AUTISM SPECTRUM AUSTRALIA (ASPECT)

NATIONAL DISABILITY CARE AND SUPPORT SCHEME DRAFT REPORT - FEBRUARY 2011

ASPECT'S RESPONSE TO THE DRAFT REPORT

General Comments

Aspect would like to acknowledge the outstanding work of the Productivity Commission in producing a ground breaking draft report on Disability Care and Support.

It comprehensively describes the feasibility, costs and benefits of replacing the current fragmented system of disability services with a new national arrangement which would provide essential care and support for Australians with disability.

In particular, Aspect endorses the statement that "The fundamental draft conclusion is that the current arrangements are systematically flawed. New national insurance arrangements are feasible and achievable."

The report endorses the themes and recommendations of a variety of Australian government and state and territory government reports, regarding the critical need for fundamental reform of the disability services system. These include the 2009 report SHUTOUT: The experience of people with disabilities and their families in Australia; the 2007 Report of the Senate Inquiry into the Commonwealth State Territory Disability Agreement; and the Federal House of Representatives Carers Inquiry.

SHUTOUT graphically describes a service system in disrepair – broken and broke: chronically underfunded and under resourced; crisis driven; road blocks where there should be pathways; queues where there should be services.

What is particularly refreshing regarding the NDIS draft report is that it conceptualises disability support as an investment in people. The NDIS will enable outcomes such as enhanced quality of life, productivity and participation for people with a disability and for their families.

These outcomes will bring increased workforce participation and, along with improved economic and personal independence and dignity, reduced welfare dependency, homelessness and family and mental health breakdown. These outcomes are particularly true for people who have an autism spectrum disorder (ASD).

The NDIS is a unique opportunity to improve outcomes for many people who have an ASD – an opportunity to ensure that all who require NDIS support are included. There is a particularly strong economic imperative because improved care and support will mean that many in this group who have particular strengths ,with improved developmental support including social , communication ,behavioural ,educational and employment services and supports, will have better educational and workforce participation outcomes .

Specific Recommendations

1. Who should be eligible for the proposed disability care & support scheme?

All people who have a diagnosis of an autism spectrum disorder (ASD) according to the Diagnostic and Statistical Manual of Mental Disorders 4th Edition (DSM-IV) should be eligible. ASDs include autistic disorder, Aspergers Disorder and Pervasive Developmental Disorder – not otherwise specified (PDD-NOS), including atypical autism.

ASDS are developmental disorders characterised by severe and pervasive impairments in social development, communication skills, and by restricted and repetitive patterns of interests and activity. The disorders are pervasive in that they affect many areas of the persons functioning including socialisation, communication, learning and behaviour. The word *developmental* is used to indicate the disorders manifest very early in a person's life and therefore, effect the course of their development across their life span .They are lifelong impacting on a daily basis many areas of the persons development, including social skills and relationships, emotional development, learning and educational, employment and independent living outcomes.

The proposed DSM-V changes likely to be implemented from 2013, will replace the current DSM-IV diagnostic grouping with one single *Autism Spectrum Disorder* category, strengthening the case for all ASDs to be recognised and supported by a National Disability Care and Support scheme.

The most reliable estimate for the prevalence of ASDs, likely to be very conservative, based on a large group of studies (as reviewed by Fombonne, 2005) is 1:160. This prevalence rate was confirmed by the Australian Advisory Board study on Autism Spectrum disorders in 2007 as the Australian experience at that time. 1:160 translates to about 137,000 people with an ASD in Australia currently.

In support of Aspect's view that all people who have a diagnosis of an ASD are eligible, is Australian Government recognition of autism spectrum disorders as severe and pervasive disabilities. For example, the Australian Government's Review of the Carer Allowance (Child) list of recognised disabilities includes autistic disorder and Aspergers Disorder when diagnosed according to the current DSM-IV. Atypical autism may also be eligible for the Carer Allowance if the child is assessed using the Child Disability Assessment Tool (CDAT).

More recently the Australian Government Helping Children With Autism package (HCWA) recognised the importance of early diagnosis and intervention for young children who have a diagnosed ASD.

Recent research highlights the fact that ASDs are consistently associated with moderate, severe or profound disability of an intellectual, physical or psychiatric nature (e.g. Rinehart et al. 2002; Tonge et al 1999; and Rutter 2011).

Families of people who have an ASD have more financial problems: they coordinate their own health care (more than 10 hours per week), and are more likely to stop or reduce work than families of other people with special needs (Honberg, Kogan, Allan, Strickland & Newacheck, 2009; Kogan et al 2008).

The National Disability Care and Support Scheme is a unique opportunity to improve outcomes for people who have an autism spectrum disorder; there is also a strong economic imperative because improved care and support will mean better educational outcomes and will encourage workforce participation. Benefits would also flow to families and other carers who play a significant supporting role. Research shows that primary carers are less likely to be in the labour force (39%) compared to non-carers (67.9%) (National Disability Strategy 2010 – 2020).

2. What services and supports do people with a diagnosed ASD require?

The 2009 Australian Government Report SHUTOUT along with various state government reports such as, in NSW, Stronger Together, and in Victoria, the Department of Human Services Autism State Plan, identify recurring themes and priority areas for services and supports.

These include the following:

- Services and supports which enable social inclusion, belonging and community participation.
- Services and supports which contribute to improved educational outcomes including attention to teacher training in main stream schools as noted by the Australian Government report SHUTOUT.
- Services which enable adults with autism who are capable of participating in the workforce to do so. Evidence from reports such as SHUTOUT and the UK I Exist research highlight negative employer attitudes and recognise the importance of services and supports which educate employers and workplace peers regarding the adaptation of communication and work environment to match individual learning style and support needs.
- Services which enable equitable outcomes for people with an ASD who become involved with legal and judicial systems.
- Life time care and support – government reports and programs recognise the critical need for a NDIS to improve economic and personal dignity, to reduce the pressures on families and to build family resilience through capacity.

There are no cures. Each person with an ASD is unique and what works in terms of intervention for one person may not work or be appropriate for another.

What is critical is that services and supports are autism specific and are highly individualised, regardless of age. Highly individualised, evidence based interventions and treatment enable people who have an ASD to make significant progress throughout their life and to continue to develop and change.

Interventions need to target communication difficulties, social difficulties, repetitive behaviours and restricted interests, learning difficulties, sensory issues and associated secondary disorders including psychiatric disorders such as anxiety and depression. In addition, carers including parents and family members require specific support such as knowledge about ASDs to build capacity, access to appropriate service information, and to emotional and psychological support.

Examples of supports and services required include for school aged people tailored learning content and methods, social skills interventions for class room and playground settings, and continuing communication interventions. These kinds of services and supports could be delivered with improved teacher training and improved access to autism specialists across a range of disciplines.

It is also critical that services and supports are available for associated or secondary symptoms such as severe sleep disturbance, and mental illness including depression and anxiety.

Young people transitioning from education to employment require transition to work support and specialist interventions in employment settings including services to address negative employer and recruiter attitudes . They require services to provide suitable employment training and employer and peer workplace management knowledge regarding the adaptation of work environments and tailored communication supports and systems to match the learning styles of people who have an ASD.

In summary ,services and supports are required so that systems can respond appropriately to individual needs rather than ,for example, as SHUTOUT notes, education systems acting as barriers to greater achievements and independence because of the systems failure to meet individual needs.

3. Assessment tools and processes for people with an ASD

Aspect supports the idea that the NDIS begin with a range of assessment tools specific to the characteristics and needs of disability types, given that currently there is no single tool or process available for use within the NDIS.

Ongoing work to determine reliable and valid assessment processes ,which ensure equitable outcomes for clients, and which also minimise repetitive and time consuming processes, is strongly supported.

Regarding ASDs, Aspect proposes that evidence based guidelines " The Assessment of Autism Spectrum Disorders in Australia :Towards a National Approach"(Aspect and the Royal Australasian College of Physicians 2008) be the basis of a national approach for the assessment of autism spectrum disorders in Australia including to determine eligibility to the NDIS.

These guidelines incorporate multi-disciplinary, collaborative and educative processes based on research. They acknowledge that the "gold standard "is a comprehensive process including functional assessment to enable outcomes such as early diagnosis, and description of individualised intervention and support needs across the persons everyday natural environments including their family ,school and community settings.

Assessment for ASDs must include specialist expertise collecting information regarding social ,communication ,language ,living skills, learning, behavioural and functional skills and needs. It must also consider differential diagnosis and co-occurring disorders ;the total individual picture therefore determines overall support needs and eligibility .The process includes ongoing multi-disciplinary and multi-agency (generic and specialist)management and review to ensure best possible outcomes for clients and their families.

4. Adequacy of the proposed three tier system

The fact is that ASDs are characterised by severe and pervasive impairments in communication, social development and restricted and repetitive patterns of interest and activities .

The disorders are lifelong, with co-occurring learning, psychiatric and medical conditions typical. There is no cure.

It is critical that tier 3 recognises that a person who has an ASD will also present with disabilities of an intellectual, cognitive, physical and/or psychiatric nature. The overall functional impact is that people who have an ASD will require support ranging from low level support to episodic support, to those who will need high level daily living support.

If we accept the conservative prevalence rate of 1:160 (McDermott, Williams, Ridley, Glasson and Ray 2007 - Australian study) then this means that 137,500 people in Australia would require tier 3 support.

5. Eligibility and monitoring of prospective service providers

Aspect endorses a high quality multi-disciplinary evidence based assessment which identifies disability related support needs. The supports or services provided should be based on the functional assessment outcomes. Regarding ASDs the assessment process previously referred to, that is the Assessment of Autism Spectrum Disorders in Australia: Towards a National Approach, would provide and guide the quality assessment process.

Aspect endorses the notion that the scheme cover expenses associated with the cost related to the disability rather than pay for ordinary life expenses. Ordinary life expenses such as food and clothing would not be covered unless highly specialised items were required such as the cost of a commercial washing machine for a family with children with autism who are also incontinent.

Accountability requirements should be established to ensure that prospective service providers deliver support and interventions that meet rigorous evidence requirements. This is particularly important given the experience of the Helping Children With Autism program where some services have been funded despite the absence of any evidence that the service or program will improve child and /or family outcomes.

Quality service delivery is in the interest of all parties : people with disability , service providers, governments, and the broader community. Aspect therefore strongly supports the notion of monitoring or accreditation, independent from government and service provider, to ensure and safeguard quality. The accreditation process needs to be appropriately funded to ensure the effective management of a quality monitoring system.

Evidence regarding effective treatments and interventions including intervention schedules should guide both the availability and duration of services and support provided. This is particularly important in regard to early intervention services where vulnerable families rely on service providers without the benefits of an effective quality assurance system. Such evidence ought to be publicly .

6. National Disability Insurance Scheme Agency (NDIA)

Aspect supports a NDIA concept where the key functions include assessing needs, funding, coordinating services, and collecting and using data to manage efficiency and cost.

The Commission notes that the NDIA would not necessarily undertake all of such functions internally rather it would have responsibility for them and would decide which functions to undertake and which to contract out.

Regarding key functions such as assessing needs, funding and quality processes, it will be critical for the NDIA to be able to access ASD specific knowledge through training and through consultancy with national leaders and experts in the field of ASD.

The Australian Advisory Board on Autism Spectrum Disorders would be a valuable resource to assist a NDIA to access evidence based ASD knowledge and expertise.

7. Delivering services equitably

Aspect endorses the recommendation that the NDIA develop and implement a quality framework for disability providers which would include:

- The development of nationally consistent standards applying to all specialist service providers and disability support organisations.
- Provision of information regarding the quality and performance of service providers on a national internet data base.
- Australian government and state and territory governments working together with service providers to overcome barriers to service delivery for indigenous people, and for people from culturally and linguistically diverse communities (CALD) by:
  - Supporting larger experienced service providers to work with smaller community based services which include local staff.
  - Employing and working with indigenous and culturally and linguistically diverse community members in the development ,promotion ,delivery and evaluation of intervention services .
  - Developing the cultural competency of non-indigenous and non CALD service provider staff.

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