

March 2005
Issue 2



ATTORNEY-GENERAL
THE HON PHILIP RUDDOCK MP

NEWS RELEASE

27 January 2005

013/2005

REVIEW OF THE *DISABILITY DISCRIMINATION ACT*

The Australian Government has announced its response to the Productivity Commission's review of the *Disability Discrimination Act 1992* (the DDA), which found that the DDA appears likely to have produced net benefits for the community.

Attorney-General Philip Ruddock said the Commission noted that the Act had been reasonably effective in raising awareness of the rights and abilities of people with disability, and in reducing overall levels of disability discrimination.

However, the report concluded that there is room for improvement and people with a disability still face too many barriers to the fullest possible participation in Australian society.

The Commission identified areas in which the effectiveness of the DDA could be improved and made a number of recommendations for improving its operation and clarifying the way various aspects of the Act work.

The Government has accepted a majority of the Commission's recommendations, either in full or in part.

"The Government accepts that it is necessary to clarify that the DDA does require organisations to make reasonable adjustments to eliminate discriminatory barriers," Mr Ruddock said.

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“However, explicit recognition of this duty is balanced by expanding the operation of the unjustifiable hardship defence.

“We must ensure that adjustments will produce net benefits for the community without imposing undue hardship on the organisations required to make them,” Mr Ruddock said.

Other recommendations accepted by the Government include clarifying the operation of the DDA by amending some definitions and providing for more options to facilitate the operation of the DDA such as actions plans and co-regulatory plans.

Mr Ruddock said the Government has not accepted some recommendations which will not improve the operation or effectiveness of the DDA, nor provide net benefits to the community.

Media Contact: Steve Ingram 0437 042 554

Eds Note: The Government response will be available at <http://www.ag.gov.au/PCDDA>

Convenor's message

Dear A4 member,

The transition from 2004 to 2005 has unfolded. Many of us have new teachers or new schools. Others are in new locations and have many new experiences. Some changes are forced on us by the progress of time. As individuals we change; others change and the world we live in changes. Sometimes we seek change hoping for improvements.

In any case, change causes stress. Someone said, “Change is inevitable”. This means that stress is inevitable. As a born optimist, I look on the bright side to minimise stress — I see change as an opportunity. Hopefully, we each benefit from change or can at least turn change to some advantage.

We should learn from change. If you have learned something that could help others, please write it down and share your experience and wisdom with fellow A4 members. Please send your stories to our editor via edit@a4.org.au.

If changes have not gone well for you, make sure people know about it. In particular, you need to tell the people who should help. Tell the service provider, case manager, your GP (see below) or a politician. In schools, tell the Principal. Sometimes a local association or support group can help. Remember, people can't help you unless they know you need it.

While A4 has no capacity to help individuals, some of the articles in this edition might give you ideas about what else to try or where else to look for help and support.

Harry Truman said, "You can accomplish anything in life, provided that you do not mind who gets the credit". So when the school says, let's do X and X is what you always wanted ... just keep quiet. Don't say, "That's what I said 3 weeks ago". Instead, act like you are genuinely impressed and say, "What a fantastic idea of yours".

Regards

Bob Buckley – A4 Convenor

Allied Health roles relating to autism/ASD

If you are responsible for care and support for a child with autism or ASD you may wonder about getting professional help. Experts tell us children with autism need assessment and early intervention from a multi- or trans-disciplinary team.

The following article looks at who the members of such a team might be and the roles they have in early intervention for autism and related disorders.

In Australia, service agencies typically think in terms of speech pathology, occupational therapy, physiotherapy, social work and psychology. The different disciplines bring varied approaches to the treatment, care and support of people with autism.

Speech pathology

The Speech Pathology Australia website is www.speechpathologyaustralia.org.au The *Scope of Practice* document on the website says:

Speech pathologists may:

1. Provide clinical services such as:
 - Assessment and diagnosis of communication and swallowing disorders (independent of other professionals)
 - Goal setting
 - Treatment
 - Counselling on aspects of communication, swallowing disorders and therapy
 - Discharge and resolution planning
 - Client/family education and support
 - Documentation
 - Screening and identification
 - Prevention
 - Collaboration
 - Onward referral to relevant services
 - Management (accommodating diverse needs of specific populations)
 - Advocacy on behalf of clients
- Provide specialist advice, selection and prescription, design and establishment of intervention programs and training in the optimal use/ maintenance of, for example:
 - Augmentative and alternative communication techniques and strategies
 - Communication technology and software
 - Tracheostoma, laryngectomy and voice prostheses
 - Assistive devices (Note: this does not include sensory devices used by individuals with hearing loss and other perceptual disorders)
- Use instrumentation (e.g. video fluoroscopy, electromyography, nasendoscopy, stroboscopy, electrical stimulation, and communication technology) for intervention/rehabilitation and diagnosis (i.e. to observe, collect data and measure parameters of communication and swallowing or upper aerodigestive functions)
- Address behaviours and make environmental modifications that affect communication, swallowing or other upper aerodigestive functions i.e. dietary modification, tracheostomy management
- Provide services such as hearing screening, auditory training, speech-reading, interpretation of audiological report, speech and language intervention/rehabilitation secondary to the hearing loss or central auditory processing disorders
- Provide services to modify or enhance communication performance (e.g. preventative voice care, accent modification)
- Conduct service management activities such as:
 - Human resource management, including supervision of speech pathology students and colleagues, mentoring, recruitment
 - Business planning
 - Financial management
 - Physical resources and facilities management
 - Marketing and public relations
 - Quality improvement
 - Education of others (students, staff, carers and significant others and the community)
 - Research

- Negotiate service delivery models, referral and prioritisation procedures and team processes
- Serve as expert witnesses in court

PURPOSES

For particular populations in Australia, speech pathology services may be aiming to achieve different outcomes. Some examples of these outcomes include:

2. Maintaining current communication and/or swallowing abilities
3. Improving the communication and/or swallowing abilities of clients
4. Facilitating access and participation in education programs, return-to-work programs and community-life activities
5. Improving educational outcomes
6. Improving general health, well-being and quality of life
7. Preventing communication disability and swallowing handicaps
8. Preventing respiratory problems associated with swallowing difficulties, reducing health risks and length of hospital stay
9. Educating others about communication and/or swallowing disorders, intervention and management
10. Improving communication performance at work
11. Improving social and family relationships
12. Facilitating independence in the community
13. Improving the communication environment

APPROACHES

Speech pathology services may be delivered using varied approaches, with speech pathologists functioning either independently of other professionals or in close partnership, according to the situation. Some examples of service delivery approaches include:

14. Early intervention
15. Use of natural contexts for assessment and intervention (i.e. home, school classrooms, work settings, community)
16. Clinic-based intervention
17. Intensive programs
18. Training volunteers and significant others as facilitators of intervention programs
19. Multidisciplinary, interdisciplinary and transdisciplinary teams
20. Collaborative and consultative partnerships
21. Family-centred approaches
22. Holistic patient care and management (i.e. considering all aspects of the individual's life and well-being)

You can talk with speech pathologists working in your local area to find out how speech pathology might help treat autism or ASD. Generally, speech pathology services start with an assessment or evaluation; usually followed by discussion to develop a treatment plan or program of intervention.

Searching Speech Pathology Australia website for “autism” or “asperger” finds no documents.

The Speech Pathology Australia website lists the Australian universities that train speech pathologists. If you are interested, you can look up course details and gauge how much training in the specific treatment of autism each university course provides.

Occupational therapy

The website for OT AUSTRALIA is www.ausot.com.au. The page “about OT” says:

“Occupational Therapists are health professionals who are trained to assist people to overcome limitations caused by injury or illness, psychological or emotional difficulties, developmental delay or the effects of aging. Their goal is to assist each individual to move from dependence to independence, maximizing personal productivity, well being and quality of life.

...

“Infants and Children. Occupational Therapy promotes normal development and stimulates learning in children with specific learning difficulties, physical disabilities, delayed development, or those recovering from illness or injury. Occupational Therapists work with

children and their families to improve their quality of life by helping them to participate in play, pre-school, school and home activities.

...

“Treatment: Depending on the nature and length of the programme, it may take place in a clinic, hospital ward, residential care centre or at the client's home, school or workplace. The goal is to maximise the client's skills for living.

I appreciate optimism. But if OT services delivered fully on these promises (e.g. to “overcome limitations caused by ... developmental delay”, to “[promote] normal development and stimulate learning in children with ... delayed development”, etc.), autism would need no other service. OT methods and approaches can help with some problems associated with autism. Contrary to these unconstrained claims, OT is not known to address the full range of developmental and learning challenges that autism typically presents.

The Evidence Based Practice web-page does not mention of “autism”, “Asperger” or “ASD”.

You can talk with OTs working in your local area to find out how OT might help treat autism or ASD. Generally, OT services start with an assessment or evaluation; usually followed by discussion to develop a treatment plan or program of intervention.

The OT Australia website lists the Australian universities that train OTs. If you are interested, you can look up course details and gauge how much training in the specific treatment of autism each university course provides.

Physiotherapy

The website for the Australian Physiotherapy Association is apa.advsol.com.au. The website tells us:

Physiotherapy is a health profession concerned with maximising mobility and quality of life by using clinical reasoning to select and apply the appropriate treatment.

Physiotherapy practice has a long history and modern clinical practice is heavily reliant on research evidence.

Physiotherapy extends from health promotion to:

- Injury prevention;
- Acute care;
- Rehabilitation;
- Maintenance of functional mobility;
- Maintenance of the best achievable health in people with chronic illness;
- Patient and carer education;
- Occupational health.

Physiotherapists are first contact practitioners who are a key element of primary care in Australia.

This description does not help me understand how a physiotherapist would help a person with autism or ASD. Searching their website for “autism” or “asperger” finds no documents.

Numerous reports show people with a developmental delay, a category that includes autism/ASD, experience high levels of chronic and undiagnosed illness; and reduced life expectancy. These reports leave doubts about whether physiotherapists are effective for people with a developmental delay in their primary care role as “first contact practitioners” extending to “acute care”, “rehabilitation” and maintaining “the best achievable health in people with chronic illness”.

You can talk with physiotherapists working in your local area to find out how they might help treat autism or ASD.

Social work

The Australian Association of Social Workers website is www.aasw.asn.au. The website says:

Social work is the profession committed to the pursuit of social justice, to the enhancement of the quality of life and the development of the full potential of each individual, group and community in society. Social workers pursue these goals by working to address the barriers, inequalities, and injustices that exist in society, and by active involvement in situations of personal distress and crisis. This is done by working with individuals towards the realization of their intellectual, physical and emotional potentials, and by working with individuals, groups and communities in the pursuit and achievement of equitable access to social, economic and political resources. Social workers also pursue their goals:

Through involvement in research, policy development and analysis, consultancy, and management.

Work with individuals, groups and communities to shape and change the conditions in which they live.

Advocate for disadvantaged members of society.

Work towards the elimination of structural inequalities in society to facilitate a more equitable distribution of resources.

Engage in research to build our knowledge base and understanding of society.

Analyze, challenge and develop social policies.

Social work practice is informed by professional education based on an analysis and understanding of human development and behaviour and of complex social processes. It accepts a commitment to working within a stated value position and code of ethics. An integral part of the education of each social worker is the demonstration in practice settings of this analysis, understanding and commitment.

It is not clear to me from this description how a social worker would help my son with autism. On the contrary, most social workers regard my son as being advantaged by our family's socio-economic position and the advantages that normally brings.

In relation to autism/ASD, it is unclear whether a social worker would have the specialised skills needed to realise "their intellectual, physical and emotional potentials". Many social workers are paid by government so their ability to act politically is limited by their self-interest. So their effectiveness in "working to address the barriers, inequalities, and injustices that exist in society" may be less than optimal.

A search of the AASW website (using Google) found a title and abstract for a conference presentation given last year on service management issues by NSW Autism Association staff. It did not look to me like it would help a social worker treat or support my son's autism.

Psychology

The Australian Psychological Society (APS) website is www.psychology.org.au. It says:

Psychologists are experts in human behaviour. Most psychologists help mentally healthy people to find ways of functioning better. For example, they train people to handle stress and family problems. Psychological therapies are also widely used by groups and organisations.

In comparison, psychiatrists work mainly with the mentally ill, such as people who have schizophrenia. Read about [differences between psychologists and psychiatrists](#).

Despite this, a significant burden of ASD assessment generally falls to psychologists.

Overseas, some psychologists who specialise in Applied Behaviour Analysis take a particular interest in treating autism. Such psychologist aim to prevent or minimise mental illness such as clinical level depression or anxiety in their clients, or recognise and treat these condition when these disorders emerge. Research reviews conducted by psychologists generally report that behavioural treatments provide the strongest empirical evidence of success in treating autism/ASD.

In Australia, psychologists routinely analyse and apply behavioural methods to treat cases of challenging behaviour; but rarely are they given responsibility for preventing challenging

behaviour associated with ASD (and other developmental delays, disabilities and mental illnesses) from developing.

With a few notable exceptions, the knowledge and skill base applicable to ASD in this discipline is largely undeveloped in Australia.

Searching the APS website for “autism” or “asperger” finds no documents.

Once again, talk with psychologists working in your local area to find out how they might help treat and manage a person’s ASD.

Discussion and conclusions

None of the allied health disciplines, as they operate in Australia, is especially equipped to treat and support children with autism/ASD. Parents need to assess the extent of knowledge and experience allied health professionals have so they can understand the quality of the treatment and support they get from the professionals.

Parents with a breadth of experience say they appreciate particular individuals rather than particular disciplines. They like individual professionals who focus on and do well with children with autism/ASD. Governments and service managers need to recognise that not all professionals are equal when it comes to services for people with ASD.

People who are effective at treating ASD are not limited to allied health professionals. A few teachers are especially good though most teachers (including many who are responsible for students with ASD) lack the training and experience they need for a role in relation to students with ASD (and some teachers lack the aptitude). Families come to appreciate the particularly well-suited individuals. These individuals may be drawn from other areas; for example GPs, child psychiatrists, dentists, childcare & respite workers, etc.

Since quality of service dependents so completely on particular individuals, continuity of services is especially difficult to manage. Few service managers’ recognise/appreciate/acknowledge how difficult transitions often are for the family of a person with ASD in the services they manage.

GP’s role in challenging behaviour

You can find out about your GP’s role from their website www.racgp.org.au. In particular, you might be interested in documents like *the assessment and treatment of behavioural problems* (see <http://www.racgp.org.au/document.asp?id=14014>). This article quotes a definition that says challenging behaviours is “behaviour of such intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to the use of ordinary community facilities”. Here are some examples of behaviour that I suggest meets this definition:

<i>Behaviour</i>	<i>... is challenging if or because</i>
Runs (absconds)	The child has no road sense so the child is likely to put itself in serious physical danger.
Not toilet trained	Seriously limits or denies access to mainstream education settings, public swimming pools, activities for children, etc.
Wakes every night	Extended sleep deprivation puts the physical and mental health of both the child and other members of the family in serious jeopardy.
Anxiety response	reactions impeding family life [e.g. inability to go to the pool, beach, mall, doctor & dentist visits, etc]
Autism/ASD	Autism/ASD limits or denies most people with the condition access to employment when they become adults... increasingly employment is treated as an ordinary community facility.

The article concludes:

“General practitioners have the skills to significantly contribute to the management of behavioural problems in people with intellectual disability or autism. Assessment for underlying medical causes is critical in most behavioural assessments. Psychiatric problems occur more commonly in this group, with depression and anxiety likely to result in behavioural change. Medication may sometimes be used in situations where there is continuing unacceptable risk to the patient and others despite well delivered behaviour management programs. In all these situations, assessment relies on an accurate description and history of the behaviour. The ultimate treatment goal should be the best quality of life for the patient.”

So ask your GP (nicely) for help. Please ensure you approach them in a way that makes them want to help you. In the event that your GP cannot help, he/she has the professional responsibility to refer to specialised health or allied health practitioners who can help.

Media Release

Minister for Family and Community Services

Take part in Australia-wide in-home care review

10/02/2005

The Minister for Family and Community Services, Senator Kay Patterson, today invited service providers and clients to take part in the Howard Government's review of In-Home Care.

In-Home Care is a flexible form of child care where care is provided in the child's home by an approved carer. It may be available for families who cannot use a standard child care service, or where their child care needs cannot be met by an existing service. This includes families where the parent or child has an illness or disability, families in rural or remote areas, parents working shiftwork or non-standard hours or breastfeeding mothers working from home.

"The review will examine the extent to which In-Home Care is meeting the needs of Australian families as part of the Australian Government's Stronger Families and Communities Strategy: Choice and Flexibility in Child Care," Senator Patterson said.

"I am encouraging service providers and clients to contact my department to take part in this valuable review which will result in the better targeting of future services.

"Providing quality In-Home Care services for families is a key priority for the Howard Government and this review will help ensure that services are targeted to children most in need.

"Families, their children and communities will gain insightful information from the Australia-wide review into qualified child care workers caring for children in the family home," Senator Patterson said.

"The \$365.8 million Stronger Families and Communities Strategy is responding to community needs by focusing on the health, wellbeing and capacity of the next generation of Australians.

"The Strategy is focused on early childhood development as guided by the latest research and consultation feedback from the National Agenda for Early Childhood," Senator Patterson said.

Service providers or clients of In-Home Care who would like to be consulted during the review should contact the Department of Family and Community Services on 02 6212 9177.

Families wanting more information on child care can contact the Child Care Access Hotline on 1800 670 305 or visit the website at <http://www.facs.gov.au/>.

Related information

Family and Community Services [<http://www.facs.gov.au>]

Parent Support Group

for
Parents of Young Adults with
High Functioning Autism Spectrum Disorders

**JAN – JULY 2005
PROGRAMME**

Our aim is to give mutual support to parents, carers and families in an informal, non-threatening but sometimes frank forum.

This may enable us to be better informed, possibly give us access to better services, increase our knowledge and find out you are not alone.

It certainly helps to share the caring and discuss our concerns with people who understand.

As a group it better enables our voice to be heard.

The evenings include informal socializing and discussion about issues affecting us as parents. The mood is relaxed and individuals may contribute ideas and experiences or simply sit back and listen. Whilst discussion is around the issues that are common for parents who have a young adult with an autism spectrum disorder, the purpose of the evenings is for parents only. It was agreed that parents often need a sounding board or another person with whom to share experiences without the presence of their respective children.

**Contact: Robyn Copeland
8379 2117**

CHAT/INFORMATION SESSIONS

Where?

Astor Hotel
437 Pulteney St, Adelaide
(Corner of Gilles Street)

Time?

7.00pm for 7.30pm start
Drinks and meals are available at reasonable prices.

Dates?

7th February – Informal meeting
4th April – “After school, then what?”
2nd May – Educationalist – Mark LeMessurier “Maintaining Educational Resilience”
6th June – Community Living
4th July – Informal meeting

INFORMATION/EDUCATIONAL SESSIONS

Where?

Autism SA premises
3 Fisher Street Myrtle Bank
Back building
Parking on premises

Time?

7.30pm – 9.30pm

Dates?

7th March – Welcome & watch video “The Asperger point of view”
18th April – Centrelink options
20th June – Tenancy Support Project Update

COFFEE SESSIONS

Where?

Se-Juiced for Lunch
70 Hindmarsh Sq, Adelaide

Time?

1.00 pm

Dates?

25th February
29th April
24th June

Contact:

Lyndall Parkin
Phone: 8344 4561

Letters to the Editor/A4

Dear Editor,

I don't know if you can help me or if you could put something in your newsletters, but:

I have a 9 year old autistic son (ADHD, Autism, Epilepsy from 20 months old onwards) and all the obsessions that go along with it. At the moment he is infatuated with breaking branches off trees. (It doesn't matter where we are either, parks etc.) After he breaks them, he has been dragging them around everywhere he goes (just finally stopped them coming into the house). He also likes hanging them over higher up branches (that can't be reached) or sawing them over the higher branches. (At xmas time, our tree was totalled by him - stripping it of all tinsel & decys & dragging it around - even taking the damn thing to bed.) Our xmas tree has been shopping with us, everywhere we went, the tree went too.

If this was happening in my own yard I wouldn't mind as much as I do in a rental property. Do any of your members have any prior experience in this field that can help me?

RachelleMcNally

Email: mcnallyr@maroochy.qld.gov.au

"Risk more than others think is safe
Care more than others think is wise
Dream more than others think is practical
Expect more than others think is possible
And never, ever give up"

A4 Contacts

Update team (newsletter)
edit@a4.org.au

A4 Convenor, Bob Buckley
convenor@a4.org.au

Treasurer (donations)
treasurer@a4.org.au

Profile

This months profile is on everyone's favourite little rabbit.

NAME: Easter Bunny

BORN: Into a large family

LIVES: Here, there and everywhere

FAMILY: Also here, there and everywhere

LIKES LISTENING: To hungry tummies that I can fill up with lots of yummy eggs

LIKES READING: Easter cards

LIKES RELAXING: In a big bath of melted chocolate

LIKES EATING: I'm positive you all know the answer to this one!!!!

LIKES: Bright coloured foil

DISLIKES: Myxomatosis

IDEAL WEEKEND: Easter weekend

LAST HOLIDAY: The week after Easter in 2004

NEXT HOLIDAY: The week after Easter this year