Submission to
Senate Community Affairs References and Legislation Committees
Inquiry into the funding and operation of the Commonwealth State/Territory Disability Agreement

from
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Contents

Introduction

People with an Autism Spectrum Disorder are now a major disability group. Australian data and data from overseas show around 1 in 166 children (or 6 per 1,000) are being diagnosed with an autism spectrum disorder by the time they leave school. This information is easily available on the internet:

- A recent article in a prestigious medical journal "found that 39 children per 10,000 had autism and 77 per 10,000 had autistic-spectrum disorder, suggesting that the total prevalence of all types of ASD is around 1% of the UK child population" (see Annex A. Article Summary below).
- Australia: see my peer reviewed paper from the last nation autism conference (http://autism.anu.edu.au/pdf_files/buckley_submit2.pdf).
- United Kingdom: see a Medical Research Council webpage says "The report of the MRC's detailed review of the current state of knowledge about autism – MRC Review of Autism Research: epidemiology and causes (PDF, 418KB) – was published in December 2001." Paragraph 68 says "… *the autism spectrum disorders affect approximately 60 … per 10,000 children under 8 [years of age].*"
- United States of America: the government's Department of Health and Human Services, Centers for Disease Control and Prevention (see http://www.cdc.gov/ncbddd/autism/asd_common.htm) says ASD prevalence is between 1 in 500 and 1 in 166.

The level of autism spectrum disorders among adults is unknown. There is evidence of substantial under-diagnosis in adults but the prevalence now observed in children has never been observed in an adult population.

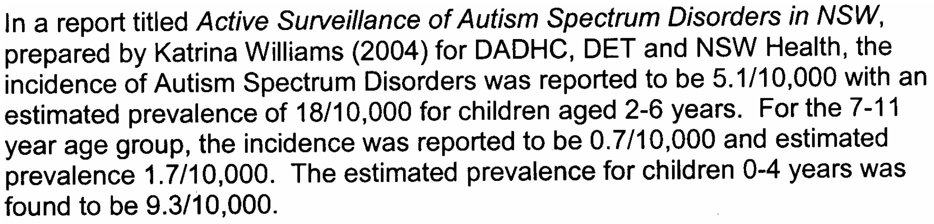
ASDs are a major disability group in children.

The Australian Bureau of Statistics (ABS) estimates from the Survey of Disability, Ageing and Carers (SDAC) in 2003 that there were 30,400 Australians diagnosed with autism or a related disorder. Of those, 20,200 (66%) were below 15 years of age; and 3,900 (13%) were aged 15 to 19 years of age.

The ABS SDAC in 1998 estimated there were 13,200 Australians diagnosed with autism or a related disorder. Of those 11,500 (87%) were below 15 years of age.

These data show the high diagnosis rates in Australian children are flowing through to young adults.

Unfortunately, many government bureaucrats and professionals still regard autism as a rare disorder. For example, the NSW Department of DADHC recent wrote



> In a report titled *Active Surveillance of Autism Spectrum Disorders in NSW*, prepared by Katrina Williams (2004) for DADHC, DET and NSW Health, the incidence of Autism Spectrum Disorders was reported to be 5.1/10,000 with an estimated prevalence of 18/10,000 for children aged 2-6 years. For the 7-11 year age group, the incidence was reported to be 0.7/10,000 and estimated prevalence 1.7/10,000. The estimated prevalence for children 0-4 years was found to be 9.3/10,000.

NSW DADHC prefers an unpublished preliminary report to published experts shown above. When I contacted the report's author, Ms Katrina Williams, she indicated that her estimate of 18 per 10,000 for children aged 2-6 years is for Autistic Disorder, just the condition at the centre of the spectrum and not for the whole autism spectrum, and that the figure of 1.7 per 10,000 for 7-11 years olds did not account for those who were diagnosed before age 7 years. The rate of 1.7 per 10,000 is below the most conservative published figures for Autistic Disorder alone (even the DSM-IV give the range 2 to 20 per 10,000 for the prevalence of Autistic Disorder).

This shows DADHC in NSW grossly underestimates the number of children with an autism spectrum disorder in their jurisdiction.

Accurate information about the number of children that ASDs affect is just a part of the picture. Planning of effective treatment, services and support depends on accurate and complete information about options and outcomes.

ASDs are severely disabling. The Diagnostic and Statistical Manual of Mental Disorders, fourth edition (1994), known as the DSM-IV, defines ASD/PDD as "severe and pervasive disorder". All forms of ASD are severe disorders[1], including Asperger's Disorder. The Australian Institute of Health and Welfare (AIHW) reports, based on ABS 1998 data, that

> "The top five conditions most likely to be associated with a severe or profound core activity restriction were autism (95%), dementia (94%), Down syndrome (92%), cerebral palsy (84%) and speech problems (76%)."[2]

Generally, government bureaucrats and professionals have a very poor knowledge of ASDs. They persist in thinking autism is a type of "intellectual disability", consequently they manage services for ASDs inappropriately. For example, most senior staff in health, disability and educations do not know that PDD is on Axis-I in the DSM-IV (PDDs were on Axis-II, with Mental Retardation in the DSM-III). Their attitude to ASDs severely prejudices their approach to ASDs.

Bureaucrats who are misinformed or ignorant about ASDs cannot provide their governments with accurate information. And governments that lack accurate information cannot make informed decisions. So the decision governments make may not benefit, or may be detrimental, to people with an ASD.

No government in Australia uses complete and accurate information to plan the provision of treatment, services and support for children with ASD. As a result governments in Australia deprive children with ASD of the treatment, services and support they need. Children with ASD do not experience equality of opportunity.

Recommendation

… that Australian governments recognise

- numerically people with an autism spectrum disorders are a major disability group.
- autism spectrum disorders mostly result in severe or profound disability that is different in nature from other type of disability.

ICD-10.

[2] AIHW (Dec 2004) *Disability and its relationship to health conditions and other factors*, Canberra, AIHW Cat. No. DIS 37, p80

Distinct needs

ASDs are distinct from other types of disability. Experts classify ASDs and intellectual disability very differently. It is crucial that governments understand ASD is distinct from intellectual disability.

The DSM-IV classifies mental retardation (intellectual disability) on Axis II. In relation to Axis II, the DSM-IV says …

> "The listing of Personality Disorders and Mental Retardation on a separate axis ensures that consideration will be given to the possible presence of Personality Disorders and Mental Retardation that might otherwise be overlooked when attention is directed to the usually more florid Axis I disorders." (page 28)

People with ASD have impairment in communication, social skills and behaviour. Intellectual impairment is not a diagnosis criteria for ASD. In fact, the criteria for a diagnosis of Asperger's disorder specifically exclude the presence on mental retardation.

The DSM-IV classifies Pervasive Developmental Disorders (or ASDs) on Axis I. Axis I is for Clinical Disorders. The DSM-IV says the conditions on Axis I are the "usually more florid disorders" that require clinical attention.

Section 5(4)(b) of the CSTDA says …

> 5(4) The Commonwealth and the States/Territories acknowledge that this Agreement and any Bilateral Agreements do not apply to the provision of …
>
> > (b)services with a specialist clinical focus, regardless of whether those services are provided to people eligible to receive services under this Agreement.

In other words, the CSTDA specifically precludes the use of CSTDA funds to provide "services with a specialist clinical focus".

The federal Department of Health and Ageing does not fund services for treating ASDs. For example, an official from the Department wrote to Autism Asperger's Advocacy Australia (known as A4, see www.a4.org.au) saying that funding for Better Outcomes in Mental Health Care could not be used for treating ASDs.

Children with other disabilities get treatment. For example, a child with hearing impairment may get a cochlea implant. Generally, children with other clinical disorders receive treatment and rehabilitation, usually in the health system. But most children with autism miss out on essential "services with a specialist clinical focus" because the government does not provide them and the services a child with autism needs are beyond the reach of most families.

The education system provides places for students with an ASD but without the benefit of "services with a specialist clinical focus" most students with an ASD do not have anything like an equal opportunity to benefit from their education. Their untreated autism remains a severe or profound barrier that prevents them from accessing an effective education.

ACD in Victoria reports that a third of the children who have developed or are at serious risk of developing problem or challenging behaviour have been diagnosed with Asperger's Disorder/Syndrome. As shown above, this is a severe disorder. Yet their needs are not assessed and they cannot access support because they do not have an intellectual disability. Typically, their school subjects them to behaviour management policy and practices that exacerbate their behaviour. These students do not have access to appropriate professional supervision and program development.

Schools, especially special schools, treat children with an ASD the same as they would a child with intellectual disability. One student with an ASD asked "Why do they treat me like this? I am not stupid. I have autism."

Some students, while they may struggle with school, can be extremely successful in their academic endeavours. In recent times, a number of young adults have completed various forms of tertiary education with impressive results.

However, they still find it extremely difficult, and often impossible, to get a job.

This is reflected in then increased number of people with ASD receiving the Disability Support Pension. Centrelink data show the number of people with ASD who receive a Disability Support Pension increased by almost 1000 from January 2004 to January 2005. This is a high proportion of the people with a diagnosis who reached the eligible age for the Disability Support Pension.

This is a clear indication that any treatment, services and education that governments provide for people with ASD do not prepare or enable them to participate economically or financially in their community.

There is some good news. There is a significant level of success for people with autism where families fund or fight to get appropriate services. Invariably, the success can be attributed to sufficiently intensive and autism-specific services that address individual needs.

Recommendations

… that Australian governments ensure children with an autism spectrum disorder can access treatment and services for their autism.

… that governments measure and report on participation and other outcomes for people with ASD to ensure the treatment, services and education they provide actually achieve equitable results.

Funding

In the time of the CSDAs and the CSTDA there has been no discernible change to funding for people with autism spectrum disorders.

This is remarkable since

1. there has been a tenfold increase in the number of people being diagnosed with autism spectrum disorders, and
2. professionals have recognised autism spectrum disorders as a clinical disorder.

Currently, the impact of disability due to autism spectrum disorders is not known. The only attempt made by a government or research organisation in Australia to consider the cost comes from the AIHW. And it is based on a chronically out-dated prevalence estimate.

There can be little doubt that enormous sums of money are involved. Translating recent estimates from the USA to Australia suggests autism spectrum disorders cost the Australian community over $3 billion per year. But we really do not know how this money is being spent.

What we do know is that we are not spending it wisely and the results we see are no where near as good as any of us would like.

Recommendation

… that Australian governments examine the cost to the community of the services they provide and that they consider all the benefits to the community of targeting treatment, disability services, education and support for people with an autism spectrum disorder and their families/carers.

Operation of CSTDA

TOR (a)

> *a. an examination of the intent and effect of the three CSTDAs to date;*

Intent

The preamble to the CSTDA makes various claims about its intent. For example, it says the intent of the CSDAs was, and the CSTDA is, to provide a common framework for "specialist disability services".

This phrase, "specialist disability service", has a particularly peculiar meaning. It refers specifically to services intended for or limited to people with a disability that are not used by people who do not have a disability. For example, the provision of access ramps might be "specialist disability services" … presumably because they are not intended to be used by people without a disability, such a people with prams, rollerblades, bicycles or skateboards.

But governments will not provide disability services under the CSTDA for specifically for people with ASD. Government policy is to provide services that meet the needs of across a range of disabilities, rather than provide services that benefit a specific disability group (such as print disability).

Governments are at great pains to point out that "specialist disability services" does not refer to services that might benefit people with a distinct disability. It seems "specialist disability services" means what one would normally expect "non-specialist disability services" to mean.

On this basis, the intent is to not provide services intended to meet the needs of people with autism. It seems quite hypocritical that the CSTDA specifically defines "print disability services", for example, in Section 3(1) and make "print disability services" a subject of the CSTDA in Section 5(3)(2)(h).

The intent is that the CSTDA "is a document of both practical and symbolic importance".

People with ASD and their associates have little interest in the symbolic importance of the CSTDA.

Since most people with ASD and their associates are confronted daily with severe and profound disability, they are primarily interested in the practical importance of the CSTDA.

Unfortunately the practical intent of the CSTDA is not stated so it is only clear to those who delve closely into the agreement and the associated legislation.

The actual intent of the Disability Services Act (DSA) and the CSTDA is deceit: the DSA and the CSTDA are intended to give the appearance that Australian governments meet the needs of their citizens who have a disability while avoiding practical obligations under international law. The CSTDA is intended to show some willingness on the part of governments to help people with a disability while ensuring Australians with a disability do not have an actual right to receive essential services. For example, the intent of the DSA and the CSTDA is that Australian children with a disability such as ASD cannot expect under international law to receive effective treatment, rehabilitation, education, etc., as described in Article 23 of the UN Convention on the Rights of the Child (see Annex B).

Recommendation

… that Australian governments pass law that provides essential services for treating, rehabilitating, educating and supporting children with a disability in a manner that ensure the provision of effective services for children with autism spectrum disorders.

Effect

A clear effect of the CSTDA is that the Commonwealth provides money to the States and Territories to spend in the name of disability services. Through the CSTDA process, the Commonwealth significantly multiplied the funding it provides for disability services.

Governments and their agents prefer to provide generic services like respite and community access. They favour services that are easier to implement, administer and account for. Such services are easier for the community to understand. But the services they offer are not the services children with autism need most.

Far less clear is whether the funds are used effectively to benefit people with a disability. While governments spent all this money on generic disability services, young children with autism, need effective early intervention services that improve their communication, social and behaviour skills. But the services governments provide do not address their key needs.

No state or territory measures or reports on actual benefits such as progress in language, social skills, self-help, etc. in children with autism.

Even the basic accounting is dubious. For example, the ACT government in the 2000-01 Budget allocated over $1 million over 4 years specifically for increasing therapy services for children with autism. Successive Ministers, have been unable to show that a single dollar of the funds allocated went to increasing therapy services for a child with autism.

The ultimate effect of the CSTDA is the influence it has on the lives of people with a disability such as ASD.

In Victoria, the **Medical Committee on Client Mortality (MCCM) (Intellectual Disability**) wrote *A Review of Client Mortality 1999-2001*. It says:

> During the period 1 January 1999 to 31 December 2002 the Medical Committee on Client Mortality (MCCM) reviewed the files of 79 people who had intellectual disabilities and who died whilst living in residential facilities run by the Department of Human Services (DHS). The Committee's role is to review the lifetime health care and the death of all people with intellectual disability who died whilst in the care of the DHS and to make recommendations, which will lead to improvements in standards of health care.
>
> ...
>
> **1.9 Probable Autism**
>
> The reviews indicate that 13 (16.5 %) clients had unrecognised autism. Knowledge about the nature of autism-related impairments and their consequent management is improving rapidly, to the considerable benefit of people with these problems. Lack of recognition denies people with these disabilities access to the benefits of this expertise.
>
> ...
>
> 5.9 Probable Autism
>
> The reviews suggest that 13 clients of 79 reviewed in 1999 to 2001 had unrecognized autism. This is not surprising. It is known that autism and intellectual disability frequently coexist and the prevalence of autism at all levels of intellectual ability is now considered to be much higher than estimated in the past.[3] When both conditions are present management challenges tend to increase. Over the past three to four decades, it has become increasingly difficult for people with intellectual disabilities to enter long term residential care and it would be expected that those with associated autism would be over-represented amongst those entering residential care during this period. Knowledge about the nature of autism-related impairments and their consequent management is improving rapidly, to the considerable benefit of affected people. Lack of recognition of autism denies them access to this expertise.

Clearly, there is a serious problem. Specialised disability services did not recognize autism in their clients, when autism is the disorder most associated with severe or profound disability.

The report found people in this group have a life expectancy of 46 years, which is significantly lower than the life expectancy that the rest of the population experience. These experts say

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[3] Charman, T. (2002). "The prevalence of autism spectrum disorders. Recent evidence and future challenges". *European Child and Adolescent Psychiatry*, 11. 249-256.

> Some reduction in life expectancy is to be expected, but the Committee's view is that to accept this is at best complacent and at worst tends to self-fulfilment.

This information is consistent with results Prof. Lennox, now the Director of the Queensland Centre for Intellectual and Developmental Disability (QCIDD) (see http://www.uq.edu.au/qcidd/index.html) at the University of Queensland told the AIHW. Prof Lennox told an audience at the AIHW that people with a developmental delay have on average 5.2 co-morbid serious health disorders with two of those unrecognised.

Unfortunately, there is very little information about the effects of CSTDA funding on people with autism spectrum disorders, or even the effects generally on people with a disability. The federal government funds the AIHW who report on the National Minimum Data Set[4] and various other bits of data[5]. But these data show only funding inputs for services that are intended to affect the lives of people with a disability and their associates.

Recommendation

… that Australian governments measure the effects on outcomes that their disability policies, and the disability services they fund, have on the lives of people with disability to ensure the funding achieves intended goals. The measures should relate to the lives of people with severe or profound disability and their associates. The measures and their reporting should particularly and distinctly describe the effects on the lives of people with autism spectrum disorders.

One effect of the CSTDA is that the states have organisations that administer disability services. These organisations develop policy.

Unfortunately, aspects of their policy are impractical, unrealistic and uninformed in relation to autism spectrum disorders.

TOR (b)

> *b. the appropriateness or otherwise of current Commonwealth/State/Territory joint funding arrangements, including an analysis of levels of unmet needs and, in particular, the unmet need for accommodation services and support;*

Professionals and parents of children with autism question the appropriateness of services available through CSTDA funding. A particular concern is the chronic lack of appropriate early intervention for young children with autism.

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[4] See http://www.aihw.gov.au/disability/csda_public/index.cfm

[5] See http://www.aihw.gov.au/disability/datacubes/index.cfm . Unfortunately, neither the 2004-5 or 2005-6 NMDS data was available yet on the AIHW website so we cannot comment on recent information in our submission.

A recent article in the Medical Journal of Australia says:

> "It is now widely accepted that between 15 and 25 hours of specific intervention is adequate, and that 40 hours per week of therapy may put unnecessary stress on families and their financial resources, with an uncertain added benefit.[36] In the typical programs of today, a child may spend time in individual therapy, in preschools with support, in special playgroups, and in home-based interventions. Services available differ between areas, and in Australia there are no government-funded programs providing the recommended amounts of intervention. There is a need for increased government financial support for early intervention programs. …"[6]

Actually, the reference quoted focuses on children with ASD aged 0 to 3 years and recommends a minimum of 20 hours of intensive early behavioural intervention. Most international experts say that to minimise the adverse effects of autism most young children with autism require a minimum of 20 hours per week of effective early intervention.

I emphasise that …

> ***"in Australia there are no government-funded programs providing the recommended amounts of intervention".***

Further, parents advise that diagnostic service providers funded through the CSTDA do not advise parents properly in the post-diagnostic follow up. For example, Therapy ACT says it does not advise parents that children with autism need intensive autism specific intervention.

The services governments and their agents provide do not offer an appropriate level of language and communication intervention, social skills development and skill development in other key areas. Typically, the programs they offer lack appropriate professional supervision and monitoring of program outcomes. These programs are not evidence-based; in fact they are programs of a type that is known to be inappropriate and ineffective for children with autism. This information has been provided to governments and they continue to ignore it.

The existing process leaves many parents without appropriate information. And it denies equality of opportunity to many children who are severely disabled by their autism. It means they do not have the opportunity to develop kills that are critical to their success in education, and subsequently in employment and community participation.

Recommendation

… that Australian governments ensure that, immediately following a diagnosis of an autism spectrum disorder, families /carers

- are given accurate and complete information about the prognosis and treatment appropriate to their diagnosis.
- can access professionally developed and supervised individual intensive ASD-specific early intervention for the child.

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http://www.mja.com.au/public/issues/182_07_040405/wra10330_fm.html

Many parents of children with autism spend large amount of money on their treatment. Government officials criticise and ridicule parents who choose programs that have the strongest evidence. As shown above, some professionals feel that parents who attempt to provide up to 40 hours per week of evidence-based treatment/therapy "may put unnecessary stress on families and their financial resources".

The CSTDA says

> The Agreement is based on the premise that communities are enriched by the inclusion of people with disabilities and that positive assumptions about the gifts and capacities of people with disabilities, including those with high support needs, are fundamental to their experience of a good life and to the development and delivery of policy, programs and services.

Section 4(2) headed Policy Priorities includes

c) strengthen individuals, families and carers by:
  - developing supports and services based on individual needs and outcomes, which enhance the well-being, contribution, capacity and inclusion of individuals, families and carers; and
  - increasing their opportunities to influence the development and implementation of supports and service at all levels.

The CSTDA does not identify "Inclusion" as the sole driver for disability services. But disability policy at state level is based primarily on the ideology of "Inclusion", an ideology based on the unfounded belief that everything will be fine when people with any disability are fully included in the community.

My concern is for people with autism spectrum disorders. Generally, I am positively inclined towards inclusive practices. But it is my considered view, and the view of some other parents of people with ASDs, that Inclusion is an insufficient ideology for people with ASDs. I am not in a position to comment on the appropriateness of Inclusion for other disabilities.

Inclusion ideology assumes all people want to be part of their community and have or can develop, through practice, the capacity to be included in their community.

It is important to appreciate that the community has social norms and even rules that its members must adhere to. In order to be included, people must conform to those rules. Some people lack the desire or the capacity to conform to community rules. As a result, depending on their behaviour, these people are not included in the community: they may be imprisoned, ostracised, deported or otherwise excluded.

People who are diagnosed with an autism spectrum disorder are recognised as having significant dysfunction in their social skills. Many of them cannot maintain compliance with community rules and norms.

Many people with ASD do not develop the capacity for inclusion through inclusion itself. The research is clear that children with autism need intensive ASD-specific early intervention so they can develop the capacity for Inclusion and their capacity to contribute to their community. We have shown above that the CSTDA does not provide the capacity-building services children with autism need for developing their capacity for inclusion. There are not appropriate transitions to inclusions and the expert support needed to include children/students with autism in mainstream setting is not available. Some states will not provide such services unless the child has a documented intellectual disability, so many children/students who are severely disabled by their autism miss out on essential services.

Current inclusion-based policy for services for children who are severely disabled by their autism is like including a paraplegic in a water polo team and limiting support to someone to hold their towel … and this would only be allowed if the support worker held the towels for the whole team.

Recommendation

… that Australian governments recognise that children with autism require capacity building services as an essential prerequisite to Inclusion.

… that Australian governments provide services that improve the capacity of children with autism for Inclusion.

Many of the foundations of current disability policy are inappropriate. For example, the ACT Government through Disability ACT says[7] its Vision is:

> *All with people with disabilities achieve what they want to achieve, live how they choose to live, and are valued as full and equal members of the ACT community.*

There are some serious flaws with this "vision". The ACT government has not asked my son what he wants to achieve or how he would choose to live. There is no discernible program that will result in his being valued by the community beyond where his family has significant personal influence.

People with autism may find it difficult to communicate what they want to achieve, and what they say is unlikely to be heard effectively. Those whose social disorder has not been treated effectively may not have appropriate or acceptable goals. The prospect that the community will value profoundly autistic behaviour is completely delusional.

Were the ACT Government to actually ask children with autism how they choose to live they would find some want to be able to:

- Walk on the road anytime with no risk of being hit by traffic.
- Take their clothes off at will and defecate when and where they feel like it.
- Once they reach puberty, masturbate anywhere they want.

It is not appropriate that the ACT Government help them *achieve what they want to achieve* … as it says it wants to. Nor will is this likely to result in their being *valued as full and equal members of the ACT community.*

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[7] see http://www.nda.gov.au/cproot/490/1561/Future%20Directions%20ACT%20final%20full%20version%20.pdf

Most governments involved in the CSTDA have a disability advisory group or committee. I am not aware that any of the various Disability Advisory Groups includes a representative for people with autism spectrum disorders and/or their associates.

Recommendation

… that Australian governments include representatives of people who are disabled by autism spectrum disorders, their families and carers in their Disability Advisory groups; and heed the advice they get from the community on disability policy.

Even when they get good advice, governments are unable or unwilling to act on it. For example, Disability ACT spent significant amounts of money on consultancies to find out what my son needs. The first consultancy, focused on two boys one of whom was my son, advised that these two boys each needed an ASD-specific program supervised by a professional with specialist of treating autism. The cost of such a program would be substantial. So instead of following their expensive advice, Disability ACT joined with Education to provide a cheap experiment[8] on four children for a fraction of the cost of a single program.

After two years, Disability ACT contracted a second consultant, with no previous knowledge or particular expertise in the treatment or education of children with autism, to review their experiment and describe its outcomes. Disability ACT and the Education department wrote and told us that the experiment would not continue irrespective of the consultant's findings (which supported the program continuing). The departments did not inform us of the outcome of their review of the findings. The specialist services for my son simply stopped after 3 years. The ACT government does not provide any autism specific service or support for my son who is severely affected (possibly profoundly affected depending on your definition) by his autism.

Therapy ACT is responsible for providing "therapy services" for people with a disability in the ACT. We asked for services for my son's autism (even during meetings with the Minister and the Head of Therapy ACT). But Therapy ACT has not seen my son in over five years.

The Commonwealth Government, while it refuses to fund essential programs for children with autism, could at least provide a more appropriate tax break for families who fund these programs themselves. And it could ensure that Private Health Insurance contributes appropriately to the cost of treatment for autism.

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[8] There is a brief description of this experiment in the ACT Department of Disability, Housing and Community Services *Annual Report Volume 1* under the heading *Applied Behaviour Analysis Program Pilot* on page 18.

Currently, only families with large financial resources or specialist skills can meet their child’s need for effective early intervention and treatment/rehabilitation for autism.

I understand there are enormous waiting lists for supported accommodation. Governments cannot meet the demand for places. So families are forced to provide full-time carer for chronically disabled adult children.

Some states and territories cannot have noticed increasing demand for foster-care for children with problem or challenging behaviours whose families are unable to continue to care for them. People with autism are among the most challenging cases.

The lack of effective early intervention and appropriate training and support for parents of children with ASD contributes to growth in the children and adolescents with (or at risk of developing) problem or challenging behaviour.

Recommendation

… that Australian governments ???

TOR (c)

> *c. an examination of the ageing/disability interface with respect to health, aged care and other services, including the problems of jurisdictional overlap and inefficiency;*

So far, very few people over 55 years of age are reported as having autism so the ageing/disability interface is not known. As shown above, it is possible that many people with autism have a truncated life-span and poor health outcomes so ageing is less of an issue.

The usual problems for ageing carers exist … possibly exacerbated by a lack of suitable placement options for adult children with autism.

There is a clear and substantial issue with government paranoia about any duplication of services, or service overlap.

The CSTDA prohibits funding “services of a clinical nature”. And the Health sector regards autism as a disability and expects the disability to provide any treatment that a person may require for their autism.

Governments’ paranoid fear of “jurisdictional overlap” means neither the health nor the disability sector provides essential clinical services for people with autism. It does not leave a gap: given the number of children affected, and the scale of the services required, there is an enormous chasm of unmet need for clinical services for people with autism.

The argument for outsourcing services is that efficiencies are supposed to come from competition. Competition is about duplication of services, and an ideal source of this duplication is “jurisdictional overlap”. Without some degree of duplication, there is no consumer choice.

Government need to decide whether it want efficiencies or not. If it wants efficiencies due to competition, then it needs to ensure there is a range of service providers competing effectively to profit from people's disabilities.

Otherwise governments and their agencies should get on with the business of providing the services people need for their disabilities. Government agencies should provide services collaboratively where there is any potential "jurisdictional overlap".

Recommendation

… that Australian governments address the large gaps in service provisions and address the indications of high levels of unmet need for people with autism spectrum disorders. Bureaucrats should use jurisdictional overlap as a basis for collaborations rather than areas of service depletion.

TOR (d)

> *d. an examination of alternative funding, jurisdiction and administrative arrangements, including relevant examples from overseas.*

Australian governments have clear alternatives available in relation to services for people with autism and their associates. These alternatives are listed above as recommendations. In the event you are interested, autism organisation can provide supporting research from overseas and we can help organise meetings for you with international experts on autism.

About Bob Buckley

Bob Buckley is

- Father to a boy with autism
- Convenor of Autism Aspergers Advocacy Australia
- President of Action for Autism in the ACT
- A member of the Autism ACT Committee
- An experience consultant and academic

Annex A. Article Summary

E. Simonoff, A. Pickles, et. al. (15 July 2006), Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP), The Lancet, Volume 368, Number 9531.

Background

Recent reports have suggested that the prevalence of autism and related spectrum disorders (ASDs) is substantially higher than previously recognised. We sought to quantify prevalence of ASDs in children in South Thames, UK.

Methods

Within a total population cohort of 56 946 children aged 9–10 years, we screened all those with a current clinical diagnosis of ASD (n=255) or those judged to be at risk for being an undetected case (n=1515). A stratified subsample (n=255) received a comprehensive diagnostic assessment, including standardised clinical observation, and parent interview assessments of autistic symptoms, language, and intelligence quotient (IQ). Clinical consensus diagnoses of childhood autism and other ASDs were derived. We used a sample weighting procedure to estimate prevalence.

Findings

The prevalence of childhood autism was 38·9 per 10 000 (95% CI 29·9–47·8) and that of other ASDs was 77·2 per 10 000 (52·1–102·3), making the total prevalence of all ASDs 116·1 per 10 000 (90·4–141·8). A narrower definition of childhood autism, which combined clinical consensus with instrument criteria for past and current presentation, provided a prevalence of 24·8 per 10 000 (17·6–32·0). The rate of previous local identification was lowest for children of less educated parents.

Interpretation

Prevalence of autism and related ASDs is substantially greater than previously recognised. Whether the increase is due to better ascertainment, broadening diagnostic criteria, or increased incidence is unclear. Services in health, education, and social care will need to recognise the needs of children with some form of ASD, who constitute 1% of the child population.

Annex B. United Nations Convention on the Rights of the Child, Article 23

Preamble

…

Recalling that, in the Universal Declaration of Human Rights, the United Nations has proclaimed that childhood is entitled to special care and assistance,

…

Article 23

1. States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.
2. States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child.
3. Recognizing the special needs of a disabled child, assistance extended in accordance with paragraph 2 of the present article shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.
4. States Parties shall promote, in the spirit of international co-operation, the exchange of appropriate information in the field of preventive health care and of medical, psychological and functional treatment of disabled children, including dissemination of and access to information concerning methods of rehabilitation, education and vocational services, with the aim of enabling States Parties to improve their capabilities and skills and to widen their experience in these areas. In this regard, particular account shall be taken of the needs of developing countries.