

Tabled 30/1/13  
Bisbee 9-24.

## PRESENTATION TO THE INQUIRY INTO THE NATIONAL DISABILITY INSURANCE SCHEME BILL 2012

### MontroseAccess

MontroseAccess was established in 1933 as The Queensland Society for Crippled Children in response to the worldwide poliomyelitis epidemic. Today the organisation is a family orientated service provider to over 600 clients with a large range of predominantly physical disabilities. Our clients ages range from infant to young adult.

The range of disabilities within our client base is diverse, with multiple disabilities being treated. Many of these disabilities are extremely rare and the client would not receive service if not for MontroseAccess.

### Market based options

#### **Option 1**

Limits clients choices by restricting the entry of new services providers into the market

#### **Option 2**

Limiting choice to providers that meet specified regulatory standards would safeguard the quality of services provided while still protecting freedom of choice. However the administration of the regulations could prove cumbersome and expensive.

#### **Option 3**

Providing unrestricted choice except for higher risk circumstances and the cognitive capacity of the consumer appears to provide the best option of a range of choice with in-built protection.

#### **Option 4**

With no restrictions on choice and no regulatory protection, this option could result in a low cost, and low quality service model which would not be in the long term interest of participants.

### Eligibility and assessment

The eligibility provisions require that a person's impairment results in substantially reduced functional capacity affecting their communication, social interaction, learning, mobility, self care or self management. While this may appear to be a comprehensive definition of eligibility I am concerned that such criteria may inadvertently preclude

individuals currently covered under existing current funding programs who may require non continuous services due to the nature of the disability e.g. juvenile rheumatoid arthritis.

Assessment of prospective participants must be able to be conducted in as expedient fashion as possible and to be effective has to be conducted by persons conversant with the nature of the disability as well as the objects of the NDIS. We have recently experienced a government introduced assessment and referral system, which rather than streamlining existing procedures, led to lengthy delays thereby impacting on clients and families.

Any assessment and referral system must be proficient and consistent in its approach so that participants have confidence in the NDIS from the very beginning.

References are made in the draft bill to people with a disability who are not participants in the NDIS. Clarification is needed in relation to this population. Many of these individuals would currently be receiving services under existing Government funded programs and any uncertainty over future funding eligibility needs to be clarified.

### **Registered plan manager**

Although the underlying premise is the provision of choice to participants, a percentage will find the choice making exercise challenging and off-putting. Such individuals would benefit from the assistance of a plan manager.

If the provision of plans is to be undertaken by non-government organisations then registration of such providers would provide some protection to participants.

If a service provider was to also undertake the role of plan manager, there could be a conflict of interest in that optimum advice may not be given to the participant if such advice was to suggest the participant should receive service from another organisation.

For this reason the roles of planned management provider and service provider should be kept at arms length to ensure transparency of advice.

### **Pricing**

Pricing is always a contentious issue, however care needs to be taken to ensure that the pricing model adopted does not reflect a short term cost model as this will result in a short term solution but create longer term problems for participants and therefore Government.

If the pricing mechanism accurately reflects cost of service then choice for participants will increase as new service providers will have the confidence to enter the market. As well as freedom of entry to the market it is also important that the ability to exit the market is not artificially impeded, as this will increase costs.

### **Early Intervention**

As a member of the Childrens Not-For-Profit Group (CNFPG) the issue of early intervention is very important. The CNFPG has made a submission to the Senate Standing Committee

and set out below are comments on functional capacity, defining what may be funded and decision making by children.

### **Early Intervention functional capacity**

Section 25 (c) states:

- (c) the CEO is satisfied that the provision of early intervention supports for the person is likely to:
  - (i) mitigate, alleviate or prevent the deterioration of the functional capacity of the person to undertake communication, social interaction, learning, mobility, self-care or self-management;

This assumes there is existing functional capacity, which may exclude some babies and young children who haven't had the chance to develop functional capacity. This clause should also include provision to build functional capacity, if this is not already demonstrated.

### **Early Intervention/defining what may be funded**

Evidence-based or the slightly more flexible evidence-informed early intervention supports are likely to form the foundation of defining what types of early intervention the NDIS will fund.

However, this should be balanced against the ability to access therapies which do not have a clinical evidence base but which have enough anecdotal evidence either in Australia or overseas to indicate their potential to benefit the child or adult with disability, and their inability to harm.

There should be recognition of the need to fund use of non evidence-based therapy within a outcomes-based early intervention program. Existing, evidence-based therapies required widespread use, assessment, review of anecdotal evidence and clinical review to be classified as 'evidence-based'. A possible indicator of whether a therapy is "in or out" could be whether it is recognised in the schedule of reputable health funds, while still not being classified as medically proven evidence-based therapy, for example acupuncture.

The NDIS could as part of its research function track and review outcomes of non-evidence-based therapies used by participants in the Scheme and make the research available to suppliers of therapies and potential NDIS users. This would align with the following clause:

- (14) Innovation, quality, continuous improvement, contemporary best practice and effectiveness in the provision of supports to people with disability are to be promoted.

### **Early Intervention Decision-making by children**

Section 74 (5) appears to provide power to act according to the wishes of the child but contrary to the wishes of the parent. The CEO may impose obligations on the parent to help achieve a plan which they did not approve. If the CEO can over-ride parental responsibility, it

does not seem fair or appropriate for the CEO to also determine how much support it is reasonable to expect a family to provide. The effects of this clause need to be considered in conjunction with Section 34 (d).

the funding or provision of the support takes account of what it is reasonable to expect families, carers, informal networks and the community to provide;

Children who demonstrate capability to make some decisions for themselves and could and should play an active role in developing their plan and choosing their supports. This is not necessarily based on the age of the child but on the maturity, natural supports and capacity for unobtrusive review.

Striking a balance in this situation is of importance naturally to children with disability and their families, but also to service providers who specialise in family-focused, child-centred supports.

There should be flexibility so that:-

- Balance is given to the needs of the child and parent, where the parents are expected to/are willing to carry out support
- The child is considered within the context of the natural family unit that he/she lives in, not an idealised structure. The needs of the child with disability should not supercede nor be subsumed by the needs of other family members. In particular, the natural role, needs and expectations of siblings are included in supports planning, not merely as carers, but as possible life-long companions who could play a key role throughout a lifetime of connecting with and valuing the person with disability
- Children are supported to gradually play a more prominent role in planning their lives, considering the types of supports they prefer and defining the goals they want the NDIS to help them pursue

### **Early Intervention Eligibility**

The definition of developmental delay in Part 4 of Chapter 1 puts an upper age limit on when a developmental delay can occur; a child must be under the age of six for the label of a developmental delay to apply. To meet the disability criteria after that age, a child must prove that their disability is likely to be permanent and support is likely to be needed for their lifetime.

Most children can be given a more specific prognosis by the age of six, but it is not clear if this is less true for some impairments than others. This age restriction also does not take into account that there may be difficulty in accessing specialist information in time to 'switch over' to other eligibility criteria before a child turns six.

Legislation should recognise the potential for developmental delay to be recognised after the age of six.