

AUTISM SPECTRUM AUSTRALIA (ASPECT)

NATIONAL DISABILITY CARE AND SUPPORT SCHEME

Productivity Commission Submission

EXECUTIVE SUMMARY & RECOMMENDATIONS

This paper describes the very significant range, and life-long support needs, of all people who have an autism spectrum disorder.

It presents the evidence for nine key recommendations regarding a national disability care and support scheme.

It proposes that the needs of all people who have a pervasive developmental disorder, including all people with an autism spectrum disorder, be supported by a national disability care and support scheme.

It recognises that each individual who has an autism spectrum disorder is unique and will require individually tailored interventions and supports.

It promotes the idea that interventions and treatments which have scientific evidence be supported and accredited by a national disability care and support scheme.

It notes the move to individualised funding packages for people with a disability under a national disability care and support scheme and highlights some of the issues related to this important question.

Aspect's proposal emphasises in the interests of prevention, equity and social justice, the importance of a national approach, particularly given the evidence regarding prevalence growth.

A national approach ought to ensure appropriately accredited providers and evidence-based interventions and treatments, to improve outcomes and to better manage risks and costs for individuals, families and their communities.

A national funding mechanism is essential to building a quality sustainable service delivery system for the future, for people who have an autism spectrum disorder.

Governments in Australia have recognised the need to support the autism community and have delivered introductory funding such as the Australian Government's Helping Children with Autism package, education funding through state governments, and the projects funded through the likes of the NSW Government Human Services department of Ageing Disability & Home Care.

The national disability care and support scheme must ensure this funding continues and is expanded to reach all of the autism community. All governments have said that particularly the early intervention programs are a start. There is a great need to give people with autism support to access funding throughout their life from diagnosis and

early intervention through to their older years so they can maximise their potential and their contribution to society.

Recommendation 1

All people who have a diagnosis of one of the pervasive developmental disorders including autism spectrum disorders (ASDs) are eligible for support by the new national disability care and support scheme on the basis of severe and pervasive impairments.

Recommendation 2

A national disability care and support scheme which includes a national funding mechanism is required to respond to the growing prevalence of ASDs to ensure equitable and sustainable funding and support across the country.

Recommendation 3

An equitable and appropriately funded national disability care and support scheme is essential to manage and minimise the risk of crisis for individuals who have an ASD and their families, and to reduce the long term social, lost productivity and economic costs to the community.

Recommendation 4

That the national disability care and support scheme fund interventions and supports which target both the core impairments of autism spectrum disorder and associated conditions, and which have a strong scientific evidence base.

Recommendation 5

That the national disability care and support scheme fund interventions and programs which target the individual developmental needs of children 0 - 6 who have an autism spectrum disorder, and includes strategies that build capacity of their families and service providers in their local communities.

Recommendation 6

That the new national disability care and support scheme fund interventions, such as speech therapy, occupational therapy and psychological support which target the individual needs of children (6 -18) who have an autism spectrum disorder, including by building the capacity of their families and service providers in their local communities.

Recommendation 7

That the new national disability care and support scheme fund the wide range of interventions required by adults with an ASD that have traditionally been funded by state and territory governments along with additional services such as speech therapy, occupational therapy and psychological support which have currently largely been unfunded in order that adults with an ASD can reach their potential and make their contribution to society.

Recommendation 8

All people who have an autism spectrum disorder, despite considerable heterogeneity in development, and regardless of their age are in need of specialist support and assistance through the national disability and support scheme because of their neurologically based impairments in the areas of communication, social development, and restricted and repetitive patterns of interests and activity.

Recommendation 9

The introduction of a national disability care and support scheme based on individualised funding must recognise:

- ***Not all individuals and families wish to self manage their funding and services***
- ***Individuals and families may require assistance and advice to effectively to manage their services and funding***
- ***Individuals and families require access to independent, reliable information about services if they are to make effective choices***
- ***Service providers require core funding to enable them to manage their administrative processes and accountability requirements***
- ***Service markets may not efficiently meet the needs of people living in regional and remote areas where demand may be low***

Introduction

Autism Spectrum Australia (Aspect) is a not-for-profit organisation committed to helping people on the autism spectrum achieve their potential. Aspect builds confidence and capacity with people with an autism spectrum disorder (ASD), their families and their communities.

Being on the autism spectrum is life-long although the diagnosis is usually not made until the child is about two years of age or more. People may experience difficulties with social interaction, impaired communication, restricted and repetitive interests and behaviours and sensory sensitivities. The word 'spectrum' is used because the range and severity of the challenges people face can vary widely. Intervention, understanding and support provide the best opportunities for many people with autism to lead productive lives.

Aspect operates a variety of services in NSW, ACT and Victoria including:

- Information services
- diagnostic assessments
- early intervention programs
- a network of autism specific schools and satellite classes
- educational outreach
- behavioural intervention
- community participation for adults with an ASD
- support groups for young people and adults with an ASD
- a parent support network
- parent education and professional development workshops.

Aspect also undertakes its own research and works in partnership with other research bodies. Aspect's research focuses on the effectiveness of interventions with people with an ASD.

Aspect is in contact with over 8,000 people with an ASD and their families annually. Founded in 1966 Aspect's evidence-based approach is designed to give people a greater capacity to succeed.

The Australian Advisory Board on Autism Spectrum Disorders found through its prevalence study in 2007 that there is one in 160 Australians with an ASD resulting in an estimated 130,000 Australians on the spectrum.

The submission does not attempt to answer all the questions posed by the Productivity Commission. Rather it has focused on Aspect's area of expertise which is people with an ASD and their families and some of the particular issues posed by this inquiry.

Aspect supports the principles proposed by National Disability Services in its submission.

WHO SHOULD BE ELIGIBLE WHEN IT COMES TO PEOPLE WITH AN ASD?

The Diagnostic and Statistical Manual of Mental Disorders 4th Edition (DSM-IV) classifies autism spectrum disorders (ASDs) under the broad category of pervasive developmental disorders. Under this internationally accepted classification system, ASDs include autistic disorder, Asperger's disorder, and pervasive developmental disorder – not otherwise specified (PDD-NOS), including atypical autism. These conditions all have similar symptoms, but they differ in terms of when the symptoms start and the exact nature of the presentation. These three conditions, along with Rett's disorder and childhood disintegrative disorder make up the broad diagnostic category of pervasive developmental disorders.

All the above identified pervasive developmental disorders are characterised by severe and pervasive impairments in communication and social development, and restricted and repetitive patterns of interests and activity. The disorders are described as “pervasive” as they affect many areas of the person's functioning including socialisation, cognition, communication and behaviour. The word “developmental” is used to indicate that the disorders manifest very early in a person's life and, therefore, effect the course of development.

All ASDs are complex neurodevelopmental disorders characterised by complex aetiology, variable presentations and widely divergent outcomes. For instance, some people who have autistic disorder yet are in the typical IQ bands are described as having high functioning autism (HFA) – see Roberts & Prior (2006) & Lord & McGee (2003).

Major changes were made to the pervasive developmental disorder – not otherwise specified (PDD-NOS) category in DSM-IV based, in part, on a large multi-site international field trial. Instead of requiring “impairment in social interaction and in verbal or non-verbal communication skills” (DSM-III-R p.39), DSM-IV states that the “category should be used where there is a severe and pervasive impairment of reciprocal social interaction accompanied by either significant communication impairments, or when stereotyped behaviour, interests and activities are present” (DSM-IV pp. 77-78).

In 1994 DSM-IV and ICD-10 – International Statistical Classification of Disease and Related Health Problems were aligned for the first time – both classification systems included diagnostic criteria for Asperger's disorder and for PDD-NOS.

Similarly the proposed DSM-V changes, likely to be implemented from 2013, will replace the current DSM-IV diagnostic groupings with one single “Autism Spectrum Disorder” category, strengthening yet again the case for all ASDs to be recognised and supported by a national disability care and support scheme, regardless of where they lie on the spectrum.

Aetiology, the Triad of Impairments and Impacts on the Individual

The recent changes to the classification systems (as outlined above) also demonstrate that there is now agreement that the impact of each of the ASDs under the broad category of pervasive developmental disorders upon the individual is severe and pervasive.

The aetiology of autism spectrum disorders (ASDs) involves interactions between genetic and environmental factors (Minshew & Sweeney, Bauman & Webb, 2005). The

DSM-IV describes pervasive impairments in social interaction, communication, and restricted and repetitive and stereotyped patterns of behaviour interests and activities, often termed the triad of impairments.

It is important to note that IQ is not a defining feature of ASD with abilities ranging from severe intellectual disability to the gifted range of functioning.

Regardless of IQ, people who have an ASD require very high levels of support. This is because ASD is the only disorder where communication develops separately from language. Although presentation can range from non-verbal through to highly verbal, communication in ALL individuals with an ASD is characterised by impairments in semantics (meaning) and pragmatics (use in social contexts) (Wetherby & Prizant, 2000). Even those individuals with advanced vocabularies face very significant challenges interpreting facial expression, body language and prosody which effects discourse and conversational competence (Twatman-Cullen, 2000).

Functioning may be further challenged by the poor development of emotional regulatory capacities, which involve an individual's ability to experience, recognise, express and regulate emotions effectively during social transactions (Laurent and Rubin, 2004). This is associated with challenges in recognition and expression of emotions, sharing attention with others, play, social understanding, self consciousness and reciprocal social interaction (Hobson, 2002; Autism Spectrum Australia (Aspect) 2005).

Australian Government's Recognition of Autism Spectrum Disorders

Carer Allowance (Child)

The Australian Government's Review of the Carer Allowance (Child) List of Recognised Disabilities (LRD) regarding Autism Spectrum Disorders amended the LRD after considering the advice of an independent review panel, including a submission from Aspect.

The revised LRD included Asperger's disorder when diagnosed according to the current Diagnostic and Statistical Manual of Mental Disorders – DSM-IV. It is important to note, that while PDD-NOS (atypical autism) was not included that the carer may still be eligible for the Carer Allowance if the child was assessed using the Child Disability Assessment Tool (CDAT), assessment of the child's abilities as measured across a series of functional categories.

These very important amendments and recognitions by the Australian Government of the support needs for people who have an Autism Spectrum Disorder were added to the List of Recognised Disabilities and introduced on 1 July 2005.

Aspect's submission to the Review of the Carer Allowance Child Disability Assessment Determination included evidence of recent research which highlights the fact that ASDs are also consistently associated with moderate, severe or profound disability of an intellectual, physical or psychiatric nature (refer attached references regarding emotional, psychiatric, behavioural and social disturbances e.g. Rinehart et al., 2002; and Tonge et al., 1999).

Helping Children with Autism Package

More recently, the Australian Government's Helping Children with Autism package (HCWA) recognised the importance of diagnosis and early intervention treatments and services for children with an ASD, along with the need for positive partnerships between their families and schools.

In announcing the \$190 million package for children with an Autism Spectrum Disorder and their families, the Minister for Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), The Hon Jenny Macklin MP, together with the Hon. Nicola Roxin MP, the Hon. Brendan O'Connor MP, and the Hon. Bill Shorten MP noted that: " the package is the first national initiative to help families deal with this challenging disorder and is a major breakthrough in support for children and their families...."

The package included access to early intervention services, education and support programs, and new Medicare items for diagnosis for children aged less than 13 years of age and for early intervention treatment for children with ASD aged less than 15 years.

Australian Government support recognises that ASDs are life-long conditions. It also recognises that there is strong research evidence that early interventions and appropriate supports across the lifespan can significantly improve life outcomes for both the person who has an ASD and their family.

Recommendation 1

All people who have a diagnosis of one of the pervasive developmental disorders including autism spectrum disorders (ASDs) are eligible for support by the national disability care and support scheme on the basis of severe and pervasive impairments.

Growth in the Prevalence of Autism Spectrum Disorders

Australian evidence

A recent Australian study auspiced by the Australian Advisory Board on Autism Spectrum Disorders into the prevalence of ASD in 6 to 12 year olds estimated that the prevalence was 62.5 per 10,000 or 1:160 (MacDermott, Williams, Ridley, Glasson & Wray, 2007). The finding from this report which is the first publication to include information about diagnostic practices, intervention services and prevalence rates for all Australian States and Territories, reflects similar prevalence rates from international studies.

A 2006 report on educating primary school students with disabilities – New South Wales Department of Education & Training (2006) by the New South Wales Auditor General's Department, identified that students with a diagnosis of ASD and mental health disorders were the fastest growing disability areas in New South Wales State schools. This trend is consistent across other states and territories in Australia.

There is no doubt that across Australia the increase and the identification of school aged children with ASD has become a significant focus and challenge for all education sectors (Roberts, 2006). A recent report (Australian Institute of Health and Welfare, 2009) also

describes that ASD is associated with high prevalence of multiple disabilities. In particular, of individuals identified as having autism as a major disability, 58% also reported a psychiatric disability and 38% also reported a sensory/speech disability.

International evidence

Research both nationally and internationally has indicated an overall increase in the incidence and prevalence of ASD. The broader definition of ASDs, that is the inclusion of people with Asperger's disorder and high functioning autism over the past 15 years, increased awareness and more systematic assessment practices may be reasons for this increase (Children's Mental Health, Ontario, 2003; Fombonne, 2003; Roberts & Prior, 2000).

The most recent US Government survey on the rate of autism by the Centre for Disease Control (CDC) found that the rate is higher than the rates found from studies conducted in the US during the 1980's and early 1990's. Summarising this and several other major studies on autism prevalence, CDC estimates that two to six per 1,000 (from 1 in 500 to 1 in 150) children have an ASD. The risk is three to four times higher in males than females.

Recommendation 2

A national disability care and support scheme which includes a national funding mechanism is required to respond to the growing prevalence of ASDs to ensure equitable and sustainable funding and support across the country.

WHAT SERVICES ARE NEEDED AND HOW SHOULD THEY BE DELIVERED?

The Economic Context

There is undeniable evidence that people who have an ASD require a life time support. Recent research regarding the economic costs, from both the US (Ganz, 2007) and the UK (Knapp, Romeo, & Beecham, 2009) has estimated costs to families of more than \$3 million beyond the ordinary life time costs of raising a child.

Compared to other children with specialised needs, children with an ASD are underserved, with more delayed or foregone healthcare, less family centred care, and more difficulties with referrals (Kogan, Strickland, Blumberg, Singh, Perrin, & Van Dyck, 2008).

Families with children with an ASD have more financial problems, provide significant amounts of healthcare coordination (more than 10 hours a week) for their own children, and are more likely to stop or reduce work than families of other groups of children with special needs (Honberg, Kogan, Allen, Strickland, & Newacheck, 2009; Kogan et al., 2008).

Recommendation 3

An equitable and appropriately funded national disability care and support scheme is essential to manage and minimise the risk of crisis for individuals who have an ASD and their families, and to reduce the long term social, lost productivity and economic costs to the community.

What are the Support Needs for People who have an Autism Spectrum Disorder?

Autism spectrum disorders are life-long conditions. There are no cures. However research indicates that specialised services and intervention can achieve significant improvements in life outcomes for both the person who has an ASD and their families.

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 programs are autism specific and are highly individualised regardless of age. Highly individualised, evidence based interventions and treatments 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, 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 including knowledge, access to appropriate information, emotional and psychological support.

Interventions and treatments

Interventions and treatments for autism spectrum disorder include a wide range of services, programs and teaching methods which aim to help the person with an autism spectrum disorder achieve his or her potential. Intervention may vary from a very intensive, comprehensive undertaking that involves a child's entire family and a team of professionals (particularly for people who have a diagnosis of autistic disorder) to interventions which may be provided in the child's mainstream settings including school. For example some social skills, learning support, and communication interventions may be provided in a specialised centre, a classroom or other community setting.

Intensive treatments for the autism spectrum disorder core symptoms address the social, communication and cognitive issues which are the core impairments.

It is critical that treatments for associated symptoms address challenges which commonly co-occur (are associated with) an autism spectrum disorder. These co-occurring and associated symptoms and disorders may include severe sleep disturbance, mental illness including depression and anxiety disorders, and food intolerances.

The USA's National Autism Centre's National Standards Report, 2009 – Established Treatments

The National Autism Centre's National Standards Report, 2009, describes compelling scientific evidence for eleven treatments which the review regards as effective while noting that "universal improvements cannot be expected to occur for all individuals on the autism spectrum".

- Antecedent Package
- Behavioural Package

- Comprehensive Behavioural Treatment for Young Children
- Joint Attention Intervention
- Modelling
- Naturalistic Teaching Strategies
- Peer Training Package
- Pivotal Response Treatment
- Schedules
- Self-management
- Story-based Intervention Package

These established treatments require extensive specialist practitioner and family training. They are interventions which the scientific evidence demonstrates are effective for some although not for all individuals on the autism spectrum.

Aspect's Comprehensive Educational Approach (ACEA) is consistent with the eleven established treatments, including structured and naturalistic teaching strategies, schedules and visual and social story supports, comprehensive positive behaviour support, and applied behavioural techniques.

The evidence for these treatments and interventions comes from fields such as behavioural psychology, speech pathology and special education.

The list of established treatments does not mean that these are the only effective approaches. There are many others which require ongoing scientific evaluation to establish their effectiveness. One of the limitations is the lack of funding research to examine the range of treatment options that are available in the market place.

Recommendation 4

That the national disability care and support scheme fund interventions and supports which target both the core impairments of autism spectrum disorder and associated conditions, and which have a strong scientific evidence base.

Support and Interventions for 0 - 6 Year Olds who have an ASD

In Australia currently there is a wide range of early intervention service delivery options available to families and children with disabilities in metropolitan centres. This is a direct result of both state and federal government funding initiatives in the early intervention area. Whilst this has proved beneficial to families and children the key areas of concern remain around intervention intensity with Roberts & Prior (2006) recommending 15-20 hours per week, service provider expertise, clear pathways for service referral and access and ensuring that programs have a strong evidence base.

Aspect Building Blocks is the early intervention service of Autism Spectrum Australia (Aspect). For more than 25 years, Aspect has developed, delivered and refined its early intervention programs for children aged 0 to 6 years with an ASD, their families and the communities they live in.

It pioneered the development of ASD specific early childhood intervention in Australia and today, Aspect Building Blocks is one of the largest independent autism specific early intervention services offered by an NGO. It is highly regarded by families and

professionals alike and demand for its various programs remains consistently high. It is described briefly below to outline the range of strategies and interventions that can be required in order to respond effectively to young children with an ASD and their families. Aspect envisages that such programs would need to be funded by a national disability care and support scheme because such interventions respond to the severe and profound impairments of young children with an ASD.

Aspect Building Blocks Comprehensive Approach

The key elements of Aspect's Comprehensive Early Intervention Approach accord with recommendations found in comprehensive reviews of research and evidence-based practice, including by Australia's Roberts & Prior (2006), are:

- Individual Education Plans developed collaboratively with families or guardians. Programs are based on developmental and functional assessment of the learner's strengths and challenges and focus on support and skill-building.
- Core curriculum competency areas including social connections, communication, cognitive and adaptive skills, sensory issues and repetitive behaviours, these relate directly to the core challenges of ASD and children with developmental disabilities.
- Environmental supports that consider the physical and ecological conditions of the learning context and the provision of learning supports tailored to group and individual needs.
- Structured teaching that integrates planning, routines, and systematic instruction. Instructional methods are based on the principles of positive behaviour support, and behaviour analysis, and incorporate child preferences, learning strengths and natural and social contingency rewards. Adaptive instruction involves modified communication, guidance for time management and the use of teaching techniques such as task analysis, prompting and modelling.
- A positive approach to behaviour support that focuses on skills development and replacement behaviours rather than simply attempting to eliminate particular problem behaviours. The aim is to increase skills and move towards self-monitoring and self-regulation.
- A multi-disciplinary team approach, which includes parents, guardians, teachers, speech language pathologists, occupational therapists, psychologists and support staff.
- A family-centred approach that includes parental or guardian involvement in educational planning and delivery and the provision of a range of parent education, skill building and support options.
- A model of service provision that focuses on inclusion in the general community. Aspect recognises that in order for learning to be effective, skills should be generalised beyond the intervention setting and home into the general community.
- Support for parents, families, carers and children from Indigenous, and Culturally and Linguistically Diverse (CALD) backgrounds and those living in rural and remote areas.

- Aspect supports transition into more inclusive educational settings, such as support classes and mainstream placements and provides transition and follow-up support.

Aspect Building Blocks Programs and their Content

Aspect's programs focus on one-on-one and small group contexts including inclusive settings as appropriate and are delivered by Aspect's multidisciplinary early intervention consultants, who have qualifications as speech language pathologists, special education teachers, psychologists and occupational therapists.

The Aspect Building Blocks programs draw their intervention techniques from behavioural, developmental and social learning, therapy based and family based interventions. Programs have a strong family-centred approach where goals and outcomes are developed in close collaboration working on achieving results in key areas of family priority. Programs have an emphasis on developing skills in the areas of:

- Teaching joint attention, play and imitation skills
- Building functional communication
- Teaching social interaction and relating skills and understanding
- Advancing daily living skills
- Modulating sensory issues
- Development of key pre-academic skills
- Positive behaviour support
- Generalisation of skills taught across environments
- Preparation and facilitation of successful transition to school.

The Aspect Building Blocks programs currently available include:

- Centre-based (concurrent child and parent components)
- Home-based
- 'More Than Words' Hanen parent training
- 'More Than Words' Hanen plus centre-based (a year long parent training program)
- Speech and Occupational Therapies
- Early Childhood Screening and Intervention.

Aspect's Comprehensive Early Intervention Approach provides the key elements (as outlined above) necessary for effective early intervention as defined by Roberts and Prior (2006), in their guidelines of best practice, in summary these include:

- An autism-specific program which focuses on the key developmental areas of attention, compliance, imitation, language and social skills.
- Highly supportive teaching environments which deal with the need for predictability and routine, and with challenging behaviour, obsessions, and ritual behaviours.
- Support for children in their transition from the preschool classroom to a formal school setting.
- Support for family members including partnerships with professionals.

Research strongly supports the value of educating and empowering parents. Dempsey and Duncanson (as cited in Wig Wag, 2007) suggests that the key elements contributing to parents' feelings of empowerment are: self efficacy, participation and collaboration, sense of control, meeting personal needs, understanding the environment, access to

resources and personal action. Aspect embraces this approach to working in partnership with parents and carers.

Recommendation 5

That the national disability care and support scheme fund interventions and programs which target the individual developmental needs of children 0 - 6 who have an autism spectrum disorder, and includes strategies that build capacity of their families and service providers in their local communities.

Support and Interventions for School Aged Children who have an ASD

The Australian Education Ministers, in collaboration with Catholic and Independent sectors, developed a new National Declaration on Educational Goals for Young Australians. The Melbourne Declaration, released December 2008, enunciates two goals:

- 1) Australian schooling promotes equity and excellence
- 2) All young Australians become successful learners, confident and creative individuals and active and informed citizens.

The nature of ASDs indicates that, although there is a need for specialised educational intervention, a 'one size fits all approach' is not appropriate for the range of individual needs of all students at all times. Aspect's Comprehensive Educational Approach (ACEA) acknowledges that within a set of standard procedures and core curriculum different teaching tools, interventions and techniques may be used at different times during a child's development. The approach also recognises the transactional and interactive nature of ASDs, whereby the learning environment, curriculum and people interacting with the individual with an ASD all influence development.

The term 'comprehensive' refers to ASD specialised programs that include a skill development focus together with therapeutic interventions, using a multi-disciplinary team including parents. Intervention takes place in multiple settings including home, school and the community. Aspect's evidence-based approach recognises the value of referring to multiple sources of information including empirical research, theoretical papers, models of best practice and autobiographical perspectives, to provide high quality education for students with an ASD.

All individuals with an ASD are identified with impairments in social interaction, communication and a tendency for inflexible patterns of thinking and behaviour. Individuals with an ASD may possess relative strengths in visual- spatial processing rote memory and attention to detail and yet experience difficulties with flexible thinking, planning and organisation.

As a result of these impairments and unique learning styles, students with an ASD experience significant challenges in education and community environments. Many struggle to cope or fail in the education system. Evidence suggest that they are significantly more likely than their typically developing peers to be suspended or excluded, targets of bullying, to suffer depression and anxiety and to under perform academically relative to their level of intelligence. They are often misunderstood by educators, peers and the wider community. A recent survey of families found many

families were concerned at the lack of understanding of the implications of their child's diagnosis among school staff.

Problem behaviours and evidence of increased level of anxiety in children with ASDs often stem from their daily challenges in socio-emotional relating, communication and learning. Positive behaviour support should be underpinned by assessment and interventions that focus on skills development and replacement behaviours rather than simply attempting to eliminate particular problem behaviours.

For young people of school age both federal and state governments provide funding to the education sectors to provide schooling. But for students with ASD to participate successfully in education their unique characteristics of ASD must be supported in their home, school and community.

In April 2008, an independent National Curriculum Board was established by COAG to "...take on the challenge of engaging the community in developing Australia's first national curriculum in English, mathematics, the sciences and history for implementation in 2011...." The ideal of an Australian Curriculum is predicated on a belief that all children should be given the same opportunities to succeed and reach their learning potential.

However, an Australian Curriculum creates a dilemma for the education of children with ASD. On the one hand, it is positive that all children are entitled to the same curricula opportunities and that the expectations of all children, whatever abilities are equal. On the other hand, professionals who work with children with ASD know that their needs are different and that the imposition of a standard curriculum can negate wider developmental needs.

To support the educational needs of children with an ASD a multidisciplinary team approach has been supported by research as best practice. Multidisciplinary teams need to provide support for students, their families and teachers. The composition of multidisciplinary teams caters to the diverse nature of development and support needs of children with an ASD. Multidisciplinary team members include psychologists, speech pathologists, occupational therapists and teaching staff. Psychologists provide support for learning, social skill development and behaviour, speech pathologists support communication and language development and occupational therapists cater to sensory support needs of children on the autism spectrum.

For children with ASD to access the Australian Curriculum, to become successful learners extra supports are needed. All children on the autism spectrum will benefit from specialised support and intervention regardless of their educational placement. This support falls to families to provide as is not provided in educational placements.

While state and federal governments fund the education sectors, for children with ASD to access the curriculum to become successful learners extra supports are needed. These extra supports include speech therapy, occupational therapy and psychological support. A new national disability care and support scheme needs to provide for children and young people with an autism spectrum disorder these extra supports so they can become successful learners, confident and creative individuals and active and informed citizens.

Recommendation 6

That the new national disability care and support scheme fund interventions, such as speech therapy, occupational therapy and psychological support which target the individual needs of children (6 -18) who have an autism spectrum disorder, including by building the capacity of their families and service providers in their local communities.

Support and Interventions for Adults who have an ASD

The range of services and supports available to adults with an ASD also highlight a number of areas of current unmet need, and the potential for a national disability care and support scheme to address this in a more targeted and client centred way in the future.

While the current funding landscape reflects a number of service options around employment, further education, community based options and day program activities for adults, there is strong anecdotal evidence that these services do not adequately meet, or address the specific needs of adults with an ASD.

Some of the main barriers to community connections and inclusion that adults with an ASD face around communication, social skills and employment options are often not fully addressed within the existing service parameters. These service models are also focused on generic disabilities, with funding based on prescribed needs and available services. This often does not allow for flexibility in the choice of interventions, or the level of support required or focused in one area of the person's life.

It is unclear what funding arrangements would be put in place for these traditionally state and territory funded services with the advent of a national disability care and support scheme. If the funding for all these program initiatives became the responsibility of the national body then Aspect would argue that along with the traditional service options for adults with an ASD outline below, the national scheme should also cater for the additional needs that are currently unmet.

Community Participation and Day Program Funding

The existing day program service options available to people with an ASD, as well as all people with a disability include Community Participation funding, Life Choices, Active Ageing, and other block funded service options funded through state and territory governments.

Adults with an ASD have particular needs around communication, social and behaviour support. The existing service and funding system, which is often a one size fits all model, does not promote collaborative practice, or client directed choice around what is most needed for a successful outcome.

An example would be an individual attending an adult day program who may require a high level of speech intervention or behaviour support, but cannot use their day program, or individual funding for this purpose. They will often have to wait for an extended period to access these external specialist services, which then exacerbates and increases the amount of services and supports required. For adults with an ASD, this can have an even further pronounced effect.

Self-managed funding has made inroads into increasing the flexibility and autonomy for families, but there are still financial limitations to overcome when attempting to design a holistic service.

Transition to Work and Supported Employment

Within the Transition to Work program and supported employment sphere program, there is again evidence that points to markedly lower outcomes for the ASD population than for other disabilities. This is due not only to the individual needs of the person, and their ASD, but some of the rigidity within this funding framework. While there are existing services that are more tailored to meet the needs of the ASD community, the particular individual needs and desired work options for many people with an ASD do not fit with the those currently offered by many supported employment services, and the areas of support needed by many people with an ASD, particularly Asperger's disorder are not linked to the funding available.

Open Employment and TAFE

Aspect's research and evidence into the needs of adults with an ASD, particularly those with Asperger's disorder, highlight the challenges this group of people face when using existing service providers and funding types to address their individual needs. Within the area of employment, the challenges of creating lasting social connections, coping with changes and communicating effectively with employers can be very difficult for someone with an ASD. Increasing the types of services and specific supports available for this group would have a marked effect on lasting and successful education, employment, and workforce participation rates for people with an ASD. This would also have an enormous economic impact, resulting in subsequent savings for the social services sector and decrease the burden on family carers.

Recommendation 7

That the new national disability care and support scheme fund the wide range of interventions required by adults with an ASD that have traditionally been funded by state and territory governments along with additional services such as speech therapy, occupational therapy and psychological support which have currently largely been unfunded in order that adults with an ASD can reach their potential and make their contribution to society.

WHAT GROUPS ARE MOST IN NEED OF ADDITIONAL SUPPORT AND HELP?

All people who have an autism spectrum disorder, despite considerable heterogeneity in development, and regardless of their age are in need of specialist support and assistance as previously described. This is because of their neurologically based impairments in the areas of communication, social development, and restricted and repetitive patterns of interests and activity.

In addition, current research states that individuals with an ASD have significantly higher rates of psychopathology in comparison with other populations (e.g. people with an intellectual disability, or a language disorder). (Brereton, Tonge and Einfield, 2006; Kim, Satmari, Bryson, Streiner, and Wilson 2000). Co-morbid symptoms have a negative impact on the individual, their family, service providers and their placements. They

further disrupt education and impair social interaction and integration within the community, and contribute to already very significant management problems and stress for parents and service providers (Leyfer et al., 2006).

Recommendation 8

All people who have an autism spectrum disorder, despite considerable heterogeneity in development, and regardless of their age are in need of specialist support and assistance through the national disability and support scheme because of their neurologically based impairments in the areas of communication, social development, and restricted and repetitive patterns of interests and activity.

INDIVIDUAL FUNDING AND A NATIONAL DISABILITY CARE AND SUPPORT SCHEME

Aspect is committed to increasing the control over services exercised by families, carers and people with an ASD and other disabilities. It believes that self - directed funding improves outcomes for people with an ASD.

Mindful of this, Aspect is committed to increasing service options and support available to people with an ASD and families and supporting people to make choices about the use of their funding.

However, Aspect is concerned that a move to greater individualised funding in the disability service system must take into consideration several important considerations:

Individuals and families may not wish to manage or direct their funding

Managing in an individualised funding system requires considerable expertise and energy which can be demanding for many families. The need to be accountable to funding bodies may provide a challenge to many families and people with an ASD.

The key benefits for families and people with ASD in receiving individualised support or packages are:

- Increased autonomy over choosing which services will meet their needs now and into the future
- The ability to 'exercise control' over ongoing service needs
- Feelings of empowerment and freedom
- Ability to choose staff or the key people in their lives
- Not feeling 'trapped' or at the will of the current service provider
- Feeling able to complain or make comments about improving service provision

However, service users who manage their own funding and services have particular challenges:

- Managing finances and service budgeting
- Working in partnership with service providers
- Recruiting, inducting and managing their own staff
- Dealing with complaints and conflict
- Defining boundaries when family members provide the service

- Insurances, public liability and risk management
- Maximizing their funding allocation

Given these challenges, some individuals or families may not wish to manage their own funding or services or may require assistance to do so.

Market asymmetry

While Aspect supports initiatives to expand individualised funding, it is mindful of the market asymmetry in information and knowledge between service users and providers on the issue of service efficacy. This is of particular concern in the ASD community where many service options may be ineffective at best or potentially harmful (Howlin 2005)

Families and individuals with an ASD need access to reliable and independent information about services if they are to make effective, informed choices about their services.

Demand and service availability

Markets flourish and organisations are drawn to participate when the price is right and demand high. It is possible that individualised funding may result in service scarcity or reduced access to some services.

This situation may arise in regions with low population densities or where for whatever reason demand is insufficient to warrant providers commencing or maintaining the provision of services.

Services operating in regional and remote areas may require core operating funding if they are to remain viable when demand is low

Support for service providers to manage their administrative processes and meet accountability

NDS has noted the key benefits brought by the shift to individualised funding. These include moving from outputs to outcomes, standardization to personalisation, and increased market efficiency as a result of client choice rather than government priorities¹.

However, NDS has also highlighted potential areas of concern particularly without proper planning, implementation and monitoring.

Of particular concern is the capacity of the not for profit service system, which provides most disability services outside of government, to manage administrative and accountability processes required by governments without adequate funding support.

Aspect recognises and fully supports that families and people with ASD should be making the key decisions about which services they need, which areas of their life they need support in (and to what extent), and who they would like to provide these services to them.

¹ National Disability Services – “Individualised Funding: What it requires to Work” - Discussion Paper August 2008

Recommendation 9

The introduction of a national disability care and support scheme based on individualised funding must recognise:

- ***Not all individuals and families wish to self manage their funding and services***
- ***Individuals and families may require assistance and advice to effectively to manage their services and funding***
- ***Individuals and families require access to independent, reliable information about services if they are to make effective choices***
- ***Service providers require core funding to enable them to manage their administrative processes and accountability requirements***
- ***Service markets may not efficiently meet the needs of people living in regional and remote areas where demand may be low***

CONCLUSIONS

This paper describes the very significant range, and life-long support needs, of all people who have an autism spectrum disorder.

It presents the evidence for nine key recommendations regarding a national disability care and support scheme.

It proposes that the needs of all people who have a pervasive developmental disorder, including all people with an autism spectrum disorder, be supported by a national disability care and support scheme.

It recognises that each individual who has an autism spectrum disorder is unique and will require individually tailored interventions and supports.

It promotes the idea that interventions and treatments which have scientific evidence be supported and accredited by a national disability care and support scheme.

It notes the move to individualised funding packages for people with a disability under a national disability care and support scheme and highlights some of the issues related to this important question.

Aspect's proposal emphasises in the interests of prevention, equity and social justice, the importance of a national approach, particularly given the evidence regarding prevalence growth.

A national approach ought to ensure appropriately accredited providers and evidence-based interventions and treatments, to improve outcomes and to better manage risks and costs for individuals, families and their communities.

A national funding mechanism is essential to building a quality sustainable service delivery system for the future, for people who have an autism spectrum disorder.

Governments in Australia have recognised the need to support the autism community and have delivered introductory funding such as the Australian Government's Helping Children with Autism package, education funding through state governments, and the

projects funded through the likes of the NSW Government Human Services department of Ageing Disability & Home Care.

The national disability care and support scheme must ensure this funding continues and is expanded to reach all of the autism community. All governments have said that particularly the early intervention programs are a start. There is a great need to give people with autism support to access funding throughout their life from diagnosis and early intervention through to their older years so they can maximise their potential and their contribution to society.

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