NSW Ombudsman

Consultations with families of children with disabilities on access to services and support

Final Report

June 2011

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1. Introduction

Approximately 72,000[1] children and young people living in NSW have a disability. Most of these children live in the community with their families. Many of these families rely on government and funded agencies to support them to meet the needs of their child and to ensure their wellbeing and access to opportunities.

Between late May and August 2010, we consulted with over 300 parents and carers of children with disability across NSW about their current experiences in accessing and using services designed to support their child, and their family as a whole.

1.1 Background

Our previous work relating to support for children with disabilities and their families

Under the *Community Services (Complaints, Reviews and Monitoring) Act 1993*, the NSW Ombudsman has certain responsibilities in relation to people with disabilities. This includes handling and investigating complaints about disability services; inquiring into major issues affecting people with disabilities and disability service providers; and monitoring, reviewing and setting standards for the delivery of disability services.

In 2004, in a special report to Parliament, we raised concerns about the way services to children and young people with disability were being provided in NSW. Among other things, we found that for families seeking support to care for children with disabilities, there was lack of clarity about how to access support. We also found the service system was fragmented and was characterised by poor coordination of support.

In 2006, we reported to Parliament on the progress of the relevant government agency, Ageing, Disability and Home Care (ADHC), to address the problems we had identified in 2004. Our 2006 report highlighted that while progress had been made to improve systems to support the provision of disability services, there had been no evaluation of the longer term impacts of the reforms on families requiring those services. At that time, we said that effective evaluation of the reform process must include identifying the extent of the need in critical areas and then determining the degree to which implementation of new and expanded programs makes a difference to families.

Consistent with this broad observation, we made two additional comments. First, while planning was underway to improve services, it remained unclear whether families were getting the support they needed. Second, it was also unclear how well government and funded agencies were working together to fully support families caring for a child with disability.

Plans to improve the provision of disability services

Shortly after the tabling of our 2006 report, the (then) NSW Government released *Stronger Together*, a 10-year plan to improve and expand services to people with disability and their families.

Stronger Together outlined plans to significantly reform the disability sector and substantially increase service capacity. The first five years were funded through an investment of $1.3 billion and set out plans to increase capacity of the disability service system by 40 per cent. In relation to children with disabilities and their families, *Stronger Together* focuses on three strategies:

- expanding agencies' capacity to respond more quickly and appropriately;
- enhancing the support to parents and other carers and intervening earlier; and
- structuring services in a way that better supports families.

In February 2007, the (then) NSW Government released *Better Together*, a four-year plan designed to make government services work better for people with disabilities and their families.

While *Stronger Together* focuses on improving the specialist disability service system, *Better Together* focuses on improving 'universal' and 'adapted' services: such as childcare; school; before and after school care; and vacation care. *Better Together* also aims to improve the linkages between specialist, adapted and universal services, and coordinate efforts 'across all government services so that people with a disability receive the assistance they need.'

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[1] Australian Institute of Health and Welfare (2009) *A Picture of Australian Children* reported that 4.3% of children between the ages of 0 and 14 had a disability. We calculated our estimate using that percentage and the Australian Bureau of Statistics (Dec 2009) *NSW Estimated Resident Population* of people aged 0 to 18 years.

Better Together comprises eight priority areas, including early intervention, therapy services, autism, carers, and Aboriginal families and communities.

1.2 Our consultations with families of children with disabilities

Against this background and the approaching mid-way point of *Stronger Together*, in 2010 we decided to consult with families of children with disabilities. The focus of our discussions was their recent experience in seeking and obtaining specialist disability services and support; and whether the type and amount of support they have been provided has met their needs. We also asked about people's experiences in accessing universal and adapted services.

Between late May and August 2010, we talked with over 300 parents and carers of children with disabilities.[2]

The experiences of the parents and carers gave us a better understanding of what it is like to currently care for a child with disability in NSW. The discussions highlighted how critical an effective service system is to the wellbeing of children with disabilities who live in the community, and to the wellbeing of their families.

In the main, families spoke positively about the increase in services and the development of new initiatives and programs that have occurred since the commencement of *Stronger Together*. However, it is clear that there are problems in getting access to information and support, including therapy, respite and equipment. For many families, it is still very difficult to get support fast enough, and for long enough, to meet the needs of their children.

Many of the people we spoke with described caring for a child with disability as an experience that has enriched their lives. However, we also heard that many struggle to achieve the best outcomes for their child and family in a service system that they often experience as unresponsive, inaccessible, inflexible, fragmented and costly.

1.3 Developments since our consultations

Since we undertook our consultations with families, there have been some significant developments in the disability sector. A number of important plans have been released that identify major areas of work for the government, ADHC and the disability sector more broadly. These plans have been informed by consultations with people with disability, their families, and key stakeholders such as disability services and representative bodies.

Stronger Together

Of particular significance has been the release, in December 2010, of the (then) NSW Government's plans for the second phase of *Stronger Together*, with $2 billion additional funding.[3] The plan for the second five years (2011-2016) includes a continued focus on increasing the capacity of the disability service system, and achieving widespread reform of the disability sector. Areas of focus in the second phase of *Stronger Together* include:

- Person-centred support, including individualised funding arrangements. The plan indicates that 'individualised funding arrangements will become available from 2011/12, and by the end of 2013/14, anyone receiving disability services will have the option of using an individualised and portable funding arrangement.'
- A lifespan approach, focusing on significant life stages and transition points in children's lives, including preschool, school, leaving school and adulthood – with intervention at any age.

Shortly after we began our discussions with families, ADHC and the (then) Minister for Disability Services conducted a series of consultations on the first five years of *Stronger Together* and the next stage of this initiative. The resulting consultation report of August 2010 directly informed the government's plan for the second phase of *Stronger Together*.

NSW Legislative Council Inquiry

Another key development since our discussions with families has been the November 2010 release of the NSW Legislative Council Standing Committee on Social Issues' final report from its inquiry into *Services provided or funded by the Department of Ageing, Disability and Home Care* ('ADHC inquiry'). The inquiry looked at the quality, effectiveness and delivery of services provided or funded by ADHC.

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[2] All of the children were under 18 years of age and living at home. Families provided information via telephone interview, written survey, focus group and email.

[3] The December 2010 plan for the second phase of *Stronger Together* states that the new investment of $2 billion is on top of the ongoing commitment of $2.02 billion over five years needed to fund expansions established in the first phase. The plan states that, for the 10 years to June 2016, the *Stronger Together* package will deliver $5.5 billion in new growth funding for disability services.

The report identified a wide range of issues across the disability service system, and also helped to inform the plan for the second phase of *Stronger Together*. The timeframe for the government response was 11 May 2011, however we note that the change of government in March 2011 will necessarily affect the response date.

Directions for Industry Development report

In June 2010, ADHC and National Disability Services (NDS) released a *NSW Disability Services Sector Directions for Industry Development* report. The report sets out directions for industry development in the disability sector for the next five years.

Common themes have emerged from all of this work. Perhaps the most important have been the calls to reform the disability service system to give people with disability choice, control and certainty of support; and to enable streamlined and fair access to adequate support when needed, irrespective of age or disability, and unburdened by excessive bureaucracy.

Given the timing of this work, and the clear and consistent messages communicated by participants, it is not surprising that these same messages also featured in our consultations with families of children with disabilities.

2 The key issues raised by families in our consultations

2.1 Getting information about disability services and support

Our consultations highlighted that families need better information and support and they need it sooner. It is difficult for families to obtain basic information about what supports are available, what they may be eligible for, and how to get necessary services. We heard that these challenges are hard even for people who are educated, articulate and assertive.

We were consistently told that the information provided at the point of diagnosis is inadequate. Families reported being given either little or no information. In some cases, this comprised a list of telephone numbers. Very few families said that they were referred or linked to ADHC at an early point, or were even told about ADHC. Our consultations indicate that families currently rely heavily on other families and the internet to obtain information about disability services and support.

We heard that while there is a lot of information available, it is not cohesive or always reliable. Families told us that in their experience many health practitioners, social workers, and even some ADHC staff, lack knowledge about the specialist disability service system.

Consultation participants consistently said that there is no central place where they can get the information they need.

Families said that it is often difficult to get clear and accurate information, even through direct contact with service providers. We heard repeatedly from families that services expect them to know what they want without providing them with sufficient information to know what exists, what is available, and what would be suitable.

Families consistently told us that they need:

- An automatic connection to information and services when disability becomes evident, and a more coordinated approach to ensure that they receive timely and accurate information about available services.
- A central place or 'one-stop shop' they can approach to get the information they need.
- Someone to 'walk with them' to guide them into and through the disability service system. People said that it is not enough to get information; they need someone to help guide the process and facilitate the support.

Relevant actions and what we will do

The difficulties families experience in trying to find information and to find their way around the disability system have been known for a long time and widely reported.

Since 2008/09, under *Stronger Together*, ADHC has started to roll out 28 new Early Diagnosis Support Worker positions to work directly with families, provide support and information, and provide people with links to mainstream and specialist services.[4] In March 2010, ADHC indicated that it is exploring options to make 'navigating' the service system easier for people with disability and their families and carers.[5]

In our September 2010 report to Parliament on *Improving service delivery to Aboriginal people with a disability*, we highlighted the importance of local support coordinators in linking people with disability and their families to services and support. The ADHC and NDS *Directions for Industry Development* plan also recommended that consideration be given to 'improving the ease of navigation of the system through establishing local coordinators/ facilitators to assist people with disability to access information about the range of supports and services available in the community and within the disability service system, and to access these supports.'

The ADHC and NDS *Directions for Industry Development* plan outlines actions to improve navigation of the service system, particularly at key transition points in people's lives, such as when a child starts school. By 2015, it is intended that people with disability and their families will have access to information on 'what services are available and how these services can be accessed (both specialist and mainstream) from any point in the service system that they initially contact.'

The final report from the ADHC inquiry also has recommendations aimed at improving the information available for, and provided to, people with disability and their families. In the main, the recommendations focus on information about disability service providers, and making information available in a variety of formats.

The Early Diagnosis Support Workers are likely to be a useful and welcome source of information and support for families at the point of disability diagnosis. However, it is important that this initiative is underpinned by a coordinated and comprehensive approach to improving the information available and provided to people. At the moment, it is not clear whether the identified actions will meet this need.

Given the longstanding nature of this issue and its impact on anyone seeking disability support, it is critical that work to address it is progressed as a priority. We will obtain information from ADHC to establish:

- how the agency intends to ensure that strategies to improve the provision of information are coordinated and comprehensive; and
- whether the proposed actions are likely to adequately address the concerns raised by families.

2.2 Getting access to services

Part of the focus of *Stronger Together* is on making access to disability services simple, fair and transparent. This includes ensuring that there are streamlined entry and access points to the disability service system, and a standardised assessment of the needs of people with disabilities and their carers.

Our consultations confirm the need for this work to occur as a matter of priority. Families told us that their current experience of trying to access disability services and support is, for many, difficult, and involves:

- Contending with excessive paperwork and bureaucracy, including having to repeatedly prove that their child has a disability which meets eligibility requirements.
- Having to tell their story over and over.
- Having to demonstrate that they aren't coping to justify the need for support.
- Competing with other families for limited services. We heard repeatedly that to access services, parents and carers have to prove that not only does their child need the support, but they need it more than other children.
- Having to make a lot of noise to access a service or to get adequate support.

We heard that many families have found that the disability service system is not responsive enough to meet their needs. Families told us that it is difficult to obtain aids and equipment in a timely way; there are extensive and prohibitive waiting lists for therapy; and it is difficult to get respite and in-home support when they need it. We heard that it can be difficult to access services and support even when a family is experiencing a crisis, such as carer injury.

Families also told us about the difficulties they have experienced in recent years in gaining an effective response from ADHC's intake and referral system.[6] Parents and carers said that their calls to ADHC to seek

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[4] The *Early Start – Diagnosis Support* program involves the creation of 20 positions since 2008/09; with a further eight specialist Aboriginal positions to be established in the 2010/11 financial year.

[5] ADHC (March 2010) *New directions for disability respite services in NSW*

[6] ADHC operates Information, Referral and Intake Teams through its regional Community Support Teams. Functions include providing information and advice, referral to other services, and assessment for eligibility for ADHC-direct support. To be eligible for ADHC-direct

assistance had not been returned, or there had been extensive delays before they received a call back. This included people who had reapplied for ADHC support after previously receiving some assistance.

Other families said that they had received a swift response after contacting ADHC, including a home visit and assessment, but had heard nothing afterwards. Some parents and carers told us that they believed that they were on a waiting list for support, but when they contacted ADHC, found out that there was no record of their contact or they had not been added to the relevant waiting list.

Once through the intake process, many families said they had a very long wait before they received the support they had requested from ADHC. This included people who contacted ADHC at the time of what they considered to be a crisis for their family.

Many parents and carers told us that they had stopped contacting and following up with ADHC to try to get support. This was because they considered that they hadn't received adequate support to date; it had taken too long to get any assistance; or because they heard from others that they would be unlikely to receive support. Many of these families did not appear to have sought assistance from services other than ADHC.

The need to simplify the intake, eligibility and assessment process for people with disability and their families to access specialist disability services has been known for many years.

Relevant actions and what we will do

Under the National Disability Agreement, governments have committed to developing a framework to make it easier to access disability services. Governments have also agreed to develop systems to ensure people are referred to the most appropriate disability services and supports. This includes consideration of single access points and nationally consistent assessment processes by the end of 2011.

At a state level, ADHC is developing an intake process that focuses on needs rather than on the type of disability. The ADHC and NDS *Directions for Industry Development* plan also includes work to create a consistent and streamlined intake and assessment process for accessing disability services. By 2015, it is intended that there will be 'a single intake point ('one door') for specialist disability services.'

The final report from the ADHC inquiry contains recommendations aimed at making it easier for people to get support and to navigate the disability service system. These include reducing the need for people to repeatedly confirm disability, and speeding up work to improve the intake and assessment process for disability services.

In relation to its information, referral and intake teams, ADHC has indicated that it has expanded the role of the teams to manage application processes for up to 28 of ADHC's funded programs. This means that only one referral is required, reducing the number of calls people are required to make. ADHC has also indicated that it continues to work with its staff on improving their skills.

While actions have been identified on a number of fronts, the work has been slow to date, and it is not yet clear whether the actions will address the problems raised with us by families. It is important that changes occur in the short-term to make it easier and fairer for people with disability to get the support they need, when they need it.

Against this background, we will be keen to ascertain:

- the specifics of ADHC's work plan for improving the intake and assessment process for disability services, including timeframes for completion;
- the progress of its work in relation to the national reforms; and
- whether the current and proposed actions adequately address the concerns raised by families.

2.3 Planning and delivery of disability supports

Greater case management and coordination support

Families repeatedly said that having someone to support them to access the disability service system would make a big difference in relation to getting information, support, service access and support coordination.

At various times, many families have the involvement of multiple government and non-government service providers which are attempting to meet their needs. During our consultations families told us that coordinating services and support is time consuming and difficult. We also heard that services do not always work cooperatively or communicate with each other, and parents and carers of children with disability often act as intermediaries between services.

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support, children must have delayed development in at least two areas of functioning (under the age of six years), or a significant intellectual disability and significant deficits in adaptive functioning in two or more areas (six years of age and over).

However, many families spoke in positive terms about the coordination of services in the early childhood intervention field. Participants told us that the ‘whole child’, ‘whole family’, and the overall integrated approach taken by early childhood intervention services lends itself to better coordination between the services involved. But, families consistently told us that this type of support ended once their child started school.

Families clearly value good case managers – we received a lot of positive feedback about specific ADHC workers and other case managers, particularly those who had provided good advocacy support, helpful information and guidance, and other excellent support such as referral to critical services.

Families emphasised the benefits of case management where the case manager has a good understanding of the child’s disability, support needs, the services available, and how to access them. However, we also heard that:

- Gaining access to a case manager is difficult, with some people reporting that they had waited two years for a case manager to be appointed.
- It is difficult to get continuity of service. We heard that case management is typically provided only for a short period of time and it can be sporadic due to multiple staff changes.
- The effectiveness of case management is heavily reliant on the individual case manager. Families reported negative experiences, including being provided with incorrect information and advice, and a reactive rather than a proactive approach being taken to arranging service provision. Some said that the only support they received was being given contact numbers for services.

Greater flexibility, choice, and control of services

Parents and carers from across NSW, who had children of varying ages and with diverse support needs, told us that they would like more control over how funds are used. Many families expressed the view that the way funds are managed in the current disability system is inefficient, with too many ‘middle men’ and insufficient direct care providers.

Brokerage arrangements were commonly cited as an example of inefficiency in the use of disability services funding. Families raised concerns with us about the inefficiencies and unnecessary restrictions involved in brokerage arrangements for respite and in-home support, with families prevented from contacting care workers directly and being required to go through a third party agency.

In relation to in-home support, we heard that insufficient flexibility, and limitations on what staff can do, affects the adequacy of the support provided. In this regard, families raised concerns that:

- There is not sufficient flexibility to enable personal care staff to also undertake domestic assistance tasks such as cleaning, and vice versa.
- Occupational health and safety restrictions mean that staff are not always able to lift children. This makes it difficult for families who do not have a hoist.
- The benefits of in-home support are reduced by the parent having to be present when the service is provided.
- It is hard to get changes to the amount of support provided in response to changes in the family’s circumstances, even for short periods.

Greater certainty and continuity of services

One of the critical issues raised by families about their current experience in receiving services for their children with disability is the lack of continuity of support. This was a central theme in relation to publicly-funded therapy services, but also featured in the information provided about case management and respite.

Families also expressed frustration that gaining access to a service is no guarantee that they will continue to receive it, despite ongoing need. Parents and carers raised concerns with us that ADHC provides assistance for short periods of time before closing their file, requiring them to have to reapply through intake and go on another waiting list in order to get further support.

Relevant actions and what we will do

Throughout our consultations, the government’s *Stronger Together* consultation, and the ADHC inquiry, families have consistently called for more choice and control, better coordination, and greater service continuity and flexibility.

Changing how disability supports are planned and delivered is central to the proposed reforms under the second phase of *Stronger Together*. The broad vision provides for a clear focus on person-centred approaches to planning and delivering disability services, and a commitment ‘to enable all people to determine the application of their support resources, whether or not they are using an individualised funding arrangement.’

Over the first five years of *Stronger Together*, 4,000 new case management places have been made available.[7] The second phase of *Stronger Together* includes the commitment to expand resources such as information, planning, advocacy, case management, service brokers and support coordination.[8]

On 2 June 2011, the Minister for Disability Services announced a 12-month program of over 100 consultations with people with disabilities and their carers on individualised funding arrangements. The consultations are to inform the development of a draft person-centred model for NSW.

We recognise that reforms on the scale of those outlined in *Stronger Together* will take time. However, it will be important for us to:

- obtain clear information about the proposals to improve case management and coordination support, and consider whether this work will adequately address the issues raised by families; and
- ascertain the specifics of ADHC's work plan for providing individualised funding arrangements.

2.4 Early childhood intervention and access to services afterwards

The vast majority of families we spoke with reported positive experiences with early childhood intervention services, stating that they are supportive and a great source of information. As previously noted, families spoke highly of the 'whole family, whole child' approach of early childhood intervention services, and said that they provide a sense of a team around the child.

Families also told us that they appreciate the continuity of service provision which early childhood intervention services can provide throughout their child's early years, and the transition to school programs offered by some of these services. We were also told that families continue to obtain information from early childhood intervention services, and maintain contact with their staff, long after the child has left the service.

However, parents and carers across NSW consistently reported that when children with disabilities start school, services and support markedly decline.

In particular, we heard that the services provided by the early childhood intervention service – such as therapy, information, and links to other services – are not replaced with anything when the child starts school. Families also said that coordination of services and an experienced worker to provide support and guidance are generally not provided once their child starts school.

Families also told us that there is a need for increased funding of early childhood intervention services to meet the needs of children with disabilities. We heard that demand for places exceeds supply, and parents often have to undertake fundraising activities to keep the services operating. Families in rural and regional NSW also told us that they have to travel long distances for their child to access an early childhood intervention service, due to a lack of services in their local area.

This feedback is highly consistent with concerns that have been raised by Early Childhood Intervention Australia (NSW Chapter).[9] While noting some improvements in early childhood intervention service capacity, flexibility and resources[10] as a result of *Stronger Together*, ECIA has reported that action is needed to address access inequities. These include access problems for people in rural areas; long waiting lists throughout NSW; and under-representation of families from CALD or Aboriginal backgrounds, and families with complex needs.[11]

Relevant actions and what we will do

The second phase of *Stronger Together* includes the commitment of 3,700 new early intervention packages for children and young people, and a strong focus on building a comprehensive lifespan approach into the disability service system. 'It will involve having the right interventions at each point in a person's life' including significant life stages and transition points, and 'will embed early intervention and prevention across a person's whole life.'

The increase in early intervention packages is likely to assist many families, although it is not clear at this stage where those places will be targeted, how many of the packages will be for children aged 0-6 years, or whether this will address the concerns about insufficient funding. The move to a lifespan approach may address families' concerns about the marked decline in services and support when children with disabilities reach

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[7] *Stronger Together: the second phase* (December 2010). The 4,000 new case management places encompass children and adults.

[8] Decision support resources will be expanded by $141.2 million over five years.

[9] ECIA is the peak statewide organisation promoting the interests of young children with developmental delays and disabilities and their families.

[10] ECIA has noted the development of resources specific to child and family concerns, including *Shoulder to Shoulder*; *Autism: Your child, your family* Building Foundations booklet and DVD; *Starting School* DVD; and *Raising Kids Together* DVD and booklet.

[11] ECIA (NSW Chapter) Inc submission to the ADHC inquiry, 13 August 2010; and *Right From The Start* campaign, December 2010.

school age. However, planning for the second phase of *Stronger Together* is still underway and there are limited details as to how the lifespan approach will work in practice.

In light of the importance of these issues, it will be crucial for us to assess the extent to which the proposed actions address the concerns raised by families in the early intervention and transition to school spheres.

2.5 Access to therapy services

Therapy services, including speech pathology, occupational therapy and physiotherapy, are very important for many children with disabilities. These therapy services help children to develop and maintain fundamental skills such as walking and speaking. The families in our consultations all emphasised the critical importance of receiving therapy as early as possible.

However, our consultations indicate that many families experience serious problems in relation to accessing therapy services in NSW. Families said they experience great difficulty in getting timely and affordable therapy that is provided for long enough to meet their child's needs.

Families reported extensive delays in accessing speech pathology, occupational therapy and physiotherapy from publicly funded sources – including those provided by ADHC, non-government services, and NSW Health. Families reported that delays ranged from six months to 11 years. We also heard that children typically receive a short block of therapy comprising a small number of sessions, and at the end of that block they go back to the bottom of the waiting list to receive further sessions.

Of particular concern to us were the families who indicated that they had given up trying to get therapy for their child due to the long wait to receive what they consider to be insufficient therapy for a short period of time. The consequences of not receiving necessary therapy can be considerable. Families told us that the inability to access therapy for their child when it is needed had meant more and earlier muscle contractures, delays in getting necessary aids and equipment, and delays in starting school.

Families of school-age children told us that access to public therapy services also significantly declines once a child starts school and they no longer gets access to therapy through their early childhood intervention services.[12]

Schools do not fund or provide therapy services. However, families reported positive experiences where therapists had been able to provide support in the school environment, and where there was good communication between therapists and school staff.

To meet the shortfall in publicly funded therapy, many families said that they have paid a significant amount of money for their child to access therapy through private practitioners. (They said that the cost of private therapy is substantial, even with the assistance of health insurance or the Enhanced Primary Care Scheme). Some families said that having to pay for private therapy has meant that they have had to forgo other services such as vacation care. One person said that they had to sell their home, while others had incurred high levels of debt.

Private therapy is not an option available to everyone, due to the cost and a lack of available therapists. Access to therapy was reported as a problem by families, irrespective of the age of the child, their disability, or the region in which they live. However, people reported that there are additional problems in rural and regional areas of NSW. We heard that some families in smaller centres and towns are travelling long distances to regional centres or Sydney to access therapy.

That children with disabilities cannot obtain sufficient therapy to meet their needs is of significant concern. If therapy needs are not being met, this can adversely impact on the effectiveness of other early intervention strategies, and substantially harm an individual's development potential and quality of life.

Relevant actions and what we will do

Therapy is one of the eight priority areas targeted by *Better Together*. Against the background of a worldwide shortage of therapists, the *Better Together* plan includes strategies to build up the therapist workforce in NSW; expand the ways therapy is delivered; streamline the assessment and intake procedures; develop cross-agency partnerships; and improve the way information about services is provided to clients.

Under *Better Together*, a *Therapy Services Memorandum of Understanding* (MOU) was signed in late 2010 between the Department of Family and Community Services, NSW Health and the Department of Education and Communities (DEC) to guide improvements in the delivery of therapy services to people with disability. An interdepartmental committee is overseeing the implementation of the MOU.

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[12] While some families were able to obtain therapy through an early childhood intervention service, we heard that not all early childhood intervention services are able to offer this support (particularly in rural areas), and the therapy tends to be provided to the child as part of a group rather than individually.

In March 2010, the (then) Minister for Disability Services announced the start of a four-year research project between ADHC and the University of Sydney on the effectiveness of the delivery of psychology and therapy services to people living in rural and remote NSW. This financial year, ADHC has also funded three two-year projects: an Aboriginal outreach program; an early intervention project to help children with disabilities to access technology in preschool; and an adult transition project to improve access to therapy services at critical life stages.

From 1 July 2011, children diagnosed with a vision or hearing impairment, Down syndrome, cerebral palsy or Fragile X syndrome will have access to funding and Medicare rebates under the Commonwealth Government's *Better Start* initiative to support access to services such as therapy.[13] *Better Start* is an extension of the *Helping Children with Autism* initiative, which was introduced in July 2008.

Better Together was a four-year plan that ended in March 2011. The plan for the second phase of *Stronger Together* states that the NSW Government will develop an implementation plan for the National Disability Strategy that will go across all NSW Government agencies and replace *Better Together*.

Given the critical importance of timely and sufficient therapy for children with disabilities, we will seek detailed advice from the relevant agencies about the progress of stated actions to improve access to therapy services.

We note that the NSW implementation plan for the National Disability Strategy, and its associated interagency work, may address many of the concerns raised by families in our consultations. We will be keen to ascertain the details of the implementation plan, including the strategies for monitoring and evaluating the work.

2.6 Respite

Following consultation in March 2010, ADHC outlined its planned respite reform agenda.[14] In the main, the information provided to us by families mirrors the key messages arising from ADHC's consultation, including the need to:

- improve the information available to families about what types of respite are available and how to obtain it, as well as information about their respite funding;
- provide access to reliable respite when needed;
- simplify the application and assessment process, with less paperwork and repetition;
- provide families with more choice and greater control over their respite funding – including the type of respite that is provided, where, when, and with which service and staff;
- provide greater flexibility and responsiveness to meet the changing needs of people with disability and their families;
- provide sibling respite and support programs, and respite to children with disability under seven years of age;
- improve the skills, availability and continuity of the respite workforce; and
- provide services to support the needs of working families, including greater access to out of school hours and vacation care.

Families in the ADHC Metro North region of Sydney also raised specific concerns about the respite intake and allocation process that has been established in that region.[15] Some services in the region reportedly allocate respite for a financial year at a time, and to access these services families are required to apply to the intake program very early in the year.

Parents and carers raised concerns about the lack of flexibility in that arrangement, particularly for families who miss the deadline due to a lack of information, a recent move to the area or for other reasons. We heard that missing the application deadline means that families miss out on respite for the year as there does not appear to be a reserve allocation of respite places.

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[13] Under *Better Start*, early intervention funding of up to $12,000 will be available to eligible children under six years of age, and able to be used for services such as therapy up until the child turns seven. Medicare rebates are available for up to four allied health diagnostic services and for up to 20 relevant allied health treatment services for eligible children up to the age of 15 (provided a treatment and management plan is in place before the age of 13).

[14] ADHC (March 2010) *New directions for disability respite services in NSW*

[15] The Respite Intake and Allocation Process (RIAP) is a centralised contact point to take referrals for flexible respite, and is coordinated by various respite services in the Metro North region.

In relation to the Metro North intake and allocation process, families also raised concerns about the lack of flexibility to meet families' changing needs. Parents and carers told us that, under the process, they do not get a choice of service provider, and they are not able to change providers during the year, even where the allocated provider is not able to meet the family's changed needs. We also heard that there is no flexibility to request additional support during the year if the family's circumstances change.

Relevant actions and what we will do

ADHC's respite reform agenda is extensive, with a focus on responding to need; giving individuals greater control and choice in the services they receive; streamlining access to services; and increasing the capacity of the service system. ADHC has indicated that it:

- has piloted the implementation of a new Project Officer position in each region to support the coordination of intake assessment and allocation to all ADHC funded flexible respite services;
- has started to develop respite services to meet needs, such as at key transition points, and will monitor the effectiveness of these services;
- will develop interest based and recreational respite programs;
- will undertake work to better understand the issues and develop a policy position for the provision of transport to respite;
- is expanding Teen Time[16] across the state, and will explore options to respond to the needs of working carers between 3pm and 7pm weekdays;
- will develop standardised assessment tools and an online booking system for all ADHC operated centre-based respite services; and
- will 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.

If successfully implemented, ADHC's respite reform agenda may address many of the concerns raised by families. However, it will be important for us to obtain direct evidence as to the actual impact of these proposed reforms. We will also be keen to discuss with ADHC the particular issues raised by families about the operation of the respite intake and allocation process in its Metro North region.

2.7 Aids, equipment and modifications

The majority of those who indicated that they had sought and/or obtained equipment for their child in recent years had applied to EnableNSW (PADP[17]).

In recent years, there have been a number of reviews or inquiries into PADP, including a review of the program by PricewaterhouseCoopers in 2006; an audit by Oakton in 2007 of each PADP lodgement centre; and a NSW Legislative Council Inquiry into the program in 2008.

This work found that PADP had an unacceptably high level of inconsistency across the program (including variation in the quality of service delivery and in relation to compliance with operational guidelines between lodgement centres), and long waiting times for provision of equipment.

The information provided by families to us during our consultations is consistent with the key issues identified in these previous reviews and inquiry. Families said that they need:

- **A simpler process for obtaining equipment.** We heard that the application process for equipment through EnableNSW is protracted, involving the submission of multiple reports and quotes in order to obtain approval before the equipment can be ordered.
- **Faster access to necessary aids and equipment.** Families told us that the waiting times for aids and equipment – from assessment to application; from application to approval; and from approval to receipt of the equipment – can take up to two years, depending on the type of equipment. Parents and carers told us that the negative effects of delays in obtaining appropriate aids and equipment can be significant. These include delays in children starting school, decline in children's health and reduced independence.

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[16] *Teen Time*, After School and Vacation Support for Working Parents, is a *Stronger Together* respite initiative that has been developed in response to findings that parents of children with disability are more likely to be financially disadvantaged. The program focuses on supporting parents and carers to gain and maintain work or study commitments.

[17] Program of Appliances for Disabled People

- **Greater options for loaning equipment.** We heard that the delays in obtaining equipment make it difficult to keep pace with the changing needs of children with disabilities as they grow up, but there are few options to loan or hire appropriate equipment while waiting. In particular, we heard that families are not able to hire communication equipment.
- **Consistent application of requirements.** Many families said that they had been told by NSW Health that the equipment their child needs – such as a standing frame or a communication aid – is not on the EnableNSW equipment list. Consequently, they have had to pay the full cost themselves or try to manage without the aid. However, we found that the stated equipment is actually on the list of approved equipment, and other families reported to us that they had successfully obtained these items through EnableNSW.

  Similarly, some families reported that EnableNSW does not cover repairs or servicing of equipment that has been provided. This is not consistent with the current guidelines.
- **Faster access to home modifications.** We heard that the waiting time for home modifications can be long, with delays in obtaining an assessment, followed by a further wait for the modifications to be done. Families reported waiting times of two to four years from assessment to completion of the work.
- **Assistance to modify vehicles.** We heard that the cost of modifying a car to make it wheelchair accessible is prohibitive, and there is no assistance for families in this regard.

Relevant actions and what we will do

Since 2008, and in response to the previous inquiries, NSW Health has been undertaking significant reform of its disability support programs relating to the provision of aids and equipment. The action that has been taken is aimed at addressing many of the concerns that have been raised repeatedly by people with disabilities and their families.

In addition to the centralisation of PADP services into a single statewide service – EnableNSW – action includes the development of key performance indicators for the provision of timely information about the status of a client's application; processing time for applications; and waiting times for the supply of equipment; and streamlining the application process to simplify access to aids and equipment.

In response to our draft report, NSW Health told us that following completion of the transition to EnableNSW in mid-December 2010, there have been significant improvements in access to aids and equipment, including:

- Significant decreases in waiting times across all equipment types and priorities. NSW Health reports that wait times for equipment have halved, and on average are between three and nine months depending on priority. We were told that there is currently no wait for continence assistance and no wait for the Prosthetic Limb Service.
- Consistent application of policy and guidelines, with the development of prescription and provision guidelines for the majority of equipment types. NSW Health has advised that these guidelines specify eligibility criteria for equipment devices, provide prompts regarding sound prescription and documentation practice, and provide a basis for consistent, transparent decision making.
- Improved communication to consumers and prescribers to keep them up to date regarding the progress of an equipment request.

NSW Health also advised that EnableNSW has been piloting a Children's Equipment Pool for 12 months. The pool provides specialist mobility and self-care equipment for children below six years of age, and aims to provide quick access to equipment such as strollers, wheelchairs and bathing equipment. EnableNSW is currently investigating wider implementation of the pool.

Improving access to aids and equipment is also one of the key priority areas of the National Disability Agreement, with the stated aim of delivering 'more consistent access to aids and equipment by the end of 2012.' In June 2010, the Disability Ministers agreed to establish a nationally consistent list of core equipment by December 2010; improve the portability of core equipment across state borders; improve the supply of equipment; review current subsidy and co-contribution arrangements; and improve assessment and prescription processes.

In relation to modification of vehicles, this issue was also raised in the 2008 Legislative Council Inquiry. The inquiry's final report recommended the implementation of a vehicle modification subsidy scheme for people with disability. The (then) NSW Government did not support the recommendation, noting that it funds various forms of targeted transport assistance for people with disability, including taxi vouchers, concessions and community transport services. However, the Government also indicated that it would consider 'establishing a cross-agency working group to investigate possible options that would better meet the broad range of needs of individuals and families for transport assistance in the future.'

The problems associated with obtaining home modifications that were highlighted by families during our consultations for this piece of work echoed feedback provided to us by Aboriginal people in 2008-09.[18] In a special report to Parliament in September 2010, we identified problems relating to a lack of understanding about eligibility for home modifications, the process for obtaining them and who is responsible for providing them; lengthy delays in obtaining occupational therapy assessments and home modifications; and confusion about whether clients must contribute to the cost of home modifications and if so, how much.

An independent review of Home and Community Care (HACC) home modification services[19] in NSW has been underway since July 2010, with the aim of improving the effectiveness, efficiency and equity of service delivery by developing an improved service model.

We are pleased to note the reported improvements that have occurred in the provision of aids and equipment in the last six months. We note that an EnableNSW Advisory Council has been established, and that one aspect of its role includes monitoring EnableNSW's performance in relation to major initiatives and annual performance targets based on key performance indicators.

It will be important for us to monitor the progress of relevant work under the National Disability Agreement, and to seek information from ADHC about the outcomes of the HACC home modifications review, in order to ascertain whether this work will address the concerns raised by families in our consultations.

We will also make inquiries to ascertain whether action has been taken to establish a cross-agency working group to look at options for transport assistance, as proposed by the (then) government in response to issues raised in the 2008 inquiry.

2.8 Access to mainstream services

We heard that some mainstream services provide excellent support to children with disabilities, but we also heard many examples of problems families experienced in trying to gain access to mainstream services for their child. These problems included difficulties in gaining access to certain preschools and schools.

From the information provided, it appears that even with inclusion and support funding and anti-discrimination legislation and requirements, children with disabilities still experience difficulty obtaining consistently fair access to mainstream services. Parents told us that, in their experience, the critical factor in whether a child with disability will be accepted into a mainstream service is the attitude of the staff.

Issues relating to schools are discussed in the next section. In relation to children's services, families reported largely positive contact. We heard of services that have 'bent over backwards' to provide support; for example, undertaking evening training of staff in PEG feeding. Several parents also spoke positively of in-home child care services. We were told these suited families where children with disabilities could not access centre-based child care.

However, other parents told us that they had to shop around to find a children's service willing to accept their child. According to some parents, non-acceptance of their child related to concerns about perceived risks associated with their behaviour. In other cases, it appeared to relate only to the fact that the child had special needs.

Parents in different regions raised concerns about their children only being allowed to attend the children's service for short periods – such as two half days or two hours per day – while children without additional support needs had no such restriction. Parents said that this was not reasonable given their understanding that the services were receiving funding for full days in addition to the inclusion subsidy.[20]

Families also reported that some mainstream out of school hours and vacation care services provide only restricted access for children with disabilities, despite receiving support funding.

Relevant actions and what we will do

The ADHC and NDS *Directions for Industry Development* report includes strategies aimed at building inclusive communities with the capacity to support people with disability and their families, and for working with mainstream services to respond to the needs of people with disability.

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[18] NSW Ombudsman (September 2010) Improving service delivery to Aboriginal people with a disability

[19] HACC funding in NSW is administered by ADHC.

[20] The Commonwealth Department of Education, Employment and Workplace Relations funds an Inclusion Support Subsidy, which is paid to child care services to support the inclusion of a child/ children with ongoing high support needs. The NSW Government funds the Supporting Children with Additional Needs (SCAN) program, which includes a contribution for Community Services' funded preschool, vacation care and occasional child care services to increase their capacity to include children with additional support needs.

The lifespan approach outlined in the plan for the second phase of *Stronger Together* includes a focus during the pre-school years on early detection and outreach to families to ‘assist mainstream services to provide therapeutic and inclusive environments for children.’

Currently, there is insufficient detail about related initiatives to enable us to assess whether the concerns raised by families about access to mainstream services will be appropriately addressed. In these circumstances, we will need to seek ongoing advice from key agencies about their initiatives to promote fair and equitable access of children with disabilities to mainstream out of school hours, vacation care, and children’s services. In addition, it will be critical to obtain evidence of any outcomes achieved from new initiatives.

2.9 Support for students with disabilities

Many of the families that we consulted who had school-aged children raised concerns about the adequacy of support for their child in school. It is important to note that the information provided by families related to all school sectors (government, Catholic and independent), and both mainstream and special schools. The issues raised by families and carers in our consultations were consistent across school sectors and regions.

Support during transition

Parents said that they find choosing a school suited to their child’s needs a daunting task, often undertaken without professional guidance. People who have had access to transition to school programs run by either government agencies or early childhood intervention services spoke positively about their experience. They said that the experience is more likely to be positive where the transition process starts early, the family has support, and the school is flexible.

However, we heard that:

- Families were not always aware of transition to school programs or able to gain a place in such a program for their child.
- There needs to be greater recognition by schools of the longer period of planned transition required by many children with disabilities between early childhood intervention services and school, and between primary and secondary school.
- The transition process would be improved by the provision of more timely advice by education authorities regarding acceptance into nominated schools. Parents and carers told us that they were not advised about where their child would be attending school until the last moment, making it difficult to adequately prepare.

Adequacy of support at school

Families raised concerns about the amount of support available and provided in primary and secondary schools to children with disabilities, indicating that it is often insufficient to meet their needs. Parents repeatedly told us that they have had to ‘fight’ for adequate support to be provided in-class. Some parents said that they are paying up to $2,000 per term for their child to have extra in-class support.

Families also told us that their children would benefit from greater flexibility in how funding is used to support students with disabilities.

Inclusion is not consistent across schools

From our consultations with families it is evident that there are considerable differences between individual schools as to the support they provide to students with disabilities. Families reported a number of inconsistencies or differences in the support provided by, and the flexibility of, individual schools. This included decisions as to whether a child could do a gradual transition into school, and whether the child’s therapy providers could provide support within the school.

Families said that the quality and adequacy of the support provided to students with disabilities hinges largely on the attitude of individual principals and teachers. We were provided with numerous examples of parents moving their child from one government, Catholic or independent school to another and having markedly different experiences and receiving quite different levels of support, even though the child’s support needs had not changed.

Families told us that the quality of the support provided hinges on whether school staff understand what inclusion means and put it into practice.

School transport

The Department of Education and Communities administers the Assisted School Travel Program (formerly the School Student Special Transport Scheme). The program provides transport assistance to eligible students with disabilities to access educational services in government and non-government schools with a maximum of two trips per day.[21]

Families and carers told us that, in their experience, there is a need to ensure that:

- Assisted School Travel Program drivers have a good awareness and understanding of children with disability;
- The screening process for drivers is rigorous, given the vulnerability of the children accessing the program; and
- The program is flexible to meet the needs of families. We heard that the program provides a valuable service that is appreciated by families, but it is not always flexible enough to meet their needs. In this regard, some parents and carers told us about the difficulty they had experienced in trying to get variations to the transport route – to shorten the travel time for the child, or to encompass respite services instead of the home address.

Relevant actions and what we will do

In November 2009, the NSW Legislative Council General Purpose Standing Committee Number 2 commenced an inquiry into the provision of education to students with a disability or special needs. The final inquiry report, issued in July 2010, made 31 recommendations to address the inadequacies reported by parents, teachers and other stakeholders.

In its response in late January 2011, the (then) Government indicated a range of actions underway to improve education services for students with disability in NSW government schools, including:

- development and implementation of a functional assessment tool to improve information about the support needs of students with disability and inform actions to meet their teaching and learning needs;
- implementation of the *School Learning Support Program*[22] to improve access to extra help for students with additional learning needs who require it;
- online learning courses to support regular classroom teachers and other education personnel;
- development and publication of additional resources to support learning support teams;
- development, in partnership with the Children's Hospital at Westmead, of a web-based resource to provide guidance for schools in supporting students with medical, developmental and psychological conditions; and
- development and implementation of protocols to support assessment and placement processes, including guidance for communicating the outcomes of decisions with parents and carers.

In relation to therapy services in schools, the (then) Government's response referred to the interagency memorandum of understanding (MoU) developed under *Better Together*. It also stated that DEC and ADHC are 'currently examining data about disability therapy service provision in schools in order to inform the development of specific strategies to strengthen the delivery of therapy services to support education outcomes for school students.'[23]

In 2011, in collaboration with Northcott Disability Services and Cerebral Palsy Alliance,[24] DEC will strengthen the provision of specialist technology services for students with disability who have additional communication or mobility support needs. This will include school-based work to demonstrate best practice in collaborative assessment and intervention.

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[21] To be eligible for the assistance, students must have an identified disability that meets DET's disability criteria, be enrolled in the closest appropriate school to their home, and be a permanent resident of NSW. The student's parent or carer must also demonstrate in writing their inability to provide or arrange travel for the student either fully or in part.

[22] The *School Learning Support Program* is currently being trialled in the Illawarra and South East region. It aims to provide more immediate support for students and their classroom teachers by allocating resources directly to each school, including the allocation of specialist learning support teachers. Schools use the resources to support students according to local needs and priorities, identified through the school learning support team.

[23] NSW Government (27 January 2011) Response to the Legislative Council Inquiry into the Provision of Education to Students with a Disability or Special Needs, p23

[24] Cerebral Palsy Alliance was formerly known as The Spastic Centre.

There is significant work underway and planned by DEC to improve support to students with disabilities, and the actions outlined by DEC are relevant to many of the concerns raised by families. There are two issues that were raised by families in our consultations that do not appear to be covered in the recent inquiry report and government response: the Assisted School Travel Program; and differences in support across schools.

Against this background, we will pursue with DEC whether, and how, it monitors:

- individual schools' application of DEC policies and their practice in promoting inclusion and meeting the needs of students with disability; and
- support provided under the Assisted School Travel Program.

3. Conclusion

There have been significant changes in the disability service system since our last report on services and support for children with disability and their families in 2006. *Stronger Together* heralds large-scale reform of the system to deliver greater and improved disability support, delivered in ways that meet the needs of individuals with disability.

What is clear from our consultations with families of children with disabilities is that, while there have been some improvements, there is still a long way to go. There are fundamental issues that need to be addressed in order to see real improvement in the support provided to families. We note that not all of the issues relate to the adequacy of funding per se. Instead, they are about:

- making it easier for families to obtain clear and helpful information and navigate the service system;
- reducing unnecessary bureaucracy and inefficiencies;
- giving people with disability and their families greater choice and control over their supports;
- improving the coordination of services and cross-agency, multidisciplinary cooperation; and
- improving inclusion of children with disabilities in the broader service system.

In the main, these issues have been identified in the proposed reforms under the second phase of *Stronger Together*, other state and national plans, and the recommendations from recent inquiries. However, what will need to be tested is whether these issues are effectively addressed in practice.

Bruce Barbour
Ombudsman

Steve Kinmond
Deputy Ombudsman
Community and Disability Services Commissioner