Submission to

Productivity Commission Inquiry into the *Disability Discrimination Act 1992*

Robert Buckley

My son has autism. This submission focuses on issues relating to children with autism. It discusses discrimination issues relating to people with autism, the social and productivity impact of discrimination as well as the role of the DDA in this context.

While this submission raises concerns, I want to first acknowledge that the DDA produces many positive outcomes for people with a disability. The DDA encourages effort to increase public and political awareness of disability issues.

Autism is a neurological disorder diagnosed on the basis of abnormal communication, social skills and behaviour. It is present from an early age and is life-long. Without effective treatment, children with autism often experience significant learning disorders and poor outcomes in the long-term. The DSM-IV, a primary reference on autism, states:

> "Available follow-up studies suggest that only a small percentage of individuals with [autistic] disorder go on as adults to live and work independently. In about one-third of cases, some degree of partial independence is possible. The highest functioning adults with Autistic Disorder typically continue to exhibit problems in social interaction and communication along with markedly restricted interests and activities." *(DSM-IV-TR, 2000, p73).*

Autism is a significant burden on our community. The AIHW estimated in 1999 that autism was fourth highest burden of disease for boys aged 0-14 years. This estimate is based on old data from overseas that reported autism occurs in children at the rate of 4 per 10,000. Recent data in Australia shows the rate of diagnosis for Autistic Disorder is now 20 to 40 per 10,000 children. The diagnosis rate for the whole autism spectrum is around 1% of Australian children. Annex A shows some of the available data for diagnosis rates. The rising level of autism in our community is alarming and demands attention; but it is largely unrecognised or ignored by Commonwealth and state authorities.

The cost to the community of adults with autism is unknown. The Gallop Inquiry[1] in the ACT was told the average cost of a place in the most basic supported accommodation is over $70,000 per annum. As people with autism typically have above average needs, the average cost of supporting an adult with autism will be significantly more than the average cost of disability support. People with autism need this level of support for most of their adult life.

Autism is a massive yet unrecognised burden on Australians. It can be a particularly debilitating condition. Autism profoundly affects the productivity of people associated directly or indirectly. The productivity of family members is affected, though the extent of the effect is unknown. Siblings are adversely affected in their education and health, so their productivity is diminished. Children with untreated autism can impact adversely on chronically under-resourced education settings; reducing teacher productivity and the progress of fellow students.

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[1] The Hon. John Gallop (Dec 2001), *Board of Inquiry into Disability Services: Final Report*, Australian Capital Territory.

The economic impact a child with untreated autism in a family is considerable. For example, I closed down my business as it was not possible to run a business successfully and support a child with autism at the same time. Through most of 1997 and 2002 there was no suitable educational placement available for my son; on both occasions my wife had no option but to stop working to support my son.

Many families do not survive a child with autism. Researchers report an increased rate for family break-up where there is a child with autism. Researchers also observe substantially increased incidence of mental health problems in families where a child has autism.

Some insight can be gained into life with a child with untreated autism from the Victorian government Disability Online website[2] that says in part:

> **Safety in the home**
>
> Parents are used to childproofing their homes, but children with autism may need extra precautions. However, it is important to find a balance between keeping your child secure and making sure your home is also still safe and easy to get out of in an emergency like a fire. Talk to a locksmith and other parents who face similar issues. Suggestions include:
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> - You may have to board up your windows if your child likes listening to breaking glass. In some cases, you can install foam. Use picture frames with plastic instead of glass.
> - Some children with autism are experts at escaping the most secure homes. Talk to a locksmith about installing lockable security doors on all exterior doors and window locks - but make sure you can still get out quickly in an emergency.
> - Use key-lock door knobs (or bolts or chains installed high on interior doors) to keep your child in their room at night, or to block access to certain rooms.
> - Fence your front and back yards.

The impact on the productivity for parents and siblings of having to live like this needs to be considered.

Relatively little has been done to understand the cost of autism and the cost/benefit of alternative approaches to addressing needs. Annex B provides some basic costs based on data from ACT government sources.

Children with autism need effective services. They get the greatest benefit from appropriate early intervention. Effective early intervention, were it available, would better prepare children with autism for school and their community. Early intervention programs that improve their communication, social skills and behaviour increase the number of people with autism who can learn to live independently and participate in some form of employment.

Delays or omission of timely services mostly compound the level of disability for people with autism. Short-term savings exacerbate the long-term expense.

The UN Convention on the Rights of the Child, a treaty ratified by the Commonwealth Government, describes treatment, rehabilitation, education, etc. as basic rights of a child.

The DDA is meant to protect those rights but in practice the DDA fails to protect some of the most vulnerable members of our community. Children with autism need effective early intervention that is autism-specific and delivered at an intensity that

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[2] On the www.disability.vic.gov.au website, follow the links to: Disability topics -> Intellectual-> Autism -> Autism - suggestions for parents. Note that "Autism" should be located in the "Neurological" group rather than the "Intellectual" disability group.

improves their functioning and long-term outcomes. Essential early intervention for children with autism is difficult or impossible to access in Australia.

Autism is a clinical diagnosis that means a person with such a diagnosis requires clinical attention. Except in a few instances, state health systems do not provide clinical intervention for children with autism. Australian authorities do not recognise the treatment and rehabilitation needs of children with autism.

The DDA specifically mentions certain areas of service but does not specifically mention Health. Any discrimination relating to health services would need to be addressed under the general services category.

The DDA is unclear. Interpretations of the DDA vary widely which makes it ineffective. The Disability Discrimination Act Inquiry Issues Paper says:

> “For example, a lack of support services, such as funding for a particular therapy or device (such as a wheelchair), may prevent access to employment or education, effectively discriminating against a person with a disability.” (page 11)

HREOC, the body that administers the DDA, has a different view from the Productivity Commission. HREOC says the DDA does not provide protection from discrimination of a form where a service, that may be essential in order to access employment or education, does not exist. A representative of HREOC wrote (30/4/2003):

> The Disability Discrimination Act … does not compel the government to have in place programs which it does not have, or to resource programs adequately, however necessary this may be for people with disabilities. It is not possible therefore to use this law to compel government to fund more adequate early intervention services.

The Productivity Commission interprets the lack of an essential treatment or therapy as effectively discriminating against a person with a disability. My observation is that the community expects the DDA to provide such protection to people, especially children, with a disability. HREOC and the courts, who together administer the DDA, do not regard the DDA as having any authority in this regard. In practice, the DDA does not protect the right of a child with autism to the treatment and rehabilitation needed.

Without treatment to rehabilitate their communication, social skills and behaviour, children with autism usually experience severe learning difficulties in school. Education authorities are reluctant to provide for the special needs of children with autism; needs that are exacerbated by the lack of effective early intervention.

Children with autism have particular needs (see for example, National Research Council — C. Lord and J. McGee,eds. (2001) *Educating Children with Autism*, National Academy Press, Washington DC) that simply are not met by education systems in Australia. While we can observe progress in providing access to education for students with physical, medical and sensory disabilities, there is little evidence that children with autism can access an effective education that meets their special needs.

Available evidence shows the DDA has not been effective in relation to disability discrimination matters in the area of education. A survey on this issue reported:

> "Of the 1307 individual respondents, 301 have lodged a complaint about discrimination in education under either the DDA or their State/Territory anti discrimination legislation. Only 2 of these were satisfied with the outcome. The remainder, 299 respondents, indicated they were unhappy with the outcome because they:

> - only settled because they couldn't afford to continue either financially or emotionally;
> - were concerned about the lengthy hiatus in their child's education;
> - felt they were getting nowhere with the process;
> - original outcome was okay but it broke down at a transition point or education provider reneged on agreement.
>
> All 301 respondents indicated that they would never lodge a complaint again, no matter how bad things got."[3]

The DDA is not an instrument that protects the rights of children with a disability to primary or secondary education, as described by the UN Convention on the Rights of the Child. In practice, bringing a discrimination complaint in relation education is a gamble at best. It is almost impossible to find knowledgeable legal assistance. The law is unclear and there are few precedents. Few Australians have the financial capacity to sustain an extended legal battle with a government agency. If a person has enough money to support their child through an extended legal battle over a discrimination matter and bring a discrimination matter under the DDA, actuarial analysis shows they would get better odds and a better outcome from buying lottery tickets.

The legal system and the law are unsympathetic on disability issues. In fact, laws in Australia condone discrimination against people with a disability in the conduct of programs. This is clearly stated in paragraph 13 of the ruling AT98/14 (ACT Health and Community Care Service vs Discrimination Commissioner, Vella, Griffin, Hill & Dempster -- see attached), where it states:

> ... nothing done in the course of a program designed to meet the special needs of disadvantaged persons can be the subject of a complaint of discrimination under the Act by any person, including a member of the class of disadvantaged persons that the program is intended to benefit.

Similar interpretations have been given in other states. HREOC says "the Vella decision was as you know under the ACT Act not the DDA; we do not regard it as representing the effect of the DDA an do not take the same broad approach to the special measures exemption in our complaint handling" (see Annex C, 6/5/2003). However, state authorities can simply hold out until a complaint reaches the court then they just cite such precedents and HREOC's view is irrelevant. Few families can obtain effective legal advice and assistance in discrimination matters, let alone sustain an extended legal battle and support a child with autism at the same time.

Without the benefit of basic preparation for school though effective early intervention, the cost of effective education for children with autism is considerable. Education authorities find it difficult to justify expensive individual programs for such challenging individuals; so many children with autism cannot access an education service that meets their needs. Without access to effective education, people with autism have little prospect of participating in productive employment.

The modern workplace is unsuitable for people who are different. Increasingly, workplaces in large organisations are designed for "normal" people: people are expected to fit into positions designed for particular types of workers. Rarely are positions in large organisations designed for "abnormal" people so large organisation employ few people with differences. Small businesses have more difficulty

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[3] Robert Jackson, James McAfee and Judith Cockram (February 1999), *Disability Discrimination in Education: Discussion Paper*, Centre for Disability Research and Development, Edith Cowan University, pp6-7.

accommodating people who are “different”; so there are fewer places for people who vary from the norm in our modern highly competitive workplaces and economy.

People with autism do not fit the modern education system and will not fit into the workforce. The number of people with ASD effectively excluded from the workplace is substantial. We have seen an alarming rise in the rate of diagnosis but there has been no recognition of the increase by governments at either Commonwealth or state level. So far, diagnosis of Autistic Disorder has risen between five and ten times in the last decade yet services remain at almost the same level. So services to the individual have been cut by 80% to 90% over the same period. And increasingly, governments and the community blame people with ASD for the circumstances they place them in.

People with abnormal communication, social and behavioural skills simply can’t compete in an increasingly competitive employment arena. Increasingly they are excluded from the workforce. As a result, the whole community may not be as productive as it might be if it were more accommodating of people with difference in a larger workforce.

In conclusion, I make the following observations:

- the DDA does not protect the rights of children with autism to treatment and rehabilitation in the form of effective early intervention for their autism;
- the DDA does not ensure children with autism have access to effective education services; and
- the cost to the community and the impact on productivity of these limitation of the DDA are unknown — and are likely to be substantial.

your sincerely

Robert Buckley

Attachments:

Annex A: Diagnosis rates for ASD

Annex B: Costs associated with a child with autism

Annex C: Dialogue with HREOC

Annex A: Autism/ASD diagnosis rates in Australia

The number of people in Australia being diagnosed with an autism spectrum disorder (ASD) has risen alarmingly over the last decade. Previously, autism was considered a relatively rare condition in Australia, little data was being collected and autism research was limited. Following is evidence that the significance of autism and autism spectrum disorders has changed.

Similar changes have been observed overseas. Major foreign agencies revised their estimates of autistic disorder (AD) and ASD prevalence significantly upward in recent times. The Medical Research Council in the United Kingdom conducted a comprehensive review of autism research and reported on the epidemiology and causes. Their panel of international experts reports[1]:

> “according to recent reviews, there appears fairly good agreement that the autism spectrum disorders affect approximately 60, and narrowly defined autism 10–30, per 10,000 children under 8 [years of age].” page 18.

The US Department of Health and Human Services, based conservatively on information provided by the NIH and the CDC, says:

> “Autism affects an estimated 10 to 20 of every 10,000 people, depending on the diagnostic criteria used. Most estimates that include people with similar disorders are two to three times greater.”[2]

The CDC found, in studying children aged 3–10 years

- for a smaller group “The prevalence of all autism spectrum disorders combined was 6.7 cases per 1,000 children. The prevalence for children whose condition met full diagnostic criteria for autistic disorder was 4.0 per 1,000 children, …”[3]
- for a large group, “The prevalence for autism was 3.4 per 1,000 (95% confidence interval [CI], 3.2-3.6) (male–female ratio, 4:1)”[4] in 1996 though “the prevalence rate of 34 per 10,000 is, however, likely to be an underestimate”[5].

Data collected in the context of education services rather than health or clinical services typically show higher occurrences of ASD in children.

The latest edition of the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorder, Fourth Edition, Text Revision (2000) known as the DSM-IV-TR reports conservatively that Autistic Disorder affects 2—20 per 10,000. It says data on Asperger’s Disorder are lacking and does not mention prevalence in relation to PDD/NOS or atypical autism.

Previously autism was regarded as a rare disorder. Based on overseas information, conventional wisdom was that Autistic Disorder affected 2—5 per 10,000. Prevalence estimates for the rest of the spectrum were largely guesswork.

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[1] see http://www.mrc.ac.uk/PDFs/autism_report.pdf.

[2] see http://www.ninds.nih.gov/health_and_medical/pubs/autism.htm.

[3] J. Bertrand, A. Mars, C. Boyle, F. Bove, M. Yeargin-Allsop, P. Decoufle (Nov 2001) *Prevalence of Autism in a United States population: the Brick Township, New Jersey, investigation*, Pediatrics 108(5), pp1155-61.

[4] M. Yeargin-Allsop, C. Rice, T. Karapurkar, N. Doernberg, C. Boyle, C. Murphy (Jan 2003) *Prevalence of Autism in a US Metropolitan Area*, JAMA, 289(1), pp49-55.

[5] E Fombonne (Jan 2003) *The Prevalence of Autism* (Editorial), JAMA, 289(1), pp87–89.

The number of children being diagnosed with an autism spectrum disorder in various regions of Australia is described below. Data show the current situation where:

> "Over the whole of Australia between 0.6 per cent and 1 per cent of children are affected by autism or a related disorder."[6]

In the ACT, most children with ASD were referred to a single centre (CAMHS) for diagnosis[7] until 1998. Due to severe gaps in disability services in the ACT more recent data is not available.

The WA Register for Autism Spectrum Disorders 2001 Report (September 2002) also provides some data. The report does not account for the rising rate of registrations.

Region	*Year*	*ASD*	*Autistic Disorder*	*AD/ASD*
ACT	1989	17	11	*65%*
ACT	1997	45	20	*44%*
WA	1999	159	*111*	70%
WA	2000	173	*121*	70%
WA	2001	204	*153*	75%

Both sets of data show that most children with autism/ASD receive their diagnosis in early childhood.

Comparing the rate of ASD or Autistic Disorder diagnosis to population birth-rate estimates the prevalence of autism/ASD in the respective populations. A simple estimate of prevalence is obtained by dividing the annual rate of autism diagnosis by the annual birth rate.

	ASD	*Autistic Disorder*	*birth rate*[8]	*ASD per 10,000*	*AD per 10,000*
ACT 1997	45	20	4500	100	44
WA 2001	204	153	26440	77	58

This method of estimating prevalence assumes the rates will remain constant; in technical terms, we assume "steady state". In practice, we know this is not the case. Firstly, the birth rate is not constant. Varying birth rate can be allowed for using a weighted average of population size but this makes very little difference to the resulting prevalence estimate.

More significantly, diagnosis rates obviously are not at steady state. This method of estimating prevalence assumes that the rate of diagnosis suddenly levels off. But

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[6] Employment, Workplace Relations and References Committee (December 2002), *Education of students with a disability*, The Senate, p54.

[7] H. Baker, (April 2002) *A Comparison Study of Autism Spectrum Disorder Referrals 1997 and 1989*, JADD, Vol. 32, No. 2.

[8] Baker provides ABS population estimate for the ACT for ages 0–19 years. For WA we estimate birth rate from data on the WA government website: 396,601 people aged 0–14 years gives a birth rate around 26440 per year.

there is no evidence supporting this assumption. Contrary to the principle of scientific induction[9], we sincerely hope the rate of ASD diagnosis will not continue its recent dramatic rise. In the absence of evidence, we hope the pattern of diagnosis plateaus at or below the level observed in the most recent data (rather than continuing to rise as suggested by the pattern of recent observations).

Both these data sets follow the commonly encountered pattern: that smaller populations show higher prevalence.

Two other recent reports show similar prevalence of ASD. These report the number of people with an ASD diagnosis in a given age range. This measure under-reports prevalence of ASD as some people in the age range have ASD but have yet to be diagnosed. Further analysis of the distribution of age of diagnosis could improve estimates of ASD prevalence based on these data.

The ABS Survey of Disabilities, Ageing and Carers 1998 data includes people with "autism and related disorders" [10]. The following table shows an estimated occurrence of people having a diagnosis for each 10,000 in various age ranges (the ABS warns the data has a high statistical "standard error" so the numbers are described as indicative). These estimates are based on a small but carefully constructed sample.

age range (years)	*Male*	*Female*	*Total*
0–4			7.8
5–9	82.2	19.8	51.0
10–14	48.7	10.7	29.7
15+			1.2

The drop in ASD occurrence from the 5–9 year age range to the 10–14 year age range suggests significantly increasing rates of diagnosis unless some other plausible explanation can be found. The survey uses self-reporting for people over 15 years of age: self-reporting may not be appropriate for people with autism and related disorders — which could account for the especially low occurrence reported. The ABS Survey of Disabilities, Ageing and Carers will be repeated in 2003.

Gateway Support Services report a comparable result for children aged 2 to 6 years of age in the Barwon region of Victoria. Gateway CEO says:

> "Gateways have identified 69 children between the ages of 2–6 years out of a total regional population of 12,800 (2-6 years) children in 2000." so ASD "may be as high as 1:200".

This rate translates to ~54 per 10,000 children aged 2–6 years having a diagnosis of ASD. If the pattern of diagnosis is like that observed elsewhere (as is likely), a significant proportion of children in this age range with ASD may have yet to be diagnosed; so the prevalence is higher again.

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[9] Scientific induction is the belief/principle that the future will resemble the past, perhaps with expectation that the near future most resemble the immediate past.

[10] This information is not published; it was obtained by asking the ABS specifically for this information. The ABS validates its survey method before conducting the survey. However, this author is concerned that self-reporting may account for significant under-reporting of autism and related disorders in people over 14 years of age.

A survey[11] in NSW has 758 children newly diagnosed with ASD reported to it in 2000. The survey method identified 222 children with Autistic Disorder and 297 children with ASD in the age range 0–14 years. The authors reject a significant number of the diagnoses made by other professionals. The survey method may have some under-reporting as the authors say:

> "Ninety-four (23%) of these professionals either declined to participate in the study or did not respond to the request for participation and were considered non-active participants. An additional 146 participants from a variety of disciplines and work settings became involved in the study following mail-outs, advertising and presentations about the study. As a result the mailing list comprised 466 active participants and 94 non-active participants."

and in relation to children reported to the survey

> "information about the eligibility of 154 is still being sought".

Based on population data from the paper, the birth rate in NSW is up to 89,000 per year. Children were reported to the survey at the rate of 85 per 10,000. Without making any allowance for non-respondents (termed "non-active participants") and/or unresolved cases, the survey confirmed the prevalence in NSW was at least 33 per 10,000 with ASD and 25 per 10,000 have Autistic Disorder. However, without explaining their method, Williams et al conclude:

> "… if a similar number of children were newly recognised each year to have autistic disorder or another ASD then these figures would represent prevalence figures of approximately 1/1000. If children with fewer problems are included along with all the children whose eligibility is still being clarified then the prevalence could be 1.5/1000."

The particularly low prevalence estimates (10 per 10,000 for Autistic Disorder and 15 per 10,000 for ASD) provided to the World Congress deserve better explanation. The NSW Autism Association says autism affects 1 in 100.

Finally, the Assistant Secretary in FaCS responsible for Disability Service Reform wrote (21 January 2001) to Action for Autism:

> "The number of people with autism who need treatment and support for their disability is not known. The Royal Children's Hospital, Melbourne estimates autism occurs in 2.5 of every 10,000 children. Autism spectrum disorders are suggested to be 10 in every 10,000 with boys more likely to be affected."

Of all available sources, FaCS chose one that presented the lowest known estimate of autism prevalence (apparently endorsed by the Victorian Autism Association) based on a misquote of an outdated edition of the DSM-IV. The error was pointed out to both parties. The hospital revised its information to say 2—5 per 10,000 (the current DSM-IV-TR that says 2—20 per 10,000); apparently deciding to present outdated information to health professionals and the public. FaCS did not acknowledge its error and may still be basing its decisions on erroneous information.

In conclusion, most Australian data presents a similar story to that observed overseas. The rate of diagnosis of Autistic Disorder has risen significantly and is generally observed to exceed 20 diagnoses for every 10,000 children. Recognition of the autism spectrum has increased and the rate of diagnosis for ASD is mostly found

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[11] K. Williams, L. Bartak, C. Mellis (November 2002), *The Incidence of Autism Spectrum Disorders in NSW*, World Autism Congress, Melbourne.

to be in the range 60 to 100 per 10,000 children (that is, approaching 1% of children) at this time.

Bob Buckley

A note on methodology

Autism spectrum disorders are conditions that people have from soon after birth and last for the whole of their life. The calculations above assume that each person who is diagnosed with ASD had that condition from an early age and will have that condition for the rest of their life.

This model of prevalence produces higher results than models that aim to count the number of people in the population who have an ASD diagnosis.

Since there is no sign that ASD diagnosis is approaching “steady state”, any single estimate of prevalence or diagnosis rate will omit important parts of the overall picture.

Service cost models
for children with autism
in the ACT

Bob Buckley

Executive Summary

This paper describes results from cost models for children with autism receiving :

- a generic program in a special school
- an ABA program in a two-student learning support unit.

The models report treatment/therapy, education and respite/accommodation costs for using ACT government data. The results indicate that projected average cost of disability services for the children in the Education Department's autism-specific LSU is significantly cheaper than the service costs for a child with autism in special school.

	age	**special school**	**autism-specific LSU**
pre-school	4-5	$19,254	$19,254
primary	6-9	$54,428	$62,575
	10-11	$75,848	$62,575
high school & college	12-20	$96,775	$62,725
average		**$73,882**	**$56,921**

Services for the children in the autism-specific LSU who are now aged 10 years and 12 years are cheaper than services needed by their counterparts in special school.

Based on the same data, the authors propose a service regime for children with autism that has the potential to provide better outcomes than any service regime existing in the ACT for children with autism, yet costs on average between $37,000 and $52,000 per student per year. The improved outcomes and cost savings are expected from early intervention that is intensive and autism-specific. The proposed service regime for the model has the support of a substantial body of quality international research.

Introduction

The increasing rate at which autism and related disorders are being diagnosed in the ACT (see Addendum 1) would alarm policy-makers were they informed of its extent and significance. Increased numbers of children diagnosed with autism means increased demand for relevant services.

Around 25% of children with an autism spectrum disorder have autism. We expect the next ABS disability survey in 2003 will show that of all Australian children aged between 5 and 9 years, over 65 per 10,000 have an autism-related disorder and over 16 per 10,000 have autism. In the early 1990s, around 4 children per 10,000 were diagnosed with autism. The ABS survey in 1998 found 51 per 10,000 Australian children aged between 5 and 9 years have autism or a related disorder.

The majority of children with autism in the ACT are taught in special schools where they also receive therapy services. Mostly, therapy and educational services provided for children with autism are indistinguishable from those designed for children with intellectual disability or mental retardation. The outcome is that children with autism have a poor prognosis. The DSM-IV-TR (2000) says:

> *… only a small percentage of individuals with the disorder [autism] go on as adults to live and work independently. In about 1/3 of cases some degree of partial independence is possible.* (p73)

Professional opinion emphasises that autism spectrum disorders are distinct from intellectual disabilities; and that children with autism can be significantly rehabilitated. Increasingly, parents, carers and the community expect that effective treatment for autism is available for those who need it.

Our community wants better outcomes for people with a disability and for outcomes to be delivered in the least restrictive setting. Authorities in Australia are obliged under the UN Convention on the Rights of the Child to be aware of research published internationally and to act on their knowledge.

ACT governments are optimistic about outcomes for people with autism. There is no basis for this optimism. Numerous submissions to the Gallop Inquiry show people with autism experience particularly poor outcomes and are unable to access the services they need.

Following are cost models showing the cost of children with autism placed in special school and in programs in an autism-specific learning support unit (LSU) at North Ainslie Primary School. We discuss the models. Finally, we propose an approach to treating autism that is cheaper, is based on (internationally recognised) best practice for autism and that we expect to be even more effective than existing approaches in the ACT.

Method

Most children with autism in the ACT are currently in special schools. The costs of service components provided for these children are collected from a range of government reports. The special school cost model sums the cost of treatment/therapy, education and respite/accommodation (support) relevant to children with autism in the ACT.

A second cost model is constructed from the costs associated with the autism-specific LSU that operated at North Ainslie Primary School until the end of 2001.

A child who is diagnosed with autism at an early age may (or may not) receive services in a CHADS early intervention unit (EIU) or an Autism Intervention Unit

(AIU). These services are omitted from the models because there is little relevant cost data, the cost is expected to be relatively small and the initial experience is shared so it makes little difference to the comparisons between models below.

The models show the cost of services for a child with autism entering school at age 5 years through to age 18 when they leave school.

In the ACT, access to therapy services for a child with autism depends on the educational placement and the child's age. Children in special schools may access therapy services from the Disability Program. Children not in special school may access CHADS services. Diagnostic services, when available, for autism were provided by CAMHS. Having obtained a diagnosis, children and adolescents with autism are prevented from further accessing CAMHS services as they then lie outside CAMHS' client base.

Education costs are collected from a number of government sources including annual reports and specific program reviews.

Children with autism and their families/carers may access support services including respite and supported accommodation.

Results

Base Data

The Disability Program, a part of ACT Community Care, provides therapy services for children in special schools, but the therapy services provided for students with autism in special schools, their costs and their effectiveness are not known.

CHADS describes a treatment/therapy service level to meet the needs of a child with autism in Appendix 5 of the Report on the Applied Behaviour Analysis Program based at North Ainslie Primary School, 6 August 1999. Both CHADS and the Disability Program provide generic (not autism-specific) therapy. The basis of this treatment model is not known (the availability of therapists, rather than individual need, may determine the level of the therapies provided). The cost per occasion of service shown in the table below is from the DECS Annual Report 2000-2001.

Generic Therapy Services for a child with autism	*per term*	*per year*
Speech pathology	4	16
Occupational therapy	6	24
Physiotherapy	4	16
Psychology	2	8
occasions of service		**64**
cost per occasion of service		$110
Therapy cost (annual)		**$7,040**

There are now over 75 children in the ACT with autism needing specialist treatment and education. Despite the demonstrated need for supervision of intensive and specialised psychology and speech pathology programs for children with autism, neither CHADS nor the Disability Program employs any professional staff with specialist autism-specific training or experience.

Between 1999 and 2001, DECS contributed $9,000 ($4,500 per student) annually to the cost of an autism-specific consultant speech pathologist from Sydney to supervise ABA programs for two students in the autism-specific LSU at North Ainslie Primary School.

The cost of teaching students with autism in special schools can be modelled using published data. Data from the DECS Annual Reports 1999–2000 is shown below.

Output Class 1: Government School Education, Principle Measures

average cost per government special school	$38,508
average cost per government special education student in mainstream schools	$18,312
overhead cost per student	$689

The cost of a place at the autism-specific LSU at North Ainslie Primary School, a mainstream school, is composed of staff (teacher and STA) costs[1] and the overheads. With two students, the cost of the teacher is shared but each student has an individual STA providing 1:1 program delivery. The salaries are shown below.

DECS staff costs (average)

teacher (level 1)	$44,722
STA full-time	$26,506

The DECS Annual Report 2000-2001 shows overheads for students in mainstream schools

With two students in an autism-specific LSU, the cost per student is shown below.

Average cost per mainstream student

	overhead
primary	$328
high school	$425
college	$478

LSU staff cost (1:1 STA)

students	cost	primary	high school	college
2	$48,867	$49,195	$49,292	$49,345

Children with autism and their families access a range of support services.

FaBRiC hour

Cost per hour	$20.50
minimum parent contribution	$2.00
maximum subsidy	$18.50
Hours per week	10
weeks per year	48
maximum annual subsidy	**$8,880**

Most families of young children with autism access respite services such as FaBRiC. The maximum subsidy provided by the ACT government for current FaBRiC respite is shown below.

The DSM-IV indicates that the prognosis for children with autism is particularly poor. The cost of supporting people with autism is substantial. The US Congress (United States Bill S512) recently observed that:

> "Three quarters of those with infantile autism spend their adult lives in institutions or group homes, and usually enter institutions by age 13."

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[1] *The salaries are 1999 figures. The model could be updated with more recent figures from DECS were they available to the author.*

In the ACT, a child with autism may be accommodated in centre-based respite or supported accommodation (group home).

Submissions to the Gallop inquiry and a recent public plea for the placement of a 12 year-old girl with autism in a group home show a similar situation exists in the ACT. The lack of pro-active psychological intervention and the unmet need for appropriate education options means support needs of children with autism often escalate quickly as they follow the well-known path to severe behavioural problems.

Submission 19 to the Gallop report shows a primary-age child placed regularly in centre-based respite five days per week. The cost of a place in ACTCC's centre-based respite (using 1998-99 figures) is shown in the following table. The cost of support for a child with autism accessing this service for five days of every seven is $36,943.

ACTCC Centre-based respite	
total cost	$310,320
places	6
cost per place	**$ 51,720**

Standing Committee on Health and Community Care, March 2000, p66.

The Health Department told the Gallop Inquiry that the average cost of a place in a group home in the ACT is $71,908 per year.

There is no data describing the general use by children with autism of respite, supported accommodation and community support. Currently, there is a significant shortage of respite in the ACT.

The cost model constructed below is meant to be conservative (significantly on the low side) for children severely or profoundly affected by autism. While the child is young (and small), FaBRiC or a similar service provides in-home or community based respite. Progressively, the family/carer of a child with autism is provided with respite through placing the child in centre-based respite. As the child reaches high-school age, a combination of FaBRiC, centre-based respite and supported accommodation is required.

Support estimates	FaBRiC	centre based	group home	average cost	years
primary 6-9	100%	0%	0%	$8,880	4
primary 10-11	50%	50%	0%	$30,300	2
secondary 12-17	20%	40%	40%	$51,227	6

Annual models

The costs collected in the previous section provide the basis for the following cost model for a child with autism attending special school. The cost of therapy while the child is in preschool is not known. Young children in special school start with half-time attendance.

The model assumes the family does not use respite or support services until the child reaches school age.

Child with autism (special education)

	age	*therapy*	*education*	*support*	*total*	*years*
pre- or special school	4-5	?	$19,254		$19,254	2
special school	6-9	$7,040	$38,508	$8,880	$54,428	4
special school	10-11	$7,040	$38,508	$30,300	$75,848	2
special school	12-20	$7,040	$38,508	$51,227	$96,775	8
average					***$73,882***	***16***

The cost of the children placed in the autism-specific LSU can also be constructed. These children started in special school but the programs provided did not meet their need for individual autism-specific programs. They were moved to the autism-specific LSU during their primary years.

The autism-specific LSU model is based on the current costs. CHADS and the Disability Program have not contributed therapy services for some time. The families have not sought centre-based respite or supported accommodation. Nor is there any indication that they will seek these services in the foreseeable future. DECS ceased the provision of the ABA program in the autism-specific LSU in 2002 so the high-school years costs are a projection assuming that the two students would continue to improve through those years.

Child with autism (autism LSU)

	age	*ABA supervision*	*education*	*support*	*total*	*years*
special school	4	?	$19,254		$19,254	1
special school	5-6	?	$38,508		$38,508	2
primary LSU	7-11	$4,500	$49,195	$8,880	$62,575	5
secondary LSU	12-15	$4,500	$49,292	$8,880	$62,672	4
college LSU	16-20	$4,500	$49,345	$8,880	$62,725	4
average					***$56,921***	***16***

Discussion

Children with autism have high support needs. The costs revealed by the two models above are substantial. In their early years, children with autism in the traditional special education settings are cheaper but once children reach upper primary or high school age the cost of extra support is considerable.

The models indicate the cost of respite but much more needs to be known about services for children with a disability and the effectiveness of the services they access. For example, current reporting appears to share the cost of hydrotherapy services across all students in special school. Around 25% of students in special school have autism spectrum disorders (we anticipate these mostly have autism). We are not aware that international peer-reviewed research supports either the efficacy of outcome or the cost effectiveness of hydrotherapy as a treatment for autism spectrum disorders. Nor is it obvious that children with autism who have (largely untreated) challenging behaviours have equitable access to outings and other educational events.

The cost of diagnosis is not included in the model. It is a relatively minor cost and should be uniform. Children with autism can be diagnosed before school age. In most cases, their early needs can be recognised by age 3 years.

The models above use a few known government costs for children with autism in the ACT. The author acknowledges the considerable contributions made by families and carers but has not been able to access data suitable for inclusion in the model.

Consistent with observations in other aspects of health, provision of effective early intervention provides overall saving and improved outcomes.

The autism-specific LSU reaches a point (students around 10 years of age) where it has a significant cost advantage. DECS constructed its autism-specific LSU with just two students so it did not have "economy of scale". Further, the students were older than the preferred starting point. And the specialist ABA consultant travels from Sydney.

The parents of children at the autism-specific LSU have repeatedly indicated to the department that a unit or units providing 1:1 ABA programs for a larger group of students could have additional advantages. Such a unit could meet student needs for mostly 1:1 program delivery and increase access to ABA expertise at a lower cost. The cost of providing individual ABA programs for collocated children with autism who need it throughout childhood is shown below. This model shares a teacher for ABA supervision among four students and increases the professional supervision provided under the therapy heading.

Child with autism (ABA, 4 students)

	age	*ABA supervision*	*education*	*support*	*total*	*years*
autism preschool or	4-5	$7,500	$38,015		$45,515	2
primary LSU	6-11	$7,500	$38,015	$8,880	$54,395	6
secondary LSU	12-15	$7,500	$38,112	$8,880	$54,492	4
college LSU	16-20	$7,500	$38,165	$8,880	$54,545	4
average					***$39,710***	***16***

This model has children starting younger in a more intensive setting, consistent with the models producing best outcomes for children with autism overseas. A child would only continue in an ABA program while the program continues to deliver observable progress for that child.

Research suggests many children who are given a suitable program would subsequently require less supervision or may access their education in a less intense program (and less restrictive settings), so the overall cost is reduced.

The research literature indicates that best outcome results from early ABA programs allow some students to access mainstream eduction without additional support. The cost for such a child is shown below.

Child with autism (ABA best outcome)

	age	*ABA supervision*	*education*	*support*	*total*	*years*
autism preschool or	4-6	$7,500	$38,015	*nil*	$45,515	3
primary	7-11	*nil*	$6,761	*nil*	$6,761	5
secondary	12-15	*nil*	$9,209	*nil*	$9,209	4
college	16-17	*nil*	$10,120	*nil*	$10,120	2
average					***$16,245***	***14***

The average cost across students in these programs depends on the fraction of students who achieve best outcome. The literature suggests this result can be close to 50%. The table below shows conservative outcomes for students in groups of four.

ABA overall (4 students average group)

best outcome	40%	20%
average cost	***$30,324***	***$35,017***

Addendum 1. Students in the ACT with autism spectrum disorders.

Setting	**'92, '93**	**1994**	**1995**	**1996**	**1997**	**'98, '99**	**2000**	**2001**
Mainstream					3		19	53
LSU/LSC					*nil*		86	58
Special Schools					54		?	71
Preschool					19		?	26
Total	**17**	**18**	**21**	**23**	**83**	**?**	**>105**	**208**

The total numbers from 1992 to 1996 are from ACT Legislative Assembly Hansard, 1996 Week 5, 16 May, p. 1433. Mr Stefaniak MLA, Minister for Education and Training, Question Number 205: Children with Disabilities — Enrolment Statistics.

DECS conducted the "Survey of Students with Autism" in 1997 and provided its results to the DECS Autism Working Party. DECS provided number to TASDACC in November 2000 and June 2001. By 2000, a significant waiting list for diagnosis had developed and new referrals were not being places on the diagnosis waiting list.

11/4/2003 2:54pm

Dr Ozdowski
Human Rights Commissioner & Disability Discrimination Commissioner
GPO Box 5218
SYDNEY NSW 1042

Dear Dr Ozdowski

I write in relation to the needs of children who are significantly disabled by their autism. Around Australia, the diagnosis rate for autism has risen alarmingly: at this time, around 1% of children are being diagnosed with autism spectrum disorders. Until the 1990s, autism was thought to affect 2 to 5 per 10,000 children.

The prognosis for the majority of children with Autistic Disorder is that they will not develop independent living skills. Autism is a distinct disability that requires specific intervention to assist children develop basic skills in the areas of socialisation, communication and behaviour.

Mostly, governments in Australia refuse to provide, or even contribute significantly to, the treatment and rehabilitation of children with autism. Instead, they offer only generic therapy which is known to be ineffective in preparing these children to function independently in education, employment and the community. Children with autism who are not prepared for school with basic communication and social skills do not have effective access to an education. Further, their untreated behaviour, a result of their autism, further excludes them from educational opportunities. Subsequently, outcomes for people with autism in employment, health (especially mental health) and community participation are particularly poor.

Mostly, children with a clinical disorder receive treatment designed specifically for their condition. Children with autism are treated differently. Most Australian children with autism do not receive the treatment they need. This issue has been addressed in courts overseas: see for example the matter recently decided in BC, Canada:

> http://www.courts.gov.bc.ca/jdb-txt/sc/01/02/2001bcsc0220.htm
> http://www.courts.gov.bc.ca/jdb-txt/ca/02/05/2002bcca0538.htm

I write to ask:

1. Are Australian governments, through their refusal to provide effective treatment for autism, systematically denying children with autism their basic human rights in relation to treatment, rehabilitation, education, etc.?
2. Does Australian law protect this form of discrimination by government agencies?
3. What, if anything, can be done to address the rights of children with autism to help them access the treatment they need?

Are you able to assist children with autism access essential treatment that is currently only available to particularly wealthy families who can access specialised services in the private sector? If you are able to do so, will you act accordingly?

Finally, a matter relating to the needs of a child with autism for effective early intervention was lodged with the ACT Human Rights Office in 1997. This matter has still not been heard by the ACT Discrimination Tribunal today. Is this how discrimination and human rights matters should be dealt with in this country? What, if anything, can be done about it?

Please feel free to contact me (02 6295 4025 work, 02 6248 9907 home) if you need further information or clarification of anything raised above.

your sincerely
Robert Buckley
President - Action for Autism.

30/4/2003 3:25pm

Dear Mr Buckley

I am sorry not to have been able to respond earlier to your email of 11 April but as I think was indicated to you by Ms Cox I have been on leave.

The matter you raise regarding the time taken from lodgement of an initial complaint to when a decision was made by the ACT Discrimination Tribunal is not one which this Commission is able to deal with, but might be more appropriately raised with the ACT Government including in relation to resources provided to the human rights office of that Territory.

The Disability Discrimination Act which this Commission administers does make discrimination unlawful against people with autism in a range of areas including education.

However, the issue you are raising as I understand it is the lack of sufficient early intervention programs prior to school to ensure that people with autism are prepared to participate, rather than subsequent discrimination in education.

The Disability Discrimination Act does make it unlawful for the Commonwealth government to discriminate against people with disabilities in the administration of programs which it provides. However, it does not compel the government to have in place programs which it does not have, or to resource programs adequately, however necessary this may be for people with disabilities. It is not possible therefore to use this law to compel government to fund more adequate early intervention services.

However, this Commission also has a range of other functions regarding promoting awareness of disability issues which could be used to influence government policy in this area. I will discuss with Dr Ozdowski what possibilities there are for pursuing the issue you raise. Any additional information you are able to provide in this respect would be appreciated.

David Mason
Director Disability Rights policy HREOC

1/5/2003 12:26am

Dear David Mason
Director Disability Rights policy HREOC

Thank you for your prompt reply. And thank you for your thoughts in relation to resources for discrimination matters in the ACT.

In your response to my questions you say the DDA "does not compel the government to have in place programs ... however necessary this may be for people with disabilities".

Australia signed the UN Convention on the Rights of the Child. In part, Article 23 of the convention says states will provide assistance "designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment". Article 24 says "States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health."And Article 2 says the state shall respect and ensure these rights without discrimination of any kind ... irrespective of ... disability.

Your response indicates that HREOC does not believe the DDA is a means through which the commonwealth government ensures children with autism have effective access to education, training, health, rehabilitation, etc. How then, in the eyes of HREOC, does the commonwealth government ensure children with with autism have effective access to education, training, health, rehabilitation, etc. that are identified as a right for these children?

It seems this issue may not be well understood. The page (http://www.pc.gov.au/inquiry/dda/issuespaper/index.html) contains links to the issues paper associated with the Productivity Commission's current review of the DDA. The issues paper says "For example, a lack of support services, such as funding for a particular therapy or device, may prevent access to employment or education, effectively discriminating against a person with a disability." (Section 1.3, page 9). Clearly the Productivity Commission interprets the DDA differently to you on this particular issue. Has the Productivity Commission misunderstood this element of discrimination law?

In my letter (11/4/03) I referred to a matter that has been before the ACT Discrimination Tribunal since 1997. The matter is about essential services for a child with autism. Would this matter still be ongoing today if there were no basis in discrimination law for such a matter? Is ACT law different from the DDA in this respect? If so, how precisely does ACT discrimination law differ from the DDA on this point?

Your interpretation of the DDA appears to be contrary to the Objects of the Act. Would you please identify the elements of the Act that overide the Objects of the Act in relation to this particular matter?

I would be interested in exploring HREOC's "other functions" that could influence government policy to develop effective access to services, especially education and employment services, for people with autism. I have a considerable range of information that I can provide relating to autism. Attached is a paper that collects data on the diagnosis rate of autism around the country. This shows that around 1% of children are now being diagnosed with autism making autism potentially one of the largest disability groups in the community. Also, I'm attaching a draft of a paper showing the cost benefit of providing appropriate services rather than providing so-called "generic" disability services that are expensive yet ineffective for children with autism. It is my firm belief that people with autism are having their disabilities ignored or are being treated as if they are people with an intellectual disability. Such an approach is discriminatory: it did not work for indigenous people and it will not work for people with autism. It also has unfavourable outcomes for people with intellectual disability. Any assistance with promoting awareness of autism and relevant discrimination issues would be greatly appreciated.

regards
Bob Buckley

30/4/2003 3:25pm

Dear Mr Buckley

I am sorry not to have been able to respond earlier to your email of 11 April but as I think was indicated to you by Ms Cox I have been on leave.

The matter you raise regarding the time taken from lodgement of an initial complaint to when a decision was made by the ACT Discrimination Tribunal is not one which this Commission is able to deal with, but might be more appropriately raised with the ACT Government including in relation to resources provided to the human rights office of that Territory.

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However, this Commission also has a range of other functions regarding promoting awareness of disability issues which could be used to influence government policy in this area. I will discuss with Dr Ozdowski what possibilities there are for pursuing the issue you raise. Any additional information you are able to provide in this respect would be appreciated.

David Mason
Director Disability Rights policy HREOC

6/5/2003 8:53am

Hi David

Several of the points you made in our correspondence continue to worry me.

In your response below, you write "The DDA ... does not hand over to discrimination authorities and the courts power to make all decisions for government to ensure adequate allocation of resources to disability needs." The DDA embodies the notion of "indirect discrimination". The DDA could provide the courts power to identify situations where decisions and advice result in indirect discrimination due to lack of adequate resources. While the courts cannot make ALL DECISIONS for government (nor should they), they could review such decisions and rule as to whether they consistitute unlawful discrimination. And the courts could insist that the discrimination be removed.

Or has there been a decision contrary to this interpretation? And has HREOC given up on all decision by government at any level?

I am alarmed and distressed that HREOC may prejudge cases involving people with a disability that prevents them from accessing a workplace. In any case, I am not sure such an issue is relevant to our discussion -- the matters I raise related to children and their rights -- rights that sometimes differ from adult rights at least as expressed in international law and in the eyes of the community.

Previously you wrote:

> The Disability Discrimination Act does make it unlawful for the Commonwealth government to discriminate against people with disabilities in the administration of programs which it provides.

Current interpretation of discrimination law is quite the reverse. The law makes it completely lawful to discriminate against people with a disability in the administration of programs. This is clearly stated in paragraph 13 of the ruling AT98/14 (ACT Health and Community Care Service vs Discrimination Commissioner, Vella, Griffin, Hill & Dempster -- see attached), where it states:

> ... nothing done in the course of a program designed to meet the special needs of disadvantaged persons can be the subject of a complaint of discrimination under the Act by any person, including a member of the class of disadvantaged persons that the program is intended to benefit.

In practice, any program at all can be said to be "designed to meet the special needs of disadvantaged persons" by simply claiming that to be the case. Contrary to your statement, this and similar precedents make it difficult if not impossible to bring any discrimination complaint whatsoever about the conduct of any existing program by any government in Australia.

So in effect, the DDA has no jurisdiction over existing programs. You claimed previously the DDA has no jurisdiction in situations where programs do not exist. Hence the DDA is powerless whether a program exists or not. By the *a priori* law of the excluded middle, the DDA has no power at all to address entrenched discrimination in any form of government program. The private sector will realise this soon enough and adopt the same argument.

What then is the point of a law such as the DDA? Where does it have effect?

regards
Bob Buckley

1/5/2003 9:19am
Dear Mr Buckley

We are of course well aware of the convention on the rights of the child here and were involved in its drafting. However, international treaties ratified by Australia do not have direct force in Australian law - they only have effect as far as legislation gives them force.

I also understand the point that lack of support services can and does result in lack of equality of opportunity. If you are talking about lack of provision of support which it is the responsibility of an education provider to provide, then yes that is covered as discrimination in education. But if I am correct in thinking that you are talking about lack of provision of earlier intervention services, then that is not covered by the DDA. Similarly for example lack of personal support services to assist people in getting out of bed etc prevents some people with physical disabilities from participating in employment but that does not mean that unlawful discrimination under the DDA is occurring in that situation.

The DDA is an important but limited instrument - it does not hand over to discrimination authorities and the courts power to make all decisions for government to ensure adequate allocation of resources to disability needs. Many issues remain subject to normal and often unsatisfactory political processes.

Thank you for the papers you attached. I will read them with interest and will also provide them to the Commissioner.We will then be in a better position to consider what assistance we may be able to provide on this issue to you and your association.

David Mason

From: Bob Buckley [ ]
Sent: Thursday, 1 May 2003 9:45 AM
To: David Mason
Subject: Re: autism

Dear Mr Mason

Thank you for your incredibly prompt response. However, I note it does not address a number of the specific issues I raised. I would really appreciate specific answers to these issues. I appreciate that specific answers may take some time to prepare.

Your response indicates that Australia may be in breach of its international treaties in relation to the provision of effective access to education for children with autism. This raises the issue of what can and should be done about such a breach. Who has responsibility for bringing a possible breach to the attention of Australia's government and those responsible for monitoring international law? What options are available and appropriate?

sincerely
Bob Buckley

1/5/2003 9:48am

Dear Mr Buckley

Yes we will be providing a further response including in relation to what can be done regarding gaps between obligations under the Convention on the Rights of the Child and practice in Australia

6/5/2003 8:53am

Hi David

Several of the points you made in our correspondence continue to worry me.

In your response below, you write "The DDA ... does not hand over to discrimination authorities and the courts power to make all decisions for government to ensure adequate allocation of resources to disability needs." The DDA embodies the notion of "indirect discrimination". The DDA could provide the courts power to identify situations where decisions and advice result in indirect discrimination due to lack of adequate resources. While the courts cannot make ALL DECISIONS for government (nor should they), they could review such decisions and rule as to whether they constitute unlawful discrimination. And the courts could insist that the discrimination be removed.

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What then is the point of a law such as the DDA? Where does it have effect?

regards
Bob Buckley

6/5/2003 9:54am
Bob:

First let me say that all that I have said is intended as advice only: I do not have control over complaint decisions - so there is no issue of prejudgment regarding possible complaints, although I continue to regard the advice I have given about the limited effect of the DDA in this area as correct.

Second, the Vella decision was as you know under the ACT Act not the DDA; we do not regard it as representing the effect of the DDA an do not take the same broad approach to the special measures exemption in our complaint handling.

David Mason