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The Director  
Standing Committee on Social Issues  
Parliament House  
Macquarie St  
Sydney NSW 2000

Dear Sir/ Madam

**Inquiry into services provided or funded by the Department of Ageing,  
Disability and Home Care (ADHC)**

We refer to our submission to the Inquiry of 16 August 2010. In the submission, we included reference to consultations we were undertaking with families of children with disabilities about access to services and supports. This further submission is to provide initial information from those consultations, relevant to the terms of reference of the Inquiry.

**Background**

Over 72,000 children and young people living in NSW have a disability. Most of these children live in the community with their families, and many of these families rely on the services and support provided by government and funded agencies to help meet the needs of their child.

For many years, this office has had a particular interest in the provision of services and support to children and young people with disabilities and their families. In 2004, in a special report to Parliament, we described our concerns about the way services to children and young people with disabilities were being provided in NSW. In 2006, we reported to Parliament on the progress of ADHC in addressing the deficiencies identified in our 2004 special report. We provided copies of both reports to the Standing Committee with our submission of 16 August 2010.

Against this background and the approaching mid-way point of *Stronger Together*, the NSW Government's 10-year plan to improve and expand services to people with disabilities and their families, we decided to undertake consultations with families of children with disabilities.

Between June and August 2010, we talked with over 300 parents and carers of children with disabilities. The focus of our discussions was their recent experience in seeking and obtaining services and support; and whether the type and amount of support provided met the needs of their children and their families as a whole. We also asked about people's experiences in accessing universal services such as child care, before and after school care, and vacation care.

We are undertaking a detailed analysis of the information from the consultations, and intend to produce a public report from that work later this year. In the interim, we consider that it is important to communicate the key messages emerging from our consultations to inform the Inquiry, and the Minister for Disability Services' consultations regarding *Stronger Together*.

With regard to the latter, we note that many of the issues raised by families during our consultations mirror many of the key themes that have emerged from the Minister for Disability Services' consultations for the next phase of *Stronger Together*. In particular, initial information from our consultations reinforces:

- the need for a person-centred and flexible approach to delivering services and support;
- the importance of early intervention and prevention;
- the need to simplify programs, application and intake processes, and improve access to information;
- the importance of increasing the capacity, availability, and quality of services to support children with disabilities and their families; and
- the need for children with disabilities to have access to, and be appropriately supported by, mainstream services.

## **Key themes emerging from the consultations**

### **The importance of disability support**

Overall, our contact with the many parents and carers who volunteered to share their stories with us reinforced 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 as a whole.

Almost half of the people we engaged with reported that they receive no practical support from family, friends, or other people in their community, in caring for their child.

Many of the people we spoke with described caring for a child with a disability as an experience that has enriched their lives. However, families also strongly communicated the significant impact on their health and wellbeing, and on that of their families. Financial stress, family breakdown, social isolation, and carer health problems were commonly reported.

Many told us that they struggle to achieve the best outcomes for their child and family in a service system that they often experience as complex and somewhat inflexible.

### **Access to early diagnosis and support**

Families emphasised the significance of obtaining a diagnosis at an early point. We heard that a diagnosis is a starting point for many things: to come to terms with their situation; to start the process of understanding their child's disability; and to begin thinking about the future. Families also said that a diagnosis tended to provide them with a gateway to services.

We heard from families about the value of being provided with support at the time that diagnosis occurs. In particular, families referred to the benefits of having access to an identified person to provide emotional support; information about their child's disability and their likely needs; and advice about, and links to, existing and appropriate services. However, few families we consulted indicated that they had had access to such a person to provide them with these kinds of supports.

A new initiative under *Stronger Together*, and provided by ADHC, is the Early Start Diagnosis Support Program – designed to support parents at the time their child is diagnosed with a disability, and to develop a more connected system of supports across universal and disability services. Our consultations reinforce the need for this type of program.

We heard from families that they are not always able to obtain an early diagnosis of their child's disability, and that this can have significant implications for obtaining information and services. Families told us about diagnosis being delayed by not being able to access an assessment service due to factors such as distance, cost, and the availability of professionals able to undertake a thorough assessment. We heard from some families that delayed assessment and diagnosis meant that their children missed out on early intervention services.

### **Need for information and help to access services**

We heard clearly in our consultations that access to comprehensive and timely information about existing services for children with disabilities and their families is critical. This includes information about what types of services and supports are available; the eligibility criteria; and how to access services.

Many people told us that identifying what services are available, and establishing whether their child is eligible for these, continues to be a real problem, regardless of the age of the child. We heard that families currently experience considerable difficulty in trying to find relevant and clear information, including from Ageing, Disability and Home Care (ADHC).

Some families were not aware of ADHC or its role. Others told us that obtaining clear and simple information from the agency's website about the available support for children with disabilities and their families is difficult, and it is not obvious from the website what services ADHC provides or to whom.

We heard that the disability services system continues to be difficult to navigate, and it is reliant on families to do the leg work. Many people spoke of the experience of being given a list of telephone numbers for services, but not really understanding the services provided or how they fitted together. In the absence of practical support, most said it was left to them to determine how to start accessing services and support for their child. Many said that they found this daunting. Many families reported that it was only by chance or luck that they found out about useful services.

Our consultations with parents indicate that families caring for children with disabilities would benefit from more streamlined information, intake, and referral systems across the specialist disability services sector. People consistently indicated that the process of obtaining information and navigating the system would be improved by:

- having a one-stop shop and a 'no wrong door' approach, irrespective of whether the child is eligible for ADHC-provided or ADHC-funded services;
- having an identified person to provide assistance with information, coordination of support and links to services;
- only having to provide information once, or on a minimum number of occasions, and having that information able to be shared among relevant agencies;
- obtaining access to advice about the range of possible support options rather than families having to formulate the kind of support options that they need in the absence of an understanding of the disability service system; and
- increased responsiveness to requests for assistance.

## **Services are valued but more is needed**

### **Early childhood intervention**

Early childhood intervention services are provided to children who have developmental delays or disabilities from birth to school entry. The services provided include therapy, education, health services, family support, and the provision of information and support for transition into the school system.

To date, *Stronger Together* has provided additional funding for the early childhood intervention sector. This has resulted in an increase in capacity in some areas. Based on our consultations, families value these services; however, access is again an issue.

Many families spoke very highly of the benefits they and their children have gained through the provision of early childhood intervention services. Parents also spoke highly of the casework support provided by early intervention workers, including help to navigate the disability system, and information about available services.

Families told us that they value the social opportunities provided for their children through playgroup sessions, and the formal and informal support provided to parents. They also told us that they appreciate the consistency of service provision over a number of years, and the transition to school programs offered in some services.

At the same time, a number of families told us that it was only by chance that they found out about the existence of early childhood intervention services. We heard that they had not known about such services until being told by friends or discovering them via the internet.

Many families pointed to the need for increased funding of early childhood intervention services to meet the needs of children with disabilities. In this regard, we heard about children being unable to access these services due to a lack of vacancies or no service in the local regional area; and the provision of group therapy rather than individual therapy due to the demand for services.

### **Therapy**

Access to therapy services was raised as a concern more broadly by families. In particular, we heard about the difficulty in obtaining access to ADHC therapy services, with families reporting long waiting lists and time-limited assistance. In some cases, parents reported that they were accessing private therapy services, but this was not always available, particularly in regional or rural areas.

### **Home and Community Care (HACC)**

Families accessing HACC services, such as personal care, housekeeping and respite, reported the benefits of this assistance, including providing parents with more time to spend with their children. However, families told us that these services can be difficult to access, due to the high levels of demand.

### **Out of school hours and vacation care**

In relation to out of school hours and vacation care, many parents praised the Teen Time program, funded by ADHC. We heard that the program is appreciated by both parents and the young people who attend, however the cost can be difficult for some families, and the program is not available in all areas.

### **Case management**

In our consultations, families pointed to the need to have a person who could provide information and guidance as to what services and supports are needed and available; link them in to appropriate and local services; and provide a human point of contact with the disability service system.

Families stressed the critically important link to services and support which case managers can provide. In addition, in some cases people cannot obtain access to services without a case manager. For example, families told us that the Family Assistance Fund, introduced as part of *Stronger Together*, is valuable, enabling them to buy items such as equipment for occupational therapy. However, to access the funds, families are required to have a case manager.

Despite the importance of this role, many families told us that case management can be difficult to access, even when the child is eligible and the family states that they are in need of assistance. In relation to ADHC, families also raised concerns that case management is provided for short periods only, and changes in personnel can mean that it is difficult to obtain a consistent case manager.

### **Respite**

Many families told us that they rely on respite as their only opportunity to do regular family activities, such as taking children to sport, doing the shopping, or having a much-needed rest. The families we spoke with were grateful for the respite they receive, and told us that it provides critical support, particularly when provided in a flexible way to meet the needs of their family.

Families also told us that high demand for respite means that the amount provided does not always meet their needs, and the options for when it can be used, and how, can be somewhat restrictive. We heard that respite services are vulnerable to being reduced or cancelled due to the high level of demand, and families spoke of the distress that can result in these circumstances.

Carers told us that the application and assessment process needs to be simplified so that it is less onerous. We heard that multiple applications and assessments are often required, and the time it takes to complete the application paperwork is substantial.

Families told us that transport is a factor that needs to be considered in relation to respite, particularly in regional and rural NSW. We heard that transport to and from respite is often not provided, or the hours for transport are otherwise deducted from the total respite allocation.

Cost was an issue raised by a number of families. In particular, families noted that costs vary considerably, and higher costs can reduce the amount of respite to such an extent that it does not meet their needs.

### **Access to aids and equipment**

For many children with disabilities, having appropriate aids and equipment is critical to enable them to do regular activities, such as move around, attend school, and access the community. Enable NSW is responsible for administering the NSW Health disability support programs relating to aids and equipment. For some people with disabilities, ADHC plays a role in relation to aids and equipment through case management, occupational therapy assessment, and referral.

Families reported that the primary issue affecting access to necessary aids and equipment is the extensive waiting times – from assessment to application; from application to approval; and from approval to receipt of the equipment. We heard that the time between assessment and receipt of the equipment can take up to two years, depending on the type of equipment. Families pointed to the adverse effects on their children of delays in obtaining appropriate aids and equipment, including delays in starting school, decline in health, and reduced independence.

We were told that the administrative processes involved in obtaining aids and equipment are lengthy, often due to the number of parties that may be involved in the process, including ADHC, area health services, and Enable NSW. We note that, for some children with disabilities, numerous applications have to be made to meet their changing needs as they grow, and in circumstances where multiple aids are required.

### **Access to mainstream services**

Our consultations indicated that families value their children being able to access mainstream services, such as childcare, school, out of school hours care, and vacation care.

In relation to mainstream childcare services, families reported positive experiences where the service had been open to learning about the child's support needs, and were working cooperatively with other service providers, such as therapists. However, we heard that families often have to shop-around to find a mainstream childcare service willing to take their child.

Families told us that inclusion support funding helps to facilitate access of children with disabilities to mainstream childcare services, but the funds are not always sufficient to meet the child's needs. We heard that this often means reduced hours of access to the service.

Parents communicated that they find choosing a school suited to their child's needs a daunting task, often undertaken without professional guidance. Where accessed, people praised transition to school programs run by government agencies or by early childhood intervention services. However, many families were not aware of these programs, had not accessed them, or had been unable to gain a place for their child.

Families also told us that transition of children with disabilities from primary to high school can be difficult, and is often complicated by delayed transition planning, and the length of time it can take to organise appropriate support.

Many families raised concerns about the adequacy of the support provided in mainstream classes in primary and secondary schools to meet the needs of their children with disabilities, and to enable them to have full integration in school life.

In relation to out of school hours care services, families told us that it can be difficult for children with disabilities to get access to mainstream services, and reported concerns about the lack of disability knowledge and training of staff.

Overall, the initial information from our consultations indicates that families with children with disabilities value the disability services and supports that are available, including new programs established under *Stronger Together*. It is clear that these services are critical to enable families to stay together, and that key improvements are needed to ensure that the support that is available and provided meets the needs of the child with a disability and their family.

Families strongly communicated the need for fundamental reforms to make it easier and faster for them to obtain the necessary information and services, as early as possible. From our consultations, it is clear that there is a need for ADHC to continue and build on the work that has been done to date under *Stronger Together* in relation to children with disabilities and their families, including increasing service capacity, flexibility, and responsiveness.

If you have any questions or would like further information, please contact Kathryn McKenzie, Principal Projects Officer, Disability, on 9286 0984 or email [kmckenzie@ombo.nsw.gov.au](mailto:kmckenzie@ombo.nsw.gov.au).

Yours sincerely



Bruce Barbour  
**Ombudsman**



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**Deputy Ombudsman**  
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