite is most effective when it is used with other formal and informal supports. Respite can provide opportunities for the parent, family or carer to continue employment, pursue interests and attend to responsibilities not associated with the care giving role. It also provides the person with a disability the opportunity to have enjoyable experiences outside the home including recreational age-appropriate activities with peers. In this way the underlying goal of respite is to provide a positive experience for the person with a disability, the carer and other family members so that, in the long term, the care-giving relationship is supported and preserved. Respite is provided on the assumption that the usual carer will resume their caring role at the end of the planned period of respite.

¹ May also include foster carers
Research has shown that respite has a number of benefits. The most consistently reported finding is that respite care has positive effects on family functioning including parents and carers being able to spend time with other children, increased participation in social activities and decreased perceived family conflict. The benefits to carers fall into two broad categories, significant stress reduction and increased self-esteem. The benefits to people with a disability are socialising and enjoying experiences outside the home.

Respite has a dual focus on both the person with a disability and the carer. The needs and aspirations of both the carer and the care recipient and the wider needs of the family should be taken into account in service delivery. Conversely, the needs of the carer or care recipient should not be met at the expense of the other. Respite is most effective when the needs of both the person with a disability and their carer are met.

Some people with a disability and their families and carers have access to regular, funded respite services but may not be experiencing the full benefits of the respite service. Reasons for this include:

- Parents/carers’ concern about the safety and quality of the service the person with a disability is receiving.
- Cumbersome administrative arrangements upon entry or exit.
- Onerous travel arrangements to and from the respite service or the person with a disability feeling dissatisfied or bored with the service.

It is worth exploring with people with a disability and their families and carers all possible avenues and strategies that provide a break both to the person with a disability and their carer that can alleviate pressure on relationships within the family.

Respite is provided through a range of service models and can have a generic or specialised focus. Respite can be effectively used as a form of early intervention, continuing support and as a response to crises and unforeseen circumstances. Respite can be provided throughout a person’s life, as long as the service model selected is age and developmentally appropriate.

When a person with a disability receives multiple services, the respite service is to be integrated with those other services to provide a holistic service that meets the specific individual and cultural needs of a person with a disability and their families and carers.

While these guidelines apply to ADHC-operated and funded respite services, informal supports and other disability services can provide a respite effect. It is worth exploring with people with a disability and their families and carers all possible avenues and strategies that provide a break to both the person with a disability and their carer that can alleviate pressure on the care-giving relationship.
3 Responding to a growing need for respite

Australia, along with all developed countries in the world, is witnessing an increase in the absolute numbers of, and the proportion of people with a longstanding disability who are ageing. These demographic factors indicate there is a growing need for respite services. These factors include:

- The numbers of people with a disability are increasing.
- An increase in the number of carers who are caring for a person with a disability.
- People with a disability are living longer often with increasingly complex and age related health care needs.
- The numbers of people with a disability including those with complex care needs and/or challenging behaviours being supported at home or in the community is increasing, and are being supported for longer.
- Parents and carers of people with a disability are ageing, and many have age related health problems or disabilities.
- Parents and carers are increasingly caring for longer periods as the life expectancy of the person with a disability has increased substantially from a life span of approximately 20 years\(^3\) in the early 1900’s to 70 years by 1993\(^4\).
- An increase in the numbers of carers including young carers\(^5\).

For the large group of people with a disability living with their families or other informal carers, respite is a key strategy to support and maintain long term care arrangements and aims to protect and promote positive relationships between the carer and the person with a disability.

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\(^3\) Carter and Jancar, 1983

\(^4\) Strauss and Eyman, 1996

\(^5\) Australian Bureau of Statistics, Disability, Ageing and Carers, Australia (2003) 4430.0s
In response to this need the NSW Government made a commitment through Better Together: A new direction to make NSW services work better for people with a disability and their families 2007–2011 to supporting and recognising families and carers. Through Stronger Together: A new direction for disability services in NSW 2006–16 the NSW Government has expanded the number, range and location of respite services for children and adults with a disability. Population planning approaches, service demand and demographic data have been used to inform the distribution of all types of respite services and to identify inequities in resource distribution or service configurations.

These guidelines support the NSW Government’s commitment to building a respite service system that is responsive to the needs of people with a disability and their families and carers. The guidelines form part of the New Directions for Disability Respite Services in NSW, developed by ADHC’s Respite Directorate to guide respite service system reform in line with Stronger Together and the NSW Carers Action Plan 2007–20126 – whole of government policy commitment recognising and supporting carers.

3.1 Flexibility and choice

Maximising flexibility and client choice with regard to the setting, type and timing of respite services promotes positive outcomes for people with a disability in respite services. ADHC is developing a range of different respite service models, described later in this document, to increase flexibility and choice of respite services available to people with a disability and their families and carers and to increase the capacity of the service system to respond to differing needs. This approach can also be applied at the local service level where opportunities for increasing flexibility and choice can be actively explored and pursued within the parameters of the funding agreements.

3.2 Providing respite services that meet changing needs

It is important to understand and respond to the changing support needs of the person with a disability and their families and carers as they move through different life stages. The needs of people with a disability and their families and carers will change over time, as a result of developmental and age related factors. It is important to match the right type and mix of respite services to individual needs, particularly at key transition points.
Age-appropriate service types and key transition points include:

- Pre-school aged children are generally best supported by mainstream services that are likely to have a secondary respite effect and reduce social isolation of the child and their primary carer/family. Appropriate service types include pre-school, child care, family day care, supported play groups and parent education/support groups. Where a specialist respite service is provided flexible and own-home respite are the preferred models for most very young children and their families. In general, centre-based respite is not provided for children who are less than seven years of age. However, centre-based respite is provided in some instances for children less than seven years old who have complex health care needs. ADHC operates two specialist state-wide centre-based respite services that cater for children who have complex health care needs.

- Commencing school gives rise to the need for additional respite services such as before and after school care and vacation care. Where a specialised respite service is provided this is best in the form of flexible respite, in home support and holiday options.

- As children move into adolescence, school, peer support and recreational services that provide for individual interests can provide an effective source of support for them as well as providing a break for their carer. A range of respite options may be suitable including flexible, recreational, camps and centre-based respite depending on their individual needs and circumstances. Their need for behaviour intervention may increase at this time. Parenting programs and assistance with the development and implementation of behaviour management strategies prior to this age may reduce this need.

- The transition from adolescence into young adulthood is a critical transition point as young people leave school. Depending on their needs and level of functional ability, a range of new service requirements and options come into play. These include adult day programs, post school programs, peer support and recreational services. Whilst not specifically respite services, they can provide a break from the usual care arrangements. Centre-based respite may be an appropriate respite option as well as flexible places, depending on the needs and circumstances of each person and their carer and family.

- For adults with older parent carers, futures planning and effective transition from the family home to one of a range of accommodation models may be the primary support need. Other significant life circumstances may also trigger the appropriate use of respite. In this age group, the person with a disability and their carer may become eligible for specialised ageing parent carer respite services.
3.3 Older carers

As people with a disability live longer, the number of older carers is projected to increase significantly over the next two decades. Older carers are now caring for considerably longer periods of time, while often facing frail health themselves in advancing years. Their need for respite can be acute and continuing, yet there are indicators to suggest that older carers exercise lower usage of respite services than younger age groups. Successful experiences with these services were found to increase families' confidence in undertaking long term care planning.

Strategies that have been found to be effective in supporting older carers include:

- building a relationship of trust with the family and then encouraging them to use respite and community access programs. Building the amount of respite time gradually can increase the confidence of the carer and the person with a disability
- strengthening the independence skills and community access experiences of the person with a disability
- strengthening the informal support networks available to the person with a disability
- a proactive approach that assists the family to plan for the future, and providing information to the person with a disability and their carer/s about alternative future accommodation options and support services.

Older carers may include a spouse, older siblings or other family members who take on care for their relative with a disability.

4 Principles

Respite services and programs must apply the principles set out in Schedule 1 of the *NSW Disability Services Act 1993* which promotes the rights of people with a disability. Additionally, respite services need to be delivered according to the following principles:

- Services are **person centred** helping people to build their own support networks and make formal and informal links connecting them to the broader community and are guided by the choices and decisions of individuals, families and carers.
- Services are **flexible** to meet changing needs of individuals and families and carers with the right level of support provided when it is needed.
- Services have a focus on **early intervention** by providing practical support at an early stage to prevent families from reaching crisis point.
- Services are responsive to the **individual needs** of both the carer and the person with a disability.
- Services are **age-appropriate** and have a focus on enabling the person with a disability to have similar opportunities and experiences as their peers.
- Services are provided in ways that are **culturally competent and respectful** and meet the needs of Aboriginal and Torres Strait Islander people and those from culturally and linguistically diverse backgrounds.
- **Access to services is prioritised based on assessed need.**
- Services are provided in **partnership** with other government and non-government service providers so that service delivery is coordinated.
- **Access to services is streamlined**, enabling the carer to navigate the system with ease.
- Services are developed using a strong **evidence base**.
- Services are **cost effective**.
5 Eligibility and priority of access

Disability services are funded to provide services to people with a disability as defined in the target group under the NSW Disability Services Act 1993. Carers are eligible to receive a respite service if the person they live with and care for has a disability:

a. That is attributable to an intellectual, psychiatric, sensory, physical or like impairment or to a combination of such impairments.

b. That is permanent or is likely to be permanent.

c. That results in:
   i. a significantly reduced capacity in one or more major life activities such as communication, learning, mobility, decision-making or self care, and
   ii. the need for support, whether or not of an ongoing nature.

Research has highlighted the need for respite services to have an early intervention and prevention focus which aims to support the caring relationship and prevent its breakdown. Families and carers require respite services that can respond quickly and flexibly and that are responsive to individual and changing need. In addition, consideration should be given to people with a disability and their carer where the ongoing care arrangement is at risk without the support of respite. These include:

- children, young people and adults with a disability living at home with their family and whose long term support would be at risk without access to respite services
- families or unpaid carers whose capacity for continued caring may be at risk without access to respite and family support
- children, young people and adults living with a sole carer
- people living at home with their family who have:
  - fragile health and complex multiple support needs;
  - assessed complex challenging or abusive behaviour;
  - involvement in the criminal justice system; or
  - limited access to other community support services.

ADHC-operated services are required to comply with the Eligibility and Priority of Access Policy and the Prioritisation Criteria for the Allocation of Planned Respite Policy (RO A3).

ADHC-funded services are required to comply with the priority for access criteria set out in the specific service descriptions schedules.
6  Service types

ADHC provides and funds a range of respite service types to meet the individual needs of people with a disability, their families and carers. The following respite service types are currently funded in NSW under the following MDS\textsuperscript{10} codes.

6.1 Own home (MDS 4.01)

Respite that is provided in the person’s own home by paid staff. Own home respite may be for a few hours or a few days, and can include the support worker staying overnight with or without the carer present. The full range of support and assistance that is provided to the person with a disability in their usual care arrangements is maintained. Own home respite can be provided to people of all ages.

6.2 Host family (MDS 4.03)

Host family respite provides for the person with a disability to spend time in the home of a volunteer host family matched to the age, interests and background of the individual and their carer. Host families are volunteers who are selected and trained to care for a person with a disability.

6.3 Peer support (MDS 4.03)

Peer support matches the individual with a peer of similar age and interests, usually for leisure, recreation and group activities. This service type is usually targeted at children or young adults up to 25 years of age.

6.4 Flexible (MDS 4.04)

Flexible respite aims to be responsive to a person with a disability and their carer’s individual needs through a combination of own home, host family and peer support respite. Flexible respite can also include recreational or cultural activities away from home where the primary purpose of the service is respite. Such activities include day outings, overnight stays, weekend breaks, camps and community based and cultural programs. The service type may also include brokerage\textsuperscript{11}, so long as it is funded under the respite program. Families and carers are increasingly seeking flexibility in respite arrangements including when and how respite is provided. This service type facilitates the opportunity for providers to maximise flexibility and choice in the service design. Teen Time, Respite camps and the Families Solutions Program are examples of innovative flexible respite models.

\textsuperscript{10} The Commonwealth State/Territory Disability Agreement National Minimum Data Set is a set of nationally significant data items that are collected in all Australian jurisdictions.

\textsuperscript{11} Brokerage refers to where an ADHC funded service provider contracts a third party to deliver a service on their behalf.
6.4.1 Teen Time – After school and vacation support

The Teen Time – After school and vacation support for working parents program provides planned after school and vacation care for secondary students with a disability. The program aims to improve access to employment and/or vocational study opportunities for parents and carers of secondary school students with a disability attending high school.

Teen Time after school program is open for 40 weeks of the year from Monday to Friday during school terms usually from 3 to 6pm.

Vacation support programs operate during school holidays for up to 8 weeks per year generally between 8am to 6pm Monday to Friday.

6.4.2 Respite camps

Respite camps for children, young people and adults provide opportunities for participation in social and recreational activities outside their normal day to day activities. The camps aim to give experiences that contribute to social independence, a sense of responsibility, team work and self reliance. Camps can benefit the person’s self esteem, social engagement and can help them develop new skills and interests. Some camps are tailored for special needs including physical disability, intellectual disability and siblings.

ADHC and Sport and Recreation a division of Communities NSW have entered a partnership to provide the Respite Camps for Teens with a Disability program.
6.4.3 Families Solutions Program

The Families Solutions Program is a three year inter-agency demonstration model for families under severe stress who care for school age children and young people with intellectual disabilities and complex behavioural needs. The program provides intensive clinical support, case management and a flexible and effective host family respite service to families who, without additional support, may be at risk of relinquishing the care of their child or young person.

The program is being piloted in ADHC’s Metro North Region and will be evaluated.

6.5 Centre-based (MDS 4.02)

Centre-based respite generally caters for people with a disability who have higher, more complex and challenging support needs who require a more structured and intense level of service than can be provided through own home and flexible respite options. However, centre-based respite can also be used when the carer has a medical emergency or is unavailable due to other commitments.

Where possible, services should try and link people with a disability of a similar age and similar interests as part of their care experience. Centre-based respite is for overnight stays or for longer periods of time and can be provided in planned blocks for holiday periods or if the carer has other commitments. A centre-based respite service may have a specialised focus or may dedicate periods of time for a specialised focus, for example:

- for exclusive use by children or young people or adults (a generalist centre may dedicate particular periods of time to a particular age group)
- for exclusive use by males or females.

Services are provided in a ‘home like’ environment in a house in the community which must conform to relevant planning, building and fire safety codes. Provision of outdoor recreational and leisure space is essential.
It is ADHC policy that children (aged 7–15 years) will not be placed in ADHC centre-based respite with adults (aged 18 years and over) except in exceptional circumstances. Young people (16–17) may be placed with either children or adults according to their individual need and the appropriateness of the placement following an assessment of the risk of harm to the young person or other children.

Placement of an adult (aged 18 years and over) in an ADHC children’s respite centre will only be considered in exceptional circumstances and must be approved by the Deputy Director-General, Accommodation and Direct Services. Approval will generally only be provided in the following two circumstances:

1. Where the adult has very high medical needs and/or such limited mobility so as to present no potential risk to others, the individual client’s needs and circumstances indicate such a placement would be appropriate and there are no other suitable options, for example, adult medical respite centre.

2. Where individual circumstances such as the physical size of a client relative to the other clients at an adult service would pose a potential risk to the client if placed in an adult respite centre.

Centre-based respite is not an alternative to long term supported accommodation. Where an accommodation option is required the person with a disability and their carer should be referred to the local ADHC Information, Referral and Intake (IRI) Team.

Flexible respite
7 Funding

7.1 Flexible respite

Flexible respite funding is provided on the basis of individual ‘places’\(^\text{12}\). Each flexible respite place funded through *Stronger Together* provides a minimum of 168 hours (or the equivalent of 7 days) of respite support per year. The number of hours allocated over a year to an individual will depend on the assessed needs of the person with a disability and their carer. Where the assessed needs of the person with a disability and their carer are very high, for example in some cases where the person with a disability has high support/medical needs and/or challenging behaviour, there is the option of providing a more highly funded respite place\(^\text{13}\).

A service provider is funded for a number of places. For example, an organisation may be funded for 44 places a year. This means that they will have approximately 7,400 hours of respite time available for allocation.

7.1.1 Teen Time – After school and vacation support

Funding for Teen Time – After school and vacation support for working parents program, is provided on the basis of the cost of an after school and vacation care place. Each after school place is generally offered for 3 hours at the completion of the school day during the school term. Each vacation care place is generally offered for 10 hours five days a week (between 8am and 6pm) for a maximum of one week per student per vacation period. The majority of Teen Time services provide for 9 students at one time however some services have been funded to operate at different student numbers. The staff/student ratio has been determined at 1:3, however there is expected to be flexibility for staff ratios based on individual student support needs.

Where a Teen Time service is school based, it is anticipated that rent will be charged by the participating school and that these rents may vary between sites.
7.1.2 Respite camps

Respite camps are new service models which are currently being piloted. Unit costs are in development.

7.1.3 Families Solutions Program

The Families Solutions Program is currently being piloted in Metro North Region. Unit costs are in development.

7.2 Centre-based respite

Funding for a centre-based respite place provides a minimum of 25 days (400 hours calculated at 25 days x 16 hours per day) respite per year. Funding is usually provided based on the operating costs of a 5 bed respite centre. The amount of centre-based respite that is allocated to an individual will depend on the assessed needs of the person with a disability and their carer.

7.2.1 Use of ADHC properties for centre-based respite

In some cases ADHC provides properties for non-government services to provide centre-based respite. In other cases the organisation provides the property or it is rented from the private market. Where a service provider is using an ADHC property for centre-based respite a Deed of License will be entered into by both parties.
8  Operational service requirements

Respite services are required to comply with the operational service expectations set out in this section.

8.1  Intake, assessment and allocation

ADHC recognises that there are currently multiple points of entry into the disability service system for people with a disability and their families and carers. ADHC is currently developing a more streamlined intake, assessment and allocation process that will include both ADHC operated and funded services. Until this is completed, respite service providers will need to comply with the current regional processes in relation to the intake and allocation of respite services.

Referrals for ADHC operated respite services are made through the regional ADHC Intake Referral and Information Teams (IRI). Referrals for ADHC funded services may be made directly to the service or through the ADHC IRI teams. Requests or referrals for respite may come directly from carers or family members, other services and ADHC staff.

Allocation of respite places for new and existing people with a disability in ADHC operated, centre-based respite services are through the Allocation Panels as outlined in the Respite Services: Allocation of Planned Respite Care Policy (v1.2, Oct 2009). The Respite Assessment and Booking System (RABS) for ADHC operated services, currently under development, will prioritise and facilitate access to ADHC centre-based services.

Decisions about the allocation of respite must be transparent and based on:

- principles of equity and fairness
- the eligibility and priority of access criteria set out in Section 5
- an holistic assessment of the person, their carer/family, the formal and informal supports available to them, family strengths and risk factors as well as cultural and linguistic needs.

The intake, assessment and allocation process for respite services should:

- be transparent and consistent in application
- aim to utilise service capacity to the maximum degree possible while meeting the needs of people with a disability and their families and carers
- be sensitive to each person’s individual needs including their cultural, religious and communication needs
where possible provide certainty about respite allocation
provide a match between the needs of the respite user and the available resources.

Table 1 identifies the relevant documents to guide the intake, assessment and allocation process.

Table 1: ADHC’s policy and procedures for intake, assessment and allocation of respite

<table>
<thead>
<tr>
<th>Funded service providers</th>
<th>ADHC respite services</th>
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<tbody>
<tr>
<td>Funding agreement and service description schedule or description of funded service</td>
<td>Intake policy</td>
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<td></td>
<td>Prioritisation and allocation policy</td>
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<td></td>
<td>Allocation of planned respite care policy (updated October 2009)</td>
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<td></td>
<td>Orientation to planned respite care policy including respite plan (updated June 2006)</td>
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<td></td>
<td>Maintaining respite capacity policy (April 2009)</td>
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8.2 Respite plans

People with a disability accessing respite services subject to these guidelines should have a respite plan that outlines the amount and type of respite that they will receive and which is linked to other existing plans and goals. The service provider will work with the person with a disability and their carer to develop a plan that identifies the goals of the person whilst in respite and the strategies to achieve those goals. Respite plans are developed using a person-centred approach with the client and their family. Person centred planning ensures that the person with a disability is central to the plan and that family members are partners in the planning.

Respite plans are to include strategies:

- for ensuring that the full range of support and assistance is provided for the person while in respite that reflects the support and assistance the person receives in their usual care arrangements. This includes personal care and support with activities of daily living.
- to manage issues relating to risks, health, safety and the provision of appropriate care to the person with a disability
- to provide opportunities for people with a disability to participate in age-appropriate recreation, leisure and skill development activities of their choice
- that outline the outcomes the respite service aims to achieve for the person with a disability and their carer/s.
Respite plans are required to be regularly monitored and reviewed with the person with a disability and their carer to determine whether the goals of service provision are being achieved, to overcome any impediments to the effectiveness of the respite service and to take into account any changes in the personal circumstances of the person with a disability and their carer/family.

Table 2 identifies the relevant main documents to guide the development of respite plans.

**Table 2: Documents relating to developing respite plans**

<table>
<thead>
<tr>
<th>Funded service providers may have their own policies or may access policies developed by ADHC</th>
<th>ADHC respite services</th>
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<tbody>
<tr>
<td>▪ Funding agreement and service description schedule</td>
<td>▪ Orientation to ADHC respite services policy (v1.0, June 2006)</td>
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<tr>
<td>▪ Health care policy and procedures (2007)</td>
<td>▪ Allocation of planned respite care policy (updated October 2009)</td>
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<td></td>
<td>▪ Ensuring good nutrition policy (2003)</td>
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<td></td>
<td>▪ Health care policy and procedures (2007)</td>
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<td></td>
<td>▪ Epilepsy policy and procedures (2007)</td>
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### 8.3 Planned and emergency respite

Planned respite services provide families and carers with predictability and enough time to plan their activities while the person with a disability is receiving respite. At times, however, crises and unforeseen circumstances can arise at which time emergency respite has an important role to play in assisting the family by providing a safe place for the person and giving the family a break from caring responsibilities so they can attend to other areas of their lives.

Emergency respite is an immediate, unplanned, time-limited response to families and carers who are unable to provide care due to an unforeseen crisis. The Australian Government provides funding specifically for emergency respite through its carer respite centres.
While Australian Government services should be the first option, centre-based and flexible respite services need to make some provision for responding to emergency or crisis needs, including responding to the needs of families who are not current service recipients, if necessary. Services will need to have capacity to deliver emergency respite where issues of high support, risk or urgency have been identified.

If a family is experiencing a crisis that is or has the potential to affect their role as carers, the family should be referred to their case manager, if they have one, or to the local ADHC IRI Team for further assessment and provision of support.

In the case of centre-based respite, beds should not be kept vacant for the sole use of emergencies. In the case of an emergency, planned respite may need to be temporarily suspended and alternative arrangements for the affected person and their family/carer developed as soon as possible.

Service providers are expected to work with other service providers and ADHC operated respite services to ensure responsive emergency service provision.

### 8.4 Fees

ADHC funded service providers can charge a small fee to offset the cost of service provision, however, people with a disability and their families and carers are not to be denied service on the basis of inability to pay fees. Out of pocket expenses relating to client activities such as admission fees for recreational activities are normally paid for by the family.

There is a ‘No Fees’ policy for ADHC operated centre based respite services.\(^\text{14}\)

### 8.5 Complaints and disputes

All service providers must have a complaints policy and procedure and provide accessible information about these to people with a disability and their families and carers who are using the service.

### 8.6 Staff

It is expected that ADHC funded and operated respite services are provided by appropriately trained and experienced staff that have the requisite competencies to provide a quality service. Criminal record checks must be carried out on all staff. Equal employment opportunities and cultural diversity principles should be reflected in recruitment processes. Staff working with children must complete a Prohibited Employment Declaration Form\(^\text{15}\) and Working with Children’s Check through the NSW Commission for Children and Young People.\(^\text{16}\)
8.7 Volunteers

If an ADHC funded respite service uses volunteers, it is expected that volunteers will receive relevant assessment and training and be supervised by qualified staff. Volunteers working with children must complete a Prohibited Employment Declaration Form and Working with Children’s Check through the NSW Commission for Children and Young People.

8.8 Hours of operation

Respite services are expected to operate at least 50 weeks a year unless otherwise specified in their service description schedule. Hours of operation will depend on the type of respite provided and the target group for respite. Centre-based respite facilities are normally closed during the day because children are usually at school and adults are attending day programs. During school holidays respite centres for children are open during the day time.

8.8.1 Children and young people

Respite should not generally be provided for children and young people (aged 6-18 years) during school hours, as it is expected that they will attend school at these times. Respite for children and young people can be offered at one or more of the following times:

- before and after school on week days
- overnight
- weekends
- school holidays, which may be delivered in a block of days
- in time-limited emergency circumstances.

8.8.2 Adults

It is expected that, in general, both centre-based and flexible respite for adults is available 7 days a week, although actual hours of respite provided will vary according to the needs of the person with a disability and their carer.

Respite will not generally be offered to adults during the hours that they would usually be attending day programs, employment or post school programs unless these programs cannot be easily accessed due to distances involved.


18 Some services may close for part of the day.
9 Service monitoring

ADHC operated services are monitored through the regional management structure. Regional Directors have responsibility for ensuring ADHC operated services are performing in line with the requirements set out in these Guidelines.

Ongoing monitoring of ADHC funded services will be undertaken in accordance with the provisions of the funding agreement and agreed description of funded service or the service description schedule as part of each funding agreement. Monitoring of funded services during the term of the funding agreement will include contract compliance, performance against agreed outputs and quality standards.

ADHC and non government respite service providers are required to submit Minimum Data Set (MDS) reports every quarter. Service providers experiencing difficulties with MDS transmission in relation to their reports are encouraged to contact the Helpdesk on 1800 643 925.

Respite camp – Mad Science Show
Respite services must be delivered in accordance with the following legislation and policy:

- **NSW Disability Services Act 1993**[^19]
- **Disability Services Standards 2003**[^20]
- **Children’s Standards in Action 2004**[^21]
- Services for children and young people must comply with the *Children and Young Persons (Care and Protection) Act 1998*[^22] and the *Children Legislation Amendment (Wood Inquiry Recommendations) Bill 2009.*
- **Occupational Health and Safety Act 2000**[^23]
- All staff and volunteers caring for children and young people must complete the Working with Children Check through the NSW Commission for Children and Young People and be confirmed as not being a Prohibited Person prior to their first working day.
- Funding agreement, which includes a requirement that providers submit quarterly reports for the Minimum Data Set.

11 Working in partnership

Working in partnership is a key component not only of an effective respite service but an effective respite service system. Partnership is one of the principles featured in these guidelines and needs to be implemented at various levels and in a range of relationships. Respite services need to work in partnership with people with a disability, families and carers, with each other, with other specialist providers and with providers of generic community services and informal and formal supports in order to respond to individual needs, to maximise service integration for and to maximise service capacity across the respite service system.

A number of ADHC regions have formed partnerships with non-government service providers to build local systems that make access to and allocation of respite services more integrated and streamlined for families and carers. These include regional centralised allocation of respite services. ADHC acknowledges that there are many examples of respite services engaging in formal and informal partnerships to make respite services more effective. ADHC further encourages services to explore all possible avenues for partnership in the provision of respite services. ADHC will also lead a number of projects to develop more streamlined and integrated systems for access to and allocation of respite services.