New directions for disability respite services in NSW

Respite Directorate

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1 Introduction

The New directions for disability respite services in NSW has been developed to assist in the reform and expansion of disability respite services. It will guide the way future disability respite services are delivered, how people access those services, the types of services provided, the settings in which they are delivered and the development of new respite services across the sector.

Stronger Together: A new direction for disability services in NSW: 2006–2016 commits the NSW Government to expanding existing respite services and building a more flexible and responsive disability respite service system. Also driving the expansion of respite services for people with a disability and their families and carers is the NSW Carers Action Plan 2007–2012.

This paper broadly outlines the direction we intend to take to reform and expand respite services in NSW. We are hoping to build a respite service system that is more responsive to the individual needs of people with a disability and their families and carers. The strategy will guide future respite service system reform, commencing in 2009/10.

In order to consider different approaches and better ways to deliver respite services, Ageing, Disability and Home Care (ADHC) has consulted with a wide range of stakeholders and reviewed national and international research along with key research conducted locally by Interchange NSW and Carers NSW.

To ensure we get the mix and balance of disability respite services right for the people who use them we undertook an extensive state wide consultation over a three month period in 2009. With the assistance of National Disability Services (NDS), Interchange Respite Care (NSW) Inc and Carers NSW we sought input from the sector. In all, more than 30 consultation forums were held across the state where families and carers told us what types of respite services they need, how they would like respite services to be delivered and the times at which they need respite support. Respite service providers and advocates suggested ways in which the respite service system could be improved to ultimately deliver the best possible respite support for their clients. In addition to the forums more than 50 separate written submissions were received from people with a disability, their families and carers, advocates and service providers. We received many detailed submissions that provided comment on a wide range of areas in which we could improve respite support and services. The feedback that we received has been invaluable and has enabled us to shape the final version of this paper to clearly set out our vision for the future provision of respite services.

ADHC would like to thank those who took the time out of their busy schedules to provide us with their comments and feedback.
2 The framework for reform

The NSW Government, along with other states and territories, has entered into a partnership with the Australian Government to focus on the national reform of the disability service system. The objective of the reform directions under the National Disability Agreement is for people with a disability to have enhanced quality of life and participate as valued members of the community. It commits all states and territories to establish a service system which enhances the social and economic participation of people with a disability and supports their families and carers.

The NSW Government understands the importance of respite for all families and carers who are caring for a person with a disability. It also acknowledges the significant role that families and carers play in supporting people with a disability. Guiding the way forward for respite services in NSW are two frameworks that clearly set out the vision and direction of these support services.

**Stronger Together: a new direction for disability services 2006–2016**

*Stronger Together* provides the framework for the delivery of services to children, young people and adults with a disability and their carers in NSW and commits to setting a new direction for respite services so they better support families and carers.

**The NSW Carers Action Plan 2007–2012**

The *Carers Action Plan* outlines the NSW Government’s commitment to the state’s 750,000 carers over its first five years. It recognises that better support for families and carers has significant long-term benefits for the whole community, not just for those being cared for. The vision of the *NSW Carers Action Plan* is to assist carers to achieve quality of life for themselves and the people they support.

The *NSW Carers Action Plan* sets out five clear priorities:
- Carers are recognised, respected and valued.
- Hidden carers are identified and supported.
- Services for carers and the people they care for are improved.
- Carers are partners in care.
- Carers are supported to combine caring and work.
3 Disability respite services

In New South Wales ADHC is responsible for providing a broad range of services for people with disabilities, including respite services.

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. ADHC understands the importance of strengthening family relationships and provides and funds many support services that help to strengthen these relationships. Respite is one of these support services which plays an important role in keeping families together.

The purpose of respite

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.

Principles

The principles that underpin and guide the provision and delivery of respite services in NSW are:

- 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 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; and

services are cost effective.
The current service system in NSW delivers a broad range of respite services in three main settings:
- home-based;
- community-based; and
- centre-based.

Many people will receive a combination of respite services though the provision of flexible respite which aims to tailor support to meet individual needs and circumstances.

As respite may be one of a number of support services provided to a person with a disability and their families and carers it should not be considered as a stand-alone service. It is important that respite services are integrated with other support services which aim to better support carers in their caring role. For example, the Home and Community Care (HACC) program provides a range of services that assist families and carers and provide direct support to people with a disability such as assistance with dressing, showering and toileting; domestic assistance such as cleaning and meal services.

Current models

The following gives an overview of disability respite service models currently being offered.

- **Flexible/combination respite** is provided in a range of settings. This can include care in the home of the person with a disability, with an alternative family carer, and/or provided in community settings through camps, holidays and social or recreational activities in the community.

- **Own home respite** provides respite in the home of the person with a disability and may be for a few hours or a few days. Respite can include the support worker staying overnight with or without the carer present.
- **Host-family programs** are where the person with a disability spends time in the home of a volunteer family. Host families are trained to care for people with a disability, particularly children. Care is taken to match host families with the interests and background of the individual and their families.

- **Centre-based respite** services are provided in a house in the community where the person with a disability stays overnight or longer. Individual houses may have a specialised focus, such as children or adults, or may dedicate periods of time for a specialist focus, for example women or young adults. Centre-based respite is not provided for children younger than seven years unless the child has complex health care needs.

- **Specialist centre-based respite**. ADHC operates two specialist centre-based respite units that cater for adults and children whose primary disability is an intellectual disability and who have complex health care needs that require specialist care.

- **Respite camps** have been implemented in partnership with Sport and Recreation, a division of Communities NSW (Sport and Recreation) and the Muscular Dystrophy Association of NSW (MDANSW). The camps aim to provide positive and meaningful recreation experiences for the person with a disability at the same time as giving their families and carers a break.

- **Peer Support**. People with a disability are supported in leisure and recreation activities that are provided by or with people of similar age and with similar interests.

- **Before and after school and vacation care** provides before and/or after school activities and support to school children with disabilities. Some involve integration with generic programs with assistance from support workers.
Other services that give carers a break

ADHC is committed to maximising opportunities for people with a disability to access mainstream services and promote community inclusion and community engagement.

There is a range of mainstream services that all individuals in the community have access to, such as school, that also give families a break. However, we recognise that some families and carers face additional challenges in caring for a person with a disability and require additional services. For these families ADHC provides specialist disability services, such as respite.

In addition to specialist respite services that give families and carers a break there is a range of community based services funded by ADHC that have a respite effect for families and carers even though this is not their primary intent.

- **Post school programs** (Transition to Work and Community Participation) assist young people to develop the skills they need to work towards their short and long term goals, increase their independence and participate as valued and active members of the community. Post school programs are person centred, flexible and specifically designed for young people with varying disabilities and support needs.

- **Day programs** provide meaningful activities and offer a range of support services that are tailored to meet the needs of the person with a disability. Day programs assist people to develop and maintain skills relating to accessing and participating in the community, independent living and life skills.

- **Holiday camps** provide outdoor education and recreation activities in a specialist camp for children or young people with disabilities or in a mainstream holiday camp with specific supports.

- **Recreation and leisure programs** are specifically designed to enable people with disabilities to make friends and/or take part in recreation activities, camps, holidays or group activities.
5 Why change?

Feedback from our clients on the services we offer, key findings from our research and increased funding are all factors contributing to the reform of disability respite services.

The continued roll-out of Stronger Together funding coupled with the increased funding opportunities that have been made available under the Australian Government’s Disability Assistance Package for older carers has given ADHC more opportunity to respond to the pressures of the current respite service system.

Under Stronger Together we have a commitment to regularly review and continually improve services to achieve the best possible outcomes for people with a disability and their families and carers.

Feedback from our consultation

A draft discussion paper was released for consultation over a three month period from March 2009. During this time we consulted with a broad range of disability respite stakeholders; including families and carers, advocates, peak bodies and service providers.

Carer consultations were held in 15 different locations across the state where a large number of families and carers attended. Families and carers related their experiences of disability respite services, and told us what services were working for them and what services they would like to see provided. In addition to the feedback received at the consultation forums, detailed submissions were received from 28 families and carers.

Across the state 17 provider workshops were held with the support of National Disability Services (NDS) and Interchange Respite Care (NSW) Inc. Service providers outlined the types of respite services they offered and made suggestions for improvements in the way disability respite services are being delivered and the types of changes that they would like to see. Overall, more than 100 non-government service providers were represented at these workshops with a further 13 organisations providing formal submissions.

In addition to the above, submissions were received from 17 peak bodies, advocacy and support groups across the state.
Families, carers and advocates told us

Feedback received from families, carers and advocates during our consultation identified a number of pressures in the respite service system:

- To assist families to navigate the disability service system consideration needs to be given to the development of an information system clearly showing what types of disability services are available to families, carers and people with a disability.
- There is a greater need for flexibility in the range of respite services available. Flexible respite services could provide recreation, interest based leisure and social programs for children and young people.
- Families want more choice in the hours that services are available, for example, programs that are offered in the evening and on weekends.
- Some families want more capacity to control how they spend their share of respite funding.
- Services need to meet the changing needs of people with a disability and their families and carers.
- There is a need for the provision of additional supports at varying transition points for families, such as when children are starting school, entering high school and leaving school.
- Services are needed to support the needs of working families.
- There is a need for the provision of sibling support programs.
- There is a growing need to provide services for people who have physical disabilities.
- Services are needed to support people with disabilities across all ages including children who are under 7 years of age who have complex health care needs and/or challenging behaviours.
- There is a need to have an early intervention approach to support families with services available at the earliest possible times.
- Planning for the future needs for both the person with a disability and their families and carers needs to be commenced earlier and supported over the long term.
- For some families the lack of transport is a barrier to accessing services.
- Families want to be able to share holidays together, with care support provided for the person for whom they are caring.

Peak bodies and service providers told us

- There is a need to align funding so services can better respond to clients with challenging behaviours and high support needs.
- There is a need to consider transport options to support those families who are unable to transport the person they are caring for to and from respite services.
There is a need to develop a uniform, structured system of training based on an agreed set of industry competencies for respite. There is also a need for improved access to specialised training.

Guidelines are urgently needed to set clear parameters on the types of flexible respite services that can be delivered. These parameters need to be reflected in Descriptions of Funded Services and Service Description Schedules (SDS).

Research tells us

National and international research and evidence-based practice has identified that respite should be part of an integrated service system which is able to respond to changing needs of individual children, young people and adults with a disability and their families and carers. There is growing recognition that respite is not a stand-alone service but part of a suite of services for people with a disability and their families and carers.

It is recognised that the needs of people with a disability and their families and carers change over time. Respite should also be considered as an evolving form of support that adapts to changes in client circumstances. The respite service system needs to respond quickly and flexibly to day-to-day needs and changes in people’s lives. Families and carers need to be able to access respite services that are responsive to their individual needs, such as support to remain in or seek employment, to receive assistance when health issues or family crises arise, or to go away on a holiday.

In addition, research indicates that there has been a shift towards viewing respite as a service that provides a positive experience for both the person with a disability and their carer, in order to improve the quality of their lives, and to support their relationships. This must be considered when developing new respite programs.

Research also shows there is a growing demand for respite services due to a number of factors, including:

- the ageing of carers;
- changes in traditional caring roles as more carers, especially women, seek employment;
- people with disabilities are living longer and have increasingly complex care needs;
- an increase in the number of young carers; and
- an increase in the number of carers who are caring for people with challenging behaviours.
Priority groups of carers

As outlined above stakeholder feedback and our research has highlighted a number of areas that require attention in terms of how and when we deliver services and what services we deliver. Research has also indicated who most needs respite services highlighting the need to prioritise respite support for the following groups of carers:

New carers

New carers may be the parents of an infant or child who has recently been diagnosed with a disability, they may have assumed a caring role for a sibling or they may be caring for a family member who has a disability resulting from a medical condition or as the result of an accident. The provision of early intervention support has been identified as being critical in the early years of caring. Specialised services to support new carers needs to be explored.

Carers of people with challenging behaviours and/or severe disabilities

Young adults in the 15 to 24 age group with challenging behaviours and severe disabilities are often excluded from family activities and other social activities. Research has also found that this group may have restricted access to respite due to their high support needs\(^2\). Expansion of existing services that are appropriate and targeted is needed to meet the needs of this group of young people.

Carers of children with challenging behaviours less than seven years have also been identified as a priority group. Options to provide support at the earliest possible stage for this group of carers need to be further explored.

Young carers

Many young people are not easily identified as carers, and may be overlooked by the service system. Approximately 90,000 young people in NSW under the age of 25 years are carers\(^3\). The literature identifies a range of potentially negative and significant effects on young carers including reduced life choices, limited future opportunities, serious risk of leaving school prematurely and poor physical and mental health.

Older carers

As people with a disability are living longer, the number of ageing carers is projected to increase significantly over the next two decades. Therefore, there is a clear need for the expansion and increased flexibility of respite programs offered to this group.


\(^3\) ABS Disability, Ageing and Carers, Australia: Summary of findings, 2003.
Working carers

The economic cost of caring is related to reduced paid workforce participation, reduced income, and reduced health and well-being on the part of the primary carer. This is in addition to costs directly related to the care needs of the person with a disability. One quarter of carers report that their employment situation has been adversely affected by their caregiving role. For example, out of school hours care is only provided for primary school aged children. Parents who are working or studying and have teenage children with a disability also need out of school hours and vacation care.

Hidden carers

Hidden carers include carers who may not identify with the word ‘carer’, be unaware of available services, be unfamiliar with models of formal service and support provision, or choose to manage alone for a variety of reasons. While many carers are well supported by family and friends and have no need for formal services, there are carers who are isolated, providing significant amounts of care and are not receiving the support they may need.

Aboriginal and Culturally and Linguistically Diverse (CALD) carers

ADHC is committed to providing a range of services that meet individual need and reflect and recognise the diversity of all individuals. We acknowledge that some families and carers face additional barriers in accessing services that meet their needs.

While the circumstances of families from Aboriginal backgrounds differ from those with a CALD background, both groups can face potential barriers in accessing services. Barriers to access for both groups may include cultural barriers, such as lack of culturally appropriate services and lack of information in appropriate formats or language. When developing new services we need to have a strong focus on building organisational capacity to provide services to a diverse range of clients.
The first sections of the paper provide an overview of the current respite service system and the models of disability respite services that are currently being provided in NSW.

Feedback from our consultations, coupled with our research, has highlighted many areas in which we can improve our services and respond to the growing demand for respite. Our consultations have confirmed that respite users and their families and carers need a flexible service system that can respond as individual needs change and where there is a greater range of services available. Families and carers also want more choice and control over the kind of services that they receive, assistance in navigating the service system and streamlined access to services. It has also highlighted the need to ensure that we offer or fund a range of services that are culturally appropriate for all our clients including those from Aboriginal and CALD communities.

We have started to respond to this feedback through the development of new service models and the expansion of new respite places through Stronger Together, along with strategies to make it easier for families and carers to access the services they need, but we need to do more. As we highlighted earlier, respite is a crucial support for some families and carers to stay together. Respite however, does not stand alone, it is part of a broader system in which ADHC and non-government organisations provide a range of services to people with a disability, their families and carers.

This section of the paper outlines our direction for the provision of a responsive service system which aligns with the broader framework of reform which is currently being undertaken by ADHC to enhance service provision across the disability service system.

In line with this broader framework our respite reform agenda is guided by four key themes:
1. Responding to need
2. Giving individuals greater control and choice in the services they receive
3. Streamlining access to services
4. Building the capacity of the service system
Responding to need

In response to unmet need and the priority groups of carers identified earlier in this paper, work has commenced to expand existing services and to develop and implement a number of new initiatives through Stronger Together. Feedback received during the consultation highlighted the need to develop a broad range of services that will focus on providing services for families and carers at the earliest possible time. Support for future planning and respite services that have a focus on leisure and recreation activities for the person with a disability have also been highlighted as areas for development.

We have also identified a need for services at key transition points in the lives of the person with a disability and their families and carers. For example, access to age-appropriate after-school and vacation care programs and recreational activities becomes important when a child starts school or enters high school.

In addition, the transition from child to adult services has been identified as a key transition point for young adults. While a number of support programs focus on the needs of young adults, for example Community Participation and Transition to Work, there is a need to ensure respite services can meet these specific needs.

We have started to develop respite services to meet some of these needs and we will monitor the effectiveness of these services and continue to monitor research, practice and client feedback to determine how else to improve our services.

Early intervention

Our research has highlighted the importance of providing early intervention, both in the very early years of life following an initial diagnosis of a disability and as soon as possible after a need for support is identified. Early intervention improves the future for people with a disability by responding swiftly to their health or other support needs to minimise negative impacts of their disability and the escalation of problems. Timely provision of services also has the potential to reduce the stress on families and carers by giving them the support when they need it most.

Providing supports at the earliest possible time, in response to assessed need, maximises opportunities for families, carers and people with disabilities to achieve the greatest benefits. Our aim is to increase opportunities for people with a disability, their families and carers to participate as fully as possible in community life.
Recreation and leisure

The provision and expansion of respite services that provide recreation and leisure services has been highlighted as an area that would receive great support from families, carers and service providers alike. Many carers support the notion that if respite is an enjoyable experience for the care recipients and knowing that those who they are caring for are enjoying themselves it makes respite more beneficial for them.

The development of interest based and recreational respite programs has been identified as having the potential to assist the person with a disability to establish their own peer support and recreational networks with other people who share similar interests.

Flexible respite

In response to feedback from families and carers for greater flexibility and choice, ADHC is developing a flexible respite program that aims to provide a wider range of service options that are better able to respond to the varied and often complex needs of families and carers.

Providers of flexible respite services have highlighted the need to have guidance around the delivery of flexible respite services. In response to this, ADHC has commenced work to develop a clear policy position for flexible respite. This policy position will clarify what types of services can be delivered, who the services can be provided for, the settings in which flexible respite can be delivered, and at the same time, promote service provision at the times when families need them. It is expected that the policy position will be finalised in 2010.

Transport to and from respite

Families, carers, service providers and ADHC regional staff have highlighted the difficulties some families face in accessing transport for the care recipient to travel to and from respite. In particular, transport to respite is a critical issue for some Aboriginal families and families who live in regional and remote areas where there are less transport options.

Families have told us that the time taken to transport the person they are caring for, even where the carer has access to transport, is time consuming and costly. At times the difficulties surrounding transport negates the benefits of respite for the carer. Consideration must also be given to the length of time some clients may spend traveling to and from respite support. Lengthy travel time may impact negatively on behaviour and also detract from the positive experience of respite.
In response to this feedback ADHC has commenced work to better understand the issues and to develop a policy position for the provision of transport to respite. To achieve the best possible outcome for families and carers we are planning to undertake this work in close consultation with the sector.

**Responding to priority groups of carers**

Feedback from the consultation has highlighted the need to improve services for the following groups of carers.

**New carers**

Providing access to support services is particularly critical for new carers. In response ADHC is currently developing a strategy to support new carers of people recently diagnosed with a disability. This project aims to identify what support services and information families and carers need at the point of diagnosis, and to develop strategies for implementing these supports in conjunction with existing services. In addition Early Diagnosis Support Worker positions are being established in non-government organisations to assist new carers of children with a disability to navigate the service system and access support services.

**Young carers**

It is vital that young carers receive the support they need to maximise opportunities to reach their full potential through participation in education, employment and community life.

ADHC is leading an initiative to support young carers in a coordinated government approach under the *NSW Carers Action Plan 2007–2012*. This initiative is being completed in partnership with a number of state and federal government agencies. We are investigating the information and training needs of service providers and other frontline staff to improve identification of young carers and referral to appropriate information and support. We are also investigating the information resources available for young carers to ensure that they are easily accessible and provide young carers with the information they need.

Cross agency approaches to supporting young carers will help these young people to fulfil their true potential in education and/or employment and allow them to have an active role in their community and social networks.
Older carers

Since mid 2006, ADHC, together with the Australian Government, has introduced respite initiatives and has created new flexible respite places across the state targeting older carers of a person with a disability. In 2009 an evaluation of the program was undertaken to tell us which components are working best to meet the needs of this group and to inform future planning and allocation decisions. As a result of client feedback and findings from our evaluation a commitment was made to continue these services. In addition, the age eligibility criteria was broadened to include carers aged 60 years and over (previously 65 years) and remain at 45 years and older for Aboriginal carers. The continuation of these services will provide ongoing respite support as well as assist families to plan for the future needs of the son and/or daughter they are caring for.

In response to the needs of older carers ADHC is exploring further ways in which we can support them. Carers, and in particular older carers, have consistently told us they are uncertain and worried about the future needs of the loved ones for whom they are caring. Assistance with planning for the future for families, carers and the person with a disability is critical. Currently, Support Coordination services provide this service for parent carers who are 60 years and older. ADHC recognises that planning for the future needs to begin earlier. ‘Younger’ older carers, parent carers who are aged 50 and over, have told us that planning for the future needs to be introduced at an earlier stage for both the carers and the person they are caring for.

Aboriginal carers

The Aboriginal Flexible Respite Program (AFRP) was established in ADHCs Western Region in 2007 to support and enhance the ability of Aboriginal families to care for a person with a disability. The Program is an innovative one that aims to provide Aboriginal families caring for someone with a disability with the opportunity to tailor their respite according to their needs. It is the only flexible respite service operating in NSW that has been specifically designed to meet the needs of Aboriginal carers and their families.

A review of the AFRP has recently been undertaken to determine if the program is responding effectively to the needs of Aboriginal families and carers in Western Region. Preliminary findings from the review have identified a number of ways in which the program can be improved to provide more responsive services to Aboriginal communities. Options for expanding the program across NSW are also being explored.
Working carers

In response to the needs of working parents the Teen Time — After School and Vacation Support for Working Parents has been developed. This program offers an after school and vacation program for secondary school students with a disability with moderate to high support needs where they can spend time with their peers in age-appropriate activities. The program has a particular focus on supporting parents and carers to pursue work or work related study. Teen Time is being provided in partnership with the NSW Department of Education and Training and involves schools which have been designed and equipped for students with a disability, thus providing a safe and secure environment. Teen Time was trialed in four locations in the Department’s Metropolitan North Region in 2008 and is currently being expanded across the state.

Feedback from our consultation told us that there is a need to support working carers in the ‘gap’ hours between 3pm and 7pm weekdays. ADHC is exploring options to respond to the needs of working carers during these times.

Carers of people with challenging behaviours

The Families Solutions program has been established to respond to the need for services for children and adolescents with challenging behaviours. Families Solutions is specifically targeted towards families who have children and young people with challenging behaviours.

Currently being piloted, the Families Solutions program is a three year inter-agency demonstration model for families under severe stress who care for 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.

In addition, the recently established Respite Camps for Teens with a Disability has components within its program that target this group. ADHC is looking at opportunities to expand these services and develop other service models for this client group.

Respite Camps for Teens has been developed in response to the need to provide meaningful recreational activities as well as providing additional supports for families and carers of teens with challenging behaviours. This program is being delivered in partnership with Sport and Recreation. Teenagers with a disability are able to utilise existing Sport and Recreation Centres and the expertise of centre staff. The program consists of two streams:
Stream one — mainstream camps
Teenagers with mild to moderate disabilities participate in existing Sport and Recreation camps with secondary students from the broader community.

Stream two — specialised camps
Teenagers with moderate to severe disabilities participate in specialised camps tailored to meet their higher support needs. This program includes a tailored sibling support stream where siblings are able to attend the camp with their brother/sister and spend meaningful time with other young people who are in similar situations.

Carers of people with high support and complex health care needs
We have identified the need to explore further an efficient and effective response for families and carers of people with high support and complex health care needs, in both metropolitan and regional areas.

One strategy to support this group is to improve access to existing services by supplementing the staff of respite centres with nursing staff. Nurses would take responsibility for the specific health care needs of clients with complex health conditions in appropriately equipped and located centre-based respite services.

Carers of people with degenerative neuromuscular illnesses and acquired brain injury
There are groups who may not necessarily be existing ADHC clients because their primary disability is not an intellectual disability, for example people with Multiple Sclerosis (MS), Muscular Dystrophy (MD), Acquired Brain Injury (ABI) and Motor Neurone Disease (MND). Services for these groups are predominately provided by the non-government sector.

We acknowledge that service access needs to be enhanced for clients with degenerative neuromuscular illnesses and acquired brain injury. Innovative ways in which the needs of these groups of clients can be integrated into the existing service system requires further exploration, as well as the development of new services that meet specific needs.

In response to the needs of this group of clients ADHC, in partnership with Muscular Dystrophy Association of New South Wales (MDANSW), has recently implemented a respite camp program for children, young people and adults with degenerative neuromuscular disorders. The camps are being provided at the Sydney Academy of Sport and Recreation Narrabeen, which is fully wheelchair accessible and designed to accommodate the needs of this target group. The camps aim to provide positive and meaningful recreation experiences for the person with a disability at the same time and giving their families and carers a break.
Giving individuals greater choice and control in the services they receive

Individualised (packaged) support

The international trend, supported by a growing evidence base, is for people with a disability and their family and carers to have greater control over and choice in the services they receive.

ADHC is progressing the provision of individualised (packaged) support for some families and individuals. Individualised support will provide expanded opportunity for people to access portable funding allocated to support their goals and needs. These families will have a key role in determining the services they receive and how they receive them, which may include formal and informal supports from traditional and non-traditional providers.

Packaged support will allow families to tailor their own respite support services to meet their individual needs. Respite services may be combined with other support options to provide the right mix and balance of available services.

To obtain the greatest benefit from individualised support arrangements ADHC recognises that people with a disability, their families and carers need adequate support to assist them in making decisions about how their care needs can be best met. We recognise that we also need to work with and support service providers to make sure that they can respond to individual family needs.

Flexible respite places

The expansion and enhanced responsiveness of flexible respite will ensure that services are tailored to best meet the individual needs of both the person with a disability and their families and carers. New models of flexible respite need to be innovative and offered at times when they are needed, including on weekends and after hours. In particular, the development of innovative models of flexible respite care will consider the following identified areas of unmet need for this service type:

- Social groups for adolescents and adults;
- School holiday programs;
- Weekend recreation, leisure and interest based programs across all age groups;
- Recreation, leisure and interest based programs offered in ‘gap’ hours between 3pm and 7pm weekdays to support working carers; and
- Appropriate flexible respite services for children less than 7 years of age.
Streamlining access to services

ADHC is working on a number of strategies to make access to disability services, including respite, easier, fairer and more transparent.

Navigating the service system

Families, carers and service providers have overwhelmingly told us of the difficulties they face trying to source information on what disability respite services are available to them. Submissions received during our consultation period noted the difficulties that families and carers face in finding what services are available and where services are located. Many submissions suggested that a booklet and a web-based resource clearly outlining available services and details on how to access these services would be extremely helpful.

ADHC is exploring options to make navigating the service system easier for families, carers, people with a disability and disability service providers.

Intake, assessment and eligibility

*Stronger Together* commits to the development of an intake, eligibility and assessment system that is simple and transparent, is based on need and involves families in the planning and decision making. A similar commitment to reform access has also been made at the national level. Under the new *National Disability Agreement*, governments have committed to a national reform program which aims to provide a person-centred approach to service delivery through a focus on simplifying access to disability services.

We are developing a consistent decision making process for intake to disability services that focuses on functional ability and needs, rather than on the type of disability.

Regional initiatives to streamline access to flexible respite

Families and carers have told us of the difficulties they face when attempting to access respite services. To address this issue, a number of ADHC regions have formed partnerships with non-government service providers to build local systems that make access to flexible respite services easier for families and carers. These include regional centralised allocation systems for flexible respite services to give families and carers equitable, streamlined and predictable access to funded respite services.

In addition ADHC has recently piloted the implementation of a new Project Officer position within each region to support the co-ordination of intake assessment and allocation to all ADHC funded flexible respite services. These positions will build on existing local systems, promote fairness and transparency in the allocation process and give more streamlined and equitable access to funded respite services for carers and their families.
Respite Assessment and Booking System (RABS)

We have begun developing standardised assessment tools and an online booking system for all ADHC operated centre-based respite services. The standardised assessment tools will capture both the individual support needs of the client and the circumstances and support needs of carers. Standardised assessment tools will give greater consistency around which clients are prioritised for centre-based respite and will assist ADHC staff in determining the best mix of client and staff groupings.

Through use of this booking system, we aim to simplify the process of applying for centre-based respite for carers and to give greater predictability for families when planning centre-based respite.

To complement our work on the booking system, we have reviewed and streamlined the forms used to apply for centre-based respite. Improvements have been made so that we collect better quality information to allow us to provide the best possible care to clients at the same time as forms being more user-friendly for carers to complete. Work is almost complete and it is expected that the revised forms will be implemented in 2010.
Building the capacity of the service system

*Stronger Together* acknowledges that the disability service system must be sustainable in the long term. A range of strategies are being implemented in ADHC and non-government disability service providers to improve the system’s capacity and accountability.

**Program guidelines**

Providers have told us they need clear directions in the ways that respite services can be delivered. Program guidelines are currently being developed clearly stating ADHC’s expectations for the delivery of respite services.

Once completed the guidelines will provide the framework for respite service delivery for ADHC operated and funded disability respite services while enabling service providers to deliver services in ways that respond to the needs of respite users and their families and carers.

**Workforce development**

The client base for respite services is diverse and constantly changing. Respite services need staff that are skilled and able to respond to the needs of individual respite users.

ADHC will continue working with the sector to develop and implement workforce development initiatives and strategies so that staff will be better equipped to understand and respond to the needs of the person with a disability and their families and carers. Work has also begun to:

- strengthen and enhance workforce planning across the sector.
- ensure the future workforce has the skills and expertise to deliver quality disability services.
- establish partnerships with health and community services sector and relevant industry bodies.
- create flexible and responsive workforce models to retain people in the workforce.

Throughout the consultation period service providers consistently flagged the need for ADHC to support the training needs of staff across the disability sector. Providers identified several gaps including the need to develop a uniform, structured system of training based on an agreed set of industry competencies.
ADHC is currently working in partnership with National Disability Services to roll out an extensive workforce development strategy to further support staff in the non-government sector. We have also established traineeships for disability workers and valuable partnerships with a number of universities have been formed which aim to encourage new graduates into the workforce.

Working with carers training package

The training package has been developed by Carers NSW with funding provided by ADHC and is currently being rolled out across NSW. The package was developed to support both ADHC and non-government organisations to understand and work more effectively with informal carers of older people and people with a disability. The package encourages staff to understand the viewpoint of carers, and provides simple strategies for working together more effectively to support the family unit.

Sector development strategies

As the rollout of funding and places under Stronger Together continues, we recognise that, for the full benefit of this funding to be realised, the disability service system needs to be strengthened.

ADHC is continuing to work closely with service providers and families to ensure that services are managed in the best possible way and improved where possible. A number of initiatives have already been implemented and more are being planned to improve the quality of the service system. These initiatives include:

- Quality Reform Project aims to continuously improve the quality of the service system through the development and implementation of a ADHC Quality Framework.
- Strategic Funding Reform Implementation Project is a key component of ADHC’s shift to an outcomes-based funding approach. This approach will help ensure that ADHC’s investment in services delivers value for money as well as improved client outcomes.
- Improving Service System Accountability aims to build ADHC’s capacity to support and monitor and improve quality in the service system through improved accountability. It aims to ensure providers meet clients’ needs at the same time as improving our capacity to report to all stakeholders on what is being delivered.
In response to sector feedback, we have developed several resources for service providers to explain the way ADHC will fund services in the future and how we want to build capacity in critical areas. These include corporate governance resources, financial management training and support tools. The implementation of these strategies is critical for respite services and will assist providers to offer services that are well run and financially sound.

Aligning funding to service delivery

Respite service providers have told us they are increasingly having difficulties in providing respite services for clients with challenging behaviours and complex medical needs within the current funding bands. ADHC acknowledges that the needs of clients who access respite support vary considerably. To be able to respond to client need, in particular those clients who have challenging behaviours and complex medical needs, careful planning for optimal service delivery is required.

ADHC is also aware that there is considerable variance in the types of respite services that are currently being delivered. As part of our ongoing commitment in reform and improvement of disability respite services ADHC is planning to examine levels of client need, appropriateness of services being offered and the effectiveness of current funding bands. We will continue to consult closely with the sector when undertaking these improvements.
7 Conclusion

The *New directions for disability respite services in NSW* paper outlines the direction for improving disability respite services across NSW. During the three month consultation period we received a large number of comments and submissions from families, carers, advocates, peak bodies and service providers that has assisted in the finalisation of the *New directions* paper. We thank all those who have contributed to the development of this final paper and acknowledge the time you have taken to assist in our vision for improvements to the disability respite service system.

Our goal is to provide a disability respite system that is truly flexible, responsive to need and promotes opportunities for both people with a disability and their families and carers to participate fully in the community.

Services should be offered at times that suit both the person with a disability and their families and carers. A broader range of programs and support options needs to be available to not only provide the carer a break from their usual care-giving duties, but give the person with a disability an opportunity to participate in a range of activities.

In addition to this, we need to ensure that improvements to the service system build system capacity and that services are sustainable and provide high quality, cost-effective services that are provided by well-trained staff. To do this, we are committed to continually reviewing respite services so we can invest in those that will provide the best possible outcomes for people with a disability, their families and carers.

We will continue to keep abreast of research and listen to our clients and their advocates so that our respite services remain responsive and appropriate and our resources are targeted to areas of priority need.

We have outlined a number of potential programs that will provide a greater choice of services for families that will focus on individual need. Access to services will be streamlined and the capacity of the service system will be improved.

We recognise that we will not be able to grant everyone’s wish but together we can build a more responsive disability respite system that continues to evolve as the needs and aspirations of our clients change.