Submission to the Productivity Commission

on

Disability Care and Support

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Recommendations

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3. Australians who are formally diagnosed with ASD "should be in the new scheme". Diagnoses of ASD are both practical and reliable processes for identifying people who must be included in new and improved services for people with a disability.
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10. The Government must ensure behavioural clinicians are trained and employed to help care for and support people with both ASD and challenging and/or pathological behaviour.
11. The Government must increase ASD research substantially.
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13. Senior managers in health, education and disability services must embrace and ensure a continuous change culture in their organisations rather than their existing “my way” mentality.
14. The clinical needs of people with ASD must be met through the health system.
15. The Commonwealth Government must ensure private health insurance covers the clinical service needs of people with ASD.
16. The Commonwealth Government must establish and fund a disability safety net system to catch clients when their individual service needs are not met in the existing service systems.
17. The Commonwealth Government must ensure people with ASD can access the full range of services that result in the care and support people with ASD need.
18. Diagnostic services for ASD must be part of a comprehensive health diagnostic service. ASD diagnosis must not be distinct or stand-alone service.

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19. The Commonwealth Government must improve behaviour support services for people with ASD.
20. The Commonwealth Government must address the needs of adults with ASD.

21. The Commonwealth Government should act on the AABASD Call to Action (see http://www.autismaus.com.au/uploads/pdfs/Autism_NationalCalltoAction_Oct07.pdf).

22. The Commonwealth Government must in future design services for people with ASD to work, and not (as is current practice) design programs to fail.

23. The Commonwealth Government must create schemes to identify service needs, design service systems to meet the needs that are identified, and a system to measure and report outcomes for people with ASD.

24. The Commonwealth Government must focus on research, workforce planning and professional development to ensure the creation of the workforce people with ASD need.

Introduction

This initial submission focusses on the Care and Support needs of Australians who are diagnosed with Autism Spectrum Disorders (ASD).

Briefly, ASD include three disorders that are defined in the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (known as the DSM-IV). The three disorders that are usually referred to as ASD include Autistic Disorder, Asperger's Disorder and Pervasive Developmental Disorder not otherwise specified (PDD-NOS).

ASD are a distinct disability type: they are not a subgroup of intellectual disability or brain injury. These disorders all involve "severe and pervasive impairment". None of these disorders are "a mild form of autism" though journalists, politicians ands bureaucrats like to describe them that way.

The DSM-IV says few people with Autistic Disorder go on to live independently. Outcomes for the two other disorders that are part of ASD are not well known.

ASD were once considered rare. Now, over 1% of Australian school students are diagnosed with ASD. The number of children diagnosed has more than doubled every five years for the last 20-30 years. This rate of increase should be a major concern for the Australian Government: the US Government considers it a serious issue.

This submission is incomplete. Time and resources have not allowed me to collect and describe all the relevant information, or even to write responses to all the questions you have asked. Hopefully, this will give an initial indication of some of the key issues for people with ASD.

Terms of Reference

The Care and Support needs of people with ASD vary depending on the other services they receive. People who receive what is essential early intervention and effective education when they are young have reduced care and support needs.

I hope the Productivity Commission in considering issues relating to Disability Care and Support will consider related issues that affect the long-term care and support needs of people who are disabled by their ASD.

Who should be eligible?

People with severe and pervasive impairment due to an autism spectrum disorder, with their families and carers, need improved access to a comprehensive and complex array of services.

In its issues paper, the Productivity Commission refers to the ABS SDAC 2003. Using the same data source, the AIHW reported[1] that

> Autism and intellectual impairment were associated with high proportions of severe or profound core activity limitation—87% and 75% of children with these respective conditions also had a severe or profound core activity limitation.

Despite the number of people diagnosed with ASD having more than doubled from the 1998 to the 2003 SDAC, people diagnosed with ASD remained predominantly those with “severe or profound core activity limitation”. This is contrary to claims from politicians and bureaucrats that the increase is due to greater awareness and better diagnosis of more marginal cases. Even the very conservative CDC in the USA acknowledges that there appears to be a real increase in prevalence of ASD.

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[1] See http://www.aihw.gov.au/publications/aus/bulletin42/bulletin42.pdf

The AIHW reported ASD as ranking second (after asthma) in the list of health burden for boys aged 0-14 years … and eighth for girls[2]. This substantial burden on the community due to ASD is not reflected in the training of health professionals in ASD or services provided in the health system for people with ASD. Nor will the current efforts to improve health and disability services related to mental health include improving services for people with ASD.

1. *People with autism spectrum disorders, their families and carers, should be among those who are eligible to access existing, new and improved services.*

Pervasive developmental disorders, a group of disorders in the DSM-IV that includes autism spectrum disorders, all involve (by definition) *severe and pervasive impairment*. People with autism spectrum disorders need access to mainstream, generic disability (specialist?) and ASD-specific services and accommodations across many aspects of living in our community in order to realise an appropriate quality of life. Currently, people with ASD need many services and service adjustments/accommodations that are simply unavailable for them. For example, appropriately trained allied health clinicians, supported accommodation, employment services & support, etc. are simply unavailable in most states/territories.

The meaning of "eligible" is unclear. Australia has signed the relevant International treaties, but so far has refused to enact the legislation needed to bring them into effect. Australians with ASD are not "eligible" to receive essential services through the rights and protections they need.

International law requires that people, children and people with a disability have rights to a basic quality of life. Our community should ensure all its members achieve a quality of life *above* a basic minimum. Our community must help people when and if they need help to rise above the minimum standard. It will help people in the manner they need help.

Australia does not have eligibility criteria to access the health or education sectors. Australians expect everyone has access to health, education, social security and a competent legal system. But *Purvis vs NSW* allows any service to exclude a person from that service if the service provider feels there may be a risk of unwanted behaviour. On this basis, any service can exclude anyone diagnosed with an ASD.

Woodbury & ors v Australian Capital Government [2007] ACTDT 4 (April 2007) shows that children with autism are not eligible for health or education services. A service of any kind can discriminate against people with a disability in anyway that it chooses and its actions are protected under Australian law.

Australians are inclined to believe our rights are protected under the law. For example, the legislators involved in an ACT Assembly Inquiry and a senior academic were discussing the rights of students who need special education. Apparently, they were all assumed incorrectly that the ACT Human Rights Act provides the right to education for students with a disability. The ACT Human Rights Act makes no mention of "education".

2. *Australians will be properly* ***eligible*** *for disability care and support only when their rights as described by the relevant international treaties are fully protected in Australian law.*

Who should be in the new scheme and how could they be practically and reliably identified?

People who are formally diagnosed with ASD which means they have "severe (or profound) and pervasive impairment" (which is how the DSM-IV describes Pervasive Developmental Disorders including ASD) "should be in the new scheme". A considerable body of research shows formal diagnosis of ASD is both practical and reliable. Diagnosis of ASD provides an individual with a label that indicates likely benefits of timely access to essential and effective services.

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[2] See Table 3.6, page 48 in AIHW 2007, *The burden of disease and injury in Australia 2003*, http://www.aihw.gov.au/bod/. Note: the ASD prevalence estimate used in this report was very conservative and is now outdated.

3. *Australians who are formally diagnosed with ASD "should be in the new scheme". Diagnoses of ASD are both practical and reliable processes for identifying people who must be included in new and improved services for people with a disability.*

Some people who are diagnosed with ASD are still reporting delays along their pathway to diagnosis of ASD. Delayed diagnoses mean delayed access to essential early intervention. Delayed early intervention for children with ASD means a real risk that the early intervention they do receive will be less effective and/or more costly.

In particular, many General Practitioners dismiss parent concerns and tell families to wait to see how their child develops despite clear indications that diagnosis of ASD should be considered. The Government must take steps to educate General Practitioners about the benefits of early diagnosis and intervention for ASD.

4. *The Government must educate health workers and professionals, especially General Practioners, about the need for early diagnosis and intervention for ASD.*

With over 1% of school-age children in Australia (2% in Queensland, see http://a4.org.au/a4/node/225) now diagnosed with ASD, the time has come to screen all young children in Australia for signs of ASD.

5. *The Government must screen all young children for signs of ASD.*

Screening and early diagnosis should not be the only means to identify service eligibility and needs. There need to be multiple pathways into services that is based on recognising individual needs. The average age of diagnosis for Asperger's Disorder is higher than for Autistic Disorder and PDD-NOS. People with Asperger's Disorder may not be picked up in early screening.

Diagnosis rates for ASD in Australian adults are much lower than for children. As in other countries, there is evidence of a substantial level of undiagnosed ASD in the Australian adult population. Strategies to improve diagnosis rates for ASD among Australian adults would involve improving awareness of ASD across the whole community, but especially in the mental health and social security sectors.

6. *The Government must conduct a thorough ASD awareness campaign.*

Increasingly, technology will provide the means to predict and identify people's care and support needs. People whose individual genome indicates that they will most likely benefit from some intervention may be offered appropriate services.

An individual may have service and support needs that are not coupled with any of his/her diagnoses. The existence of the need or the recognised risk of a need is the basis for including someone in a disability service scheme.

7. *The Government must recognise an individual's need for a service either through a relevant diagnosis or from professional advice stating an individual needs a service provided by "the scheme". Being "in the scheme" is recognition that an individual needs a service that "the scheme" provides.*

Which groups are most in need of additional support and help?

Currently, essential or core needs of people with a disability are not being met. When dealing with essential or core service needs, it is not appropriate to discuss "most in need". Nor is it appropriate to discuss "additional support and help" when essential and core support and help are not available for our most vulnerable citizens.

Since the essential needs of people with a ASD are not being met, Australia needs to focus on meeting the core needs of people with a disability before it considers any "additional support and help".

People with ASD have unmet essential needs that must be recognised as their rights. A number of relevant rights are defined in:

- UN Convention on the rights of the child ... especially treatment, rehabilitation and education described in Article 24.
- UN Convention on the Rights of the people with a disability

From the outset, the essential needs of children with ASD are unmet. The Commonwealth Health Department advises[3] that essential "treatment and rehabilitation" for children with autism means intensive ASD-specific early intervention. Specifically, "intensive ASD-specific early intervention" involves a program designed for each individual child that is delivered largely one-on-one for a minimum of 20 hours per week (or 1000 hours per year) for two to three years. Yet Government health and disability services do not meet this essential need for Australian children with ASD.

For example, the ACT Government told its Select Committee on Estimates 2010-11[4] ...

> **MR DOSZPOT**: And does the department provide 1,000 hours per year of intensive autism-specific clinical intervention, which is apparently best practice according to the commonwealth health department for children with autism in the ACT?
>
> **Ms Hayes**: No.

The same situation exists in all Australian states and territories.

8. *The Government must ensure children with ASD can access 1000 hours per year of effective "intensive ASD-specific early intervention" immediately after their ASD is diagnosed and continue to receive these essential services for two to three years as needed by the individual child.*

Few clinicians in Australia offer or have the knowledge, training and experience needed to deliver the types of programs that are described in the Health Department's guidelines or review.

9. *The Government must ensure clinicians and allied health professionals who work with children with ASD are trained to provide appropriate, complete and individualised early intervention programs.*

Clinicians and allied health professionals who offer early intervention services for children with ASD do not agree on an appropriate service model or system for children with ASD. Many alleged professionals give families conflicting, biased, incorrect and incomplete information about early intervention choices. Too often, self-interest and vitriol dominate their "advice" .

It is impossible for most families to evaluate the complex information available about early intervention for ASD in a timely manner. Currently, the Autism Advisor service funded through the Government's Helping Children with Autism package provides families with information about the existence of clinicians in their area and presumably about the review and guidelines available from the Health Department. But most families of a child newly diagnosed with ASD will need help interpreting this information.

In the existing climate of "self-interest and vitriol" around early intervention for ASD, it is crucial that families decide about early intervention for their child.

Ideally, the clinicians would come together and develop processes and procedures that help families navigate the various service options. But this depends on appropriate options being funded and available for children with ASD. At present, appropriate options are only available for families who can

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[3] Prior, M., & Roberts, J. M. A., (2006). *Early intervention for children with autism spectrum disorders: guidelines for best practice.* Australian Government Department of Health and Ageing, Australia. See http://www.health.gov.au/internet/main/publishing.nsf/Content/mental-child-autbro-toc~mental-child-autbro-best and
Roberts, J. M. A., & Prior, M. (2006). *A review of the research to identify the most effective models of practice in early intervention of children with autism spectrum disorders.* Australian Government Department of Health and Ageing, Australia. See http://www.health.gov.au/internet/main/publishing.nsf/Content/846804F6D67F34F3CA257280007853DE/$File/autrev.pdf

[4] See **http://www.hansard.act.gov.au/hansard/2009/comms/estimates21.pdf**

afford to organise and pay for 1000 hours of intensive early intervention per year for several years. The cost to the family typically exceeds $40,000 per year. Few families can afford essential early intervention for children with ASD who are among our most disabled citizens.

As well as early intervention, people with ASD have substantial unmet needs across other key disability service areas including education, accommodation support and employment.

The ACT government does not provide appropriate behavioural intervention, service and support for people with ASD in education ... or in the home. The ACT Government told its Select Committee on Estimates 2010-11 that "We do not actually use the ABA intervention method … "[5]. This means that their only available approach to challenging or pathological behaviour in clients is restraint[6].

10. *The Government must ensure behavioural clinicians are trained and employed to help care for and support people with both ASD and challenging and/or pathological behaviour.*

People with ASD have been missing out on essential services for a long time. The lack of appropriate services for children with ASD increases their needs as adults for long-term support and care. Since the number of people diagnosed with autism is growing far faster than service provision is growing, then individuals with ASD face rapidly decreasing levels of service.

The situation for adults with ASD in Australia is poorly understood.

11. *The Government must increase ASD research substantially.*

In the UK, the report *Autism Spectrum Disorders in adults living in households throughout England - report from the Adult Psychiatric Morbidity Survey 2007* published in 2009 (see http://www.ic.nhs.uk/pubs/asdpsychiatricmorbidity07) found:

Key facts

- Using the recommended threshold of a score of 10 or more on the Autism Diagnostic Observation Schedule, 1.0 per cent of the adult population had ASD. Published childhood population studies show the prevalence rate among children is also approximately 1.0 per cent.
- The ASD prevalence rate was higher in men (1.8 per cent) than women (0.2 per cent). This fits with the gender profile found in childhood population studies.
- There is no indication of any increased use of treatment or services for mental or emotional problems among adults with ASD. This is borne out by the recent National Audit Office publication "Supporting People with Autism Through Adulthood".
- A greater proportion of single people were assessed with ASD than people of other marital statuses combined. This was particularly evident among men.
- Prevalence of ASD was associated with educational qualification, particularly among men. The rate for men was lowest among those with a degree level qualification and highest among those with no qualifications.

Note that the third point above is improbable. It may relate more to undiagnosed (therefore untreated) mental illness and/or denial of service (as happens in Australia).

In Australia, the AIHW's online data on service provision that is collected in association with the CSTDA shows that fewer than 50% of children with ASD get any service at all. Very few adults with ASD get any service funded through the CSTDA (which includes most Government funded disability services).

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[5] See http://www.hansard.act.gov.au/hansard/2009/comms/estimates21.pdf

[6] See http://www.cddh.monash.org/assets/chabev.pdf

Some initial data suggests that most people who leave school diagnosed with an ASD qualify for a Disability Support Pension (DSP) soon after leaving school.

What could be done about reducing unfairness, so that people with similar levels of need get similar levels of support?

It is not only unfair, it is illegal that people with ASD do not have the rights described in the various international conventions. Even though Australia has signed the relevant treaties, it has never enacted the laws that are required to provide those rights to its citizens.

The result is that Governments deny people with ASD essential services including treatment, rehabilitation, education, accommodation and employment services that are appropriate and effective.

While discrimination matters relating to young children with ASD can take ten years to process[7], people with ASD do not have the basic human right to a competent legal system.

Australian law does not protect people with ASD from discrimination. The ACT Discrimination Tribunal says the law protects any discrimination that the Government undertakes.

> 122. Even if there had been discrimination, a number of "defences", in particular section 27, would have applied in favour of the respondents.

It is unfair that people with ASD cannot get essential services. Australia must first ensure its citizens can access essential services. It should only compare needs for services that are non-essential.

I'd like to aim for appropriate outcomes rather than similar levels of support.

Recognise quality of life ... measure it carefully and make a basic quality of life a right. Australia must protect the rights of its most vulnerable citizens.

12. *The Australian Government must enact laws to protect all the rights of citizens with severe and profound disability.*

Who gets the power?

Politicians, the judiciary and bureaucrats have the power. Next in line comes service managers, the professional and workers ... then carers.

People diagnosed with ASD have little power and many have little means to exert what power they have.

How could people with disabilities or their carers have more power to make their own decisions (and how could they appeal against decisions by others that they think are wrong)?

As indicated previously, Australia must protect the Rights of people with ASD.

For people with ASD, the issue is not about their making decisions; instead it is about their ability to communicate their decisions and whether their decisions will be respected.

Some people with ASD express their own decisions through challenging and pathological behaviour.

It is essential that the focus is on the person with ASD rather than on the services. People providing care and support for a person with ASD should get to know the person properly. They should work in a number of settings so they understand the person in a range of contexts. They need training in how to recognise and interpret behaviour as a means through which people with ASD can communicate.

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[7] *Woodbury & ors v Australian Capital Government [2007]* ACTDT 4 (5 April 2007) see http://www.austlii.edu.au/au/cases/act/ACTDT/2007/4.html

Service systems need to appreciate how people with ASD communicate through behaviour and then to recognise and act on their communication.

Currently, families of people with ASD are given "take or leave it" or "least-worst" choices. Their choices are hardly decisions at all.

Complaints processes are adversarial in nature. And even those who win a complaint or appeal, find they are unlikely to benefit in an increasingly adversarial and vengeful aftermath.

Culture change is needed. It is better to encourage people to solve problems in the disability sector before they become complaints. Disability services need to adopt a culture of "continuous change" that embraces suggestions from clients, families, carers and employees alike. The culture in disability services should be to act immediately on suggestions rather than maintaining the *status quo* and resisting change. It is better to have people working continuously on improvements for people with ASD rather than focussing on problems and complaints.

13. *Senior managers in health, education and disability services must embrace and ensure a* continuous change *culture in their organisations rather than their existing "my way" mentality.*

How should the amount of financial support and service entitlements of people be decided (and by whom)?

A better aspect of our so-called universal health system is that it does not focus on how services are financed when dealing with an individual patient. The focus is on delivering essential services and the system is expected to finance services that meet patient needs.

People with ASD need a range of services. Some of the services they need are clinical in nature but these clinical services are not provided through Australia's so-called universal healthcare system. They should be part of the health system, not regarded as part of the education or disability sectors as they are in various states and territories in Australia.

14. *The clinical needs of people with ASD must be met through the health system.*

Private health insurance must be required to cover the clinical services for people with ASD as it does for other health issues.

15. *The Commonwealth Government must ensure private health insurance covers the clinical service needs of people with ASD.*

The health and disability sectors need to work together seamlessly in the provision of treatment, rehabilitation, care and support. There needs to be a service safety net that ensures the needs of people with ASD are met. The disability safety net needs its own funding.

16. *The Commonwealth Government must establish and fund a disability safety net system to catch clients when their individual service needs are not met in the existing service systems.*

What services are needed and how should they be delivered?

There needs to be a service to ensure the rights of people with ASD are recognised and respected.

Autism Spectrum Disorders affect people through their whole life. As well as the mainstream services available to all Australians, people with ASD, their families and carers needs a range of ASD-related services through their whole life. These include ...

1. timely, accurate and comprehensive diagnosis
2. appropriate and effective early intervention, treatment and rehabilitation
3. appropriate and effective education including behaviour service and support as necessary

This includes communication skills, independent living skills and social/community engagement.

4. health services for all aspects of diagnosis, treatment and recovery
5. respite services for people with ASD, their families and carers.
6. appropriate post-school accommodation and living support
7. employment services and support
8. recreation and leisure support
9. forensic support

Some of these services would be provided in a universal health system or as generic (specialist?) disability services. Some of them may even be available for some people with ASD through appropriate accommodations in mainstream services settings.

All of the services need to recognise, understand, respect and address the particular needs of individual people with ASD, their families and carers.

17. *The Commonwealth Government must ensure people with ASD can access the full range of services that result in the care and support people with ASD need.*

What kinds of services particularly need to be increased or created?

Diagnosis of ASD should be an integral part of diagnostic services available for young children. The diagnostic manual is clear that correct differential diagnosis of ASD can involve consideration of ADD/ADHD or Reactive Attachment Disorder. Increasingly, diagnosis of ASD will also involve genetic tests. And any ASD diagnosis should trigger a comprehensive review of a person's general health to identify other undiagnosed or misdiagnosed conditions.

18. *Diagnostic services for ASD must be part of a comprehensive health diagnostic service. ASD diagnosis must not be distinct or stand-alone service.*

Children with ASD need effective early intervention. The Health Department has published guidelines on the essential needs of children with ASD. These need to be implemented.

FaHCSIA allowed the allied health professional bodies to hijack its early intervention provisions in the *Helping Children with Autism* package. FaHCSIA requires that clinicians provided face-to-face therapy for children with ASD. The cost of such a service exceeds $120 per hour, so 1000 hours of therapy per year for an individual child would cost in excess of $120,000 per year of which the Commonwealth Government contributes $6,000 or 5%. This service model is impractical: it is too expensive and there are far too few appropriately trained clinicians available. The published research does not support this model of service delivery.

In the ACT, some families can access another 6 hours with different clinicians (which costs the ACT Government $190 per hour). The object of this service is to teach families in just 6 hours to meet their child's therapy needs. But families of children with ASD lack the unbounded energy and copious spare time that they would need. The published research does not support this model of service delivery.

Published research (and the Health Department's advice) supports a model where clinicians with specific knowledge of ASD supervise the delivery of early intervention, treatment, rehabilitation and therapy in a range of settings that best meet the individual child's needs. The cost of this type of early intervention is comparable to the cost of a place in a special school. The research shows that children who receive effective early intervention for their ASD do better on average in their education and make substantial long-term gains. They are less of a burden on their families and the community generally. The overall cost benefits are substantial.

Some children with ASD need ongoing clinical services through their school years and adult life. There are particular difficulties accessing behavioural services for people with ASD since few professionals are trained and Australia's so-called universal health system provides little or no services of this type.

19. *The Commonwealth Government must improve behaviour support services for people with ASD.*

Accommodation services and support for adults with ASD are in crisis. The whole area of post-school options for people with ASD is grossly inadequate. There are enormous problems for people with ASD who want employment.

20. *The Commonwealth Government must address the needs of adults with ASD.*
21. *The Commonwealth Government should act on the AABASD Call to Action (see http://www.autismaus.com.au/uploads/pdfs/Autism_NationalCalltoAction_Oct07.pdf).*

The Government's service planning needs to be fixed. One major problem is that services are designed consistently to fail. The basic laws of mathematics (in queueing theory) shows that any service where the service time and/or the arrival time is not constant, cannot maintain steady state if the service capacity is designed to be 100% of the arrival rate.

In practice, a service that is provided by a human or provides services to a human will involve growing waiting lists if it tries to meet any more than 80% of its apparent capacity. It does not help that overstretched services are burdened with “efficiency dividends” and ever increasing bureaucracy.

The Government's policy of persistently cutting funds for its effective programs until they can no longer function needs review. Government should design services to work, not design them to fail. It should get advice from people who provide services, not from career bureaucrats with limited or negligible experience of the services they design and administer.

22. *The Commonwealth Government must in future design services for people with ASD to work, and not (as is current practice) design programs to fail.*

How could the ways in which services are delivered — including their coordination, costs, timeliness and innovation — be improved?

In many instances, essential services for people with ASD simply do not exist. Previously, I pointed out that no state or territory in Australia provides essential early intervention for children with ASD. People with ASD cannot access clinical services to address their behavioural pathologies.

Many service systems have extensive waiting lists … or have abandoned waiting lists as meaningless. Essential services are not being delivered for people who are on waiting lists.

In the ACT, core services such as supported accommodation are unavailable for most people who need it. There is a lottery for Individual Support Packages.

Note that an Individual Support Package in the ACT is a process where the ACT Government, instead of providing essential services; gives families a small fraction of the cost of a services and expects families to assemble and manage an individual support system without the economies of scale that are available to Government coordinated services. The Government requires additional bureaucratic impediments to ensure service delivery is as difficult as possible for families.

The fact that fewer than half the people with ASD receive any service at all through the CSTDA (see above) shows that services are not being delivered for people with ASD.

I suggest that services could be developed and improved by:

1. identifying service needs
2. designing service systems with the capacity to deliver services at the required level (note that this requires systems with some spare capacity)
3. measuring and reporting the service outcomes for people with ASD and their families.

23. *The Commonwealth Government must create schemes to identify service needs, design service systems to meet the needs that are identified, and a system to measure and report outcomes for people with ASD.*

In most instances, this will require the training of staff and the participation of clinicians in supervising aspects of service delivery. The service system must involve research and development that feeds into professional development at all levels.

The health and disability service sector needs a workforce plan that includes incentives to attract and retain good staff into this service sector.

24. *The Commonwealth Government must focus on research, workforce planning and professional development to ensure the creation of the workforce people with ASD need.*

As indicated above, the organisations that deliver services for people with ASD must have a culture of continuous change to ensure timely and effective improvement.

Service coordination must start with the individual. The challenge is to recognise the needs of the individual and to meet those needs. We need to move away from services and service providers as the focus of the system.

There are many ways centre service coordination on individual clients. These include having a case manager or having a client-centred process.

The challenge is to ensure that identification and recognition of a clients needs leads immediately to service provision. The system must be create services quickly to meet demand from clients. The system must recognise that clients have different needs and that a particular provider of X may not meet a client's need for X.

Governments use simplistic and superficial costings in the disability sector. For example, finance and treasury official account only for the basic cost of early intervention. They do not consider the benefit that results.

The reality is that people who “fall through the cracks” in service provision end up being very expensive. In its reports *Responding to people with multiple and complex needs* (July 2003)[8] about its most challenging clients, DHS in Victoria observed

> … that currently each [challenging] client costs the Department of Human Services and other government agencies (for example, police, courts) around $248,000 per annum.

and

> Families, carers and services highlighted the following gaps or omissions:
>
> Lack of targeted responses to individuals with autism spectrum disorders, particularly Asperger’s Syndrome. These people are often identified as falling into service gaps, frequently deemed ineligible for both mental health and intellectual disability services.
>
> ...

At these cost levels, any early intervention, behaviour support program or post-school option that reduces the overall cost of care and support for adults with ASD in any way will be cost effective despite the views of Government finance and treasury officials.

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[8] See http://www.dhs.vic.gov.au/__data/assets/pdf_file/0003/160725/complex-clients-phase1-rep.pdf

Currently, the bulk of the burden of ASD falls on families.

Economic Costs of Autism Spectrum Disorder

This study of the economic costs of Autism Spectrum Disorder (ASD) in Australia has been undertaken for the Autism Early Intervention Outcomes Unit (AEIOU).

The objective of this study is to develop a better understanding of the likely resource cost incurred by people with ASD, their carers, Government and society. The cost-based approach that is employed here seeks to estimate the resources required to deliver services that specifically relate to the condition of ASD.

Click to Download the Executive Summary of 07

Click to Download the "Economic Costs of Autism Spectrum Disorder"

Click to Download the AEIOU Research "Economic Report Released Into Costs of Autism"

from http://a4.org.au/a4/node/54

Government officials will say almost anything to avoid responsibility. In the ACT, officials from the Department of Disability, Housing and Community Services (DHCS) told the Select Committee on Estimates 2010-11[9]

> **Mr Hehir**: I think it is also worth clarifying that the 1,000 hours, which translates roughly from 20 hours per week ... are actually not exclusively required to be with a therapist. It is actually intended to reflect work in the home that the family can do, work at school that the teacher can do, work in a variety of settings. It is important to make sure that people understand what are the appropriate responses. And I think we did actually clarify that with the authors of the report. The intent is that it does not actually have to be with a therapist. It is that a broad therapeutic approach is applied.
> **Ms Hayes**: That is correct. So the report that said that 20 hours of intervention per week is ideal for young children with an autism diagnosis does not say that that has to be one-on-one therapy time. And in fact, there is quite a deal of research now that the most effective intervention is done by families and is done in circumstances where the child is naturally, rather than in a fairly artificial therapy environment, because one of the hallmarks of autism is an inability to generalise.
> ...
> **MR DOSZPOT**: So you are saying that clinical intervention broadly can encompass parental intervention as well?
> **Ms Hayes**: Yes, because there is nothing particularly magic about what a therapist does. It is something that other people can learn to do as well. And effective intervention can certainly be done by families, and most is.

I asked the Government for a copy of the clarification they got from the authors. They did not provide it.

I also spoke with the authors of these reports. They did not intend that *clinicians* deliver all the intensive ASD-specific therapy. Nor did they intend that therapy would be left entirely to family members as the ACT Government suggests.

It appears that these officials do not appreciate that appropriately trained and experienced clinicians (or allied health professionals) can design and supervise an individual program for a

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[9] See http://www.hansard.act.gov.au/hansard/2009/comms/estimates21.pdf

child with ASD. Clinicians can train and supervise others to act as therapists to deliver most of the face-to-face therapy for the child.

These DHCS officials expect the aussie battlers and working families to come home from their working day and deliver 20 hours per week of therapy for their child … in addition to providing care and support for all but their working hours. Families have to navigate the complex and incomplete disability service sector. After a few hours of simple instruction families are expected to deliver a complete complex intervention. And children whose families are not suited to this role miss out.

There is a major problem with expecting families to meet the clinical needs of their child. Not all children progress as we want. The family, and especially the mother, is devastated if their efforts do not deliver significant benefits for their child.

My experience is that the really expert clinicians I have seen are quite magical in how their methods work for children with ASD.

Expert clinicians prefer that families are involved in their child's program; they say that the child with ASD benefits when their family contributes. But evidence does not support making families responsible for their child's program. We do not ask families to become clinicians for their families for other disorders. ASD must not be singled out in this way.

I wonder whether these officials have qualifications and experience that would allow them properly to offer such advice. I doubt the professional bodies would agree with these officials' advice. Community groups do not agree with their advice.

The ACT Government's position is opposite to FaHCSIA's insistence that providers/clinicians on its early intervention panel for the *Helping Children with Autism* package deliver early intervention face-to-face. It seems FaHCSIA's *Helping Children with Autism* model for early intervention does regard what clinicians do as “magic”.

Of course, the evidence from research supports neither of these Government models.

The burden on families is compounded since having a child with ASD reduces family income.

> Montes G., Halterman J.S. (2008) *Association of Childhood Autism Spectrum Disorders and Loss of Family Income*, PEDIATRICS Vol. 121 No. 4, pp. e821-e826, see http://pediatrics.aappublications.org/cgi/content/full/121/4/e821
>
> RESULTS. Both having a child with autism spectrum disorder and having a child with other disabilities were associated with decreased odds of living in a higher income household after controlling for parental education, type of family, parental age, location of the household, and minority ethnicity. The average loss of annual income associated with having a child with autism spectrum disorder was $6200 or 14% of their reported income.
>
> CONCLUSION. Childhood autism is associated with a substantial loss of annual household income. This likely places a significant burden on families in the face of additional out-of-pocket expenditures.

Service timeliness depends on realistic service design. Typically, services are planned to meet a 100% capacity model. This is *design for failure*. Services must cater for contingencies and variance in client presentation. Mathematics indicates that they must plan for a maximum service provision of around 80% of their apparent capacity or their clients will experience delays and service failures.

Innovation has become too hard for Government. The best we can hope for is a degree of continuous improvement. Even that will challenge most bureaucrats and administrators.

Are there ways of intervening early to get improved outcomes over people's lifetimes? How would this be done?

The answer is a clear "Yes" for people with ASD.

The Commonwealth Department of Health and Ageing published two documents that provide relevant information about early intervention. They are

> Prior, M., & Roberts, J. M. A., (2006). *Early intervention for children with autism spectrum disorders: guidelines for best practice.* Australian Government Department of Health and Ageing, Australia. See http://www.health.gov.au/internet/main/publishing.nsf/Content/mental-child-autbro-toc~mental-child-autbro-best and
>
> Roberts, J. M. A., & Prior, M. (2006). *A review of the research to identify the most effective models of practice in early intervention of children with autism spectrum disorders.* Australian Government Department of Health and Ageing, Australia. See http://www.health.gov.au/internet/main/publishing.nsf/Content/846804F6D67F34F3CA257280007853DE/$File/autrev.pdf

As indicated above, no Australian Government (or combination thereof) currently provides essential early intervention for children with ASD.

Essential early intervention could be provided, at little extra cost, by:

- formally training clinicians in in the supervision and delivery of intensive ASD-specific early intervention;
- requiring (or just allowing) HCWA panel providers and CSTDA therapy services for children with ASD to deliver early intervention using recognised intensive ASD-specific approaches; and
- allowing integration/inclusion, childcare, pre-school and respite support programs to be guided or supervised by trained clinicians to prepare young children with ASD for more inclusive settings.

I am happy to discuss in detail practical delivery of essential early intervention and the associated costs with any Government decision maker who is genuinely interested.

Effective education is the foundation for a better life as an adult with ASD . The challenges in education involve managing:

- a child's individual curriculum and delivering it through effective pedagogy;
- behavioural challenges and pathology in school;
- to avoid bullying for students with ASD in mainstream settings; and
- the provision of ASD-specific programs in generic special education settings.

Children and adolescents with ASD risk developing challenging or pathological behaviours both at school and at home. Currently, the law (see *Purvis vs NSW*) encourages schools to exclude from education students whose behaviour is challenging … despite the disability standards in education. Families are left to deal with their child's behavioural pathology.

Families need timely access to behavioural clinicians (see recommendation 19. above).

In many instances, behavioural services are available for people with intellectual disability, mental illness, brain injury and/or dementia. But people with ASD are denied access to essential behavioural services. For example, in the ACT DHCS's Intensive Treatment and Support (*ITAS*) service is not available for people with ASD unless they also have both an intellectual disability and mental illness.

How could a new scheme encourage the full participation by people with disability and their carers in the community and work?

Previously, I indicated that people with ASD need early intervention, effective education and behavioural services. Ensuring these services were available and effective would result in more people with ASD being employed, participating in their community and living more independently.

Carers could participate more in their community and work if their children with ASD needed less care and supervision.

Carers would also participate more in the community and in work through improved services such as respite services, after school care and school holiday programs for students with ASD.

We never know whether we will be able to work full-time. Recently, the Commonwealth Government changed its YouthLinx program so that it would no longer fund after-school care for my son. When I inquired about it, I was given a complete run-around between DEEWR and FaHCSIA. Eventually, I wrote to (now) Prime Minister Gillard and got an especially unhelpful response from a department official (see Annex). The response was unhelpful because it did not address the questions I asked and referred me to Autism Asperger ACT (as Vice-President and being active in the design and maintenance of its services database ... I know what help Autism Asperger ACT provides and what services are available in the ACT).

The only break longer than 10 hours that we have had from having to constantly supervise my son in years was when he went away on school camp. We cannot put him in overnight respite in the ACT because people with ASD die in care[10]. A similar situation exists in Tasmania.

The Government has very low expectations. My son Kieran's ILP assumes as he has autism, he will only get access to part-time work. I know of no reason why he could not work full-time.

While 1% of school leavers now have ASD, HR department's in Government and in industry do not plan to include people with ASD in their workforce. The Government could offer training and incentives, or impose penalties.

How can a new system ensure that any good aspects of current approaches are preserved?

Ensuring a culture of continuous change will preserve or reintroduce the good aspects of current approaches.

What should be done in rural and remote areas where it is harder to get services?

People with ASD in rural and remote settings cannot access services that do not exist in the major cities or anywhere in the country. The first step is to ensure essential services actually exist or could exist in the regions.

FaHCSIA is (was?) trying to relate service provision for its HCWA early intervention panel to the location of clients. I do not know how this effort went.

It should be possible to use the coming national broadband network for clinicians who are located in population centres to train and supervise therapy delivery in rural and remote regions.

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[10] The ACT Auditor's Review of respite services did not include the recent death of Jack Sullivan in Government funded respite (see Annex below), no Coroner's report has been completed and the Standing Committee reviewing Respite in the ACT is keeping my submission secret.

How could a new system get rid of wasteful paper burdens, overlapping assessments (the ‘run around’) and duplication in the system?

Focussing service delivery on the individual will reduce the need to duplicate information about the individual. Hopefully, services will adjust to meet individual needs … so individuals do not need to try out several services in their quest for an appropriate service.

Bureaucrats and administrators must understand that a degree of duplication is essential to competition … and economists say competition leads to improved services.

Funding

How should a new scheme be financed?

A new scheme for disability care and support must be financed comprehensively.

Autism Spectrum Disorders already impose an enormous cost on the community. We do not account for most of the cost. Much better outcomes could be realised through recognising the true cost and deciding to get better value for the money we already spend.

The Rudd Government missed its initial opportunity to use stimulus funding relating to the GFC to improve and develop Australia's disability sector. Possibly, community groups in the disability sector would have kept a closer eye on spending and some of the political fallout of the Rudd Government's stimulus spending might have been avoided. Funding the disability sector might even get better bi-partisan support.

Hopefully, the disability sector will be considered if a second round of economic stimulus is required.

Government must understand the costs associated with ASD (and disability more generally). Most of the cost of a new scheme can be covered through redeploying and better managing existing expenditure. Some investment may be required in the short term, but we can expect savings in the longer term.

There are two obvious options:

1. through a specific purpose tax/levy as with Medicare, our allegedly universal health system
2. from general revenue as for our allegedly universal education system

The level of funding required is probably beyond what could be raised through lottery profits.

How can it be ensured that there is enough money to deliver the services that are needed and provide greater certainty about adequate care in the future?

The Government and the community must appreciate people with ASD need complex set of services in order to achieve a basic quality of life. Australian's must commit to meeting their basic needs whatever the cost. Discussion should centre on how best to meet their basic needs.

Importantly, Government and the community must appreciate that disability funding needs to grow. Improvements in our health services save an increasing number of lives many of which involve a degree of disability. The amount of disability in our community will continue to rise. The funding needed to deliver the expected standard of care will continue to rise.

Government's are reluctant to increase health care funding. Unless they act to properly explain the need to the community, any new disability scheme will experience the same lack of Government leadership and the funds allocated will quickly become inadequate for the task.

Organising and implementing a new disability policy

What are your views about the 'nitty gritty' aspects of a scheme that will make it work practically?

The Government must involve people with ASD, their carers and family in policy development and decision making. Families provide the vast majority of care, support and services for people with ASD yet they are not included appropriately in the relevant processes. Involvement in decisions must reflect involvement in care, support and service … after people with ASD themselves, family and carers have precedence, then teachers (and therapists) have more direct say than clinicians and service (or program) managers. Of course, families and teachers can choose to be influenced by clinicians and others. And clinicians have more say on clinical matters.

The culture of continuous change can involve these people in operational decisions.

We need more information about the needs of people with ASD and clear measures of unmet need. We need much more research. We need appropriately trained clinicians. We need processes for managing service provision for people with ASD.

The Government needs to measure health and quality of life outcomes for people with ASD. Then it must report the outcomes.

How long would be needed to start a new scheme, and what should happen in the interim?

This depends on the Government's commitment. It could be done either quickly with an injection of funds or a little slower when redeploying existing resources.

I am not inclined to speculate on this until Government decides what it wants to achieve. Suffice it to say that the existing scheme (or lack thereof) must be replaced as soon as possible.

Some things need few resources and can be done immediately such as changes to training in the health sector to reflect the burden of disease and injury due to ASD. Also, the Government could emphasise ASD research immediately.

You may have many other ideas for a good scheme

Australians with ASD need legal rights as the foundation "for a good scheme" for people with severe or profound disability.

People with ASD have complex needs that span government agencies. The focus needs to be on the individual to overcome service barriers resulting from administrative silos in government.

Background

Autism Spectrum Disorders

Dr Larry Cashion for A4
from http://a4.org.au/a4/asd

Autism Spectrum Disorders are diagnosed on the basis of behaviour. This is because at this time there are no specific genetic or biological markers that accurately identify a person as being on the autism spectrum. People on the spectrum have in common three main types of difficulties. These difficulties are:

1. Impairment in social interaction
2. Impairment in communication
3. Restricted and/or repetitive patterns of behaviour, interests and activities

Autism first manifests in childhood, with age of onset for a diagnosis being under the age of 3 years. This does not necessarily mean that a person is diagnosed before turning 3 years of age, only that symptoms were present at that developmental stage.

Although not stated in the main diagnostic schedules, many clinicians use the term "Autism Spectrum Disorder" (ASD) to describe a continuum of related disorders, including Autistic Disorder, Asperger's disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). The categories within the autism spectrum are related to both severity and the presence or absence of some symptoms.

Impairments in social interaction

The type of impairment in social interaction in ASD is varied. These can include marked problems with nonverbal behaviours, such as eye contact, facial expression, gestures, and body position, which are commonly used to regulate social interactions. It is often the case that people with an ASD do not develop relationships with children and adults from their peer groups at school and work. They may also feel no need to share personal experiences of achievement or enjoyment with others, and may also be unresponsive to social or emotional displays by others, especially those that are not immediately obvious.

Impairments in communication

Delay in development of spoken language (including not developing language at all) is also a symptom of ASD. It is important to understand that language delay or absence is an indicator of autism only where a person does not try an alternative strategy to communicate actively, such as through gestures or mime. For people with an ASD who are able to speak, it is often the case that they do not initiate or sustain conversations. People with autism who are able to use language will often use words and phrases that are repetitive. They can also use language in a very formal way when communicating with familiar people, or adopt a style of speech that they maintain at all times, regardless of the listener. In addition, children with an ASD tend not to engage in the types of pretend play commonly observed in children at their developmental level.

Restricted and/or repetitive patterns of behaviour, interests and activities

Some people with an ASD show an intense interest in one type of activity. In these cases, the object of interest, for example trains and train schedules, consumes an unusually large amount of time or attention. People with autism often find it difficult to be socially flexible with regard to routines and rituals. Small changes to routine may cause these people significant distress, especially if specific rituals are associated with the disturbance. Repetitive mannerisms, such as hand flapping and finger flicking can be observed in those with an ASD, especially when they are feeling anxious. Another aspect of ASD is that some people with autism are preoccupied with parts of objects rather than objects themselves. An example of this is can be seen where a child with autism persistently spins one wheel of a toy car, when other children of that age are playing with the car as a toy vehicle.

Other behaviours commonly observed in ASD

As well as the triad of symptoms outlined that are observed in ASD, many researchers and clinicians believe that other criteria are valid and important to consider when diagnosing ASD. Susan Mayes includes sensory disturbances in her diagnostic criteria, as well as fear of crowds, sleep disturbances, limited food preferences, and highly tolerance to pain while being sensitised to light touch. There is a significant body of evidence to suggest that people with ASD are more likely to demonstrate heightened response in all sensory domains, and this also is regarded as an important indicator of autism by Christopher Gillberg. It is also common to find motor clumsiness in people with ASD. Tony Attwood has suggested that these problems can affect gross motor skills, such as walking and balance, as well as fine motor skills such as handwriting and cutting with scissors. Motor problems can also affect timing and rhythm, as well as causing difficulties in imitating others as often occurs in social interaction.

ASD Prevalence

Section 3 of the Issues Paper on *The prevalence and incidence of disability* estimates of the number of Australians with a disability in 2009 ...

> "Based on Productivity Commission estimates using 2009 ABS population estimates and assuming that the 2003 age-specific rates of disability recorded in the ABS *Survey of Disability, Ageing and Carers* (cat. no. 4430.0) remained fixed over the ensuing six years."

This underestimates the number of people with ASD since the number of people diagnosed with ASD has more than doubled every 5 years for the last 20-30 years. Data provided by FaHCSIA show the number of children with Autism or Asperger's Disorder, the two main disorders in the ASD category, and who get Carer's Allowance more than doubled from 2004 to 2009. These data show ASD diagnoses doubled again since 2003.These data were present at APAC '09 (see below).

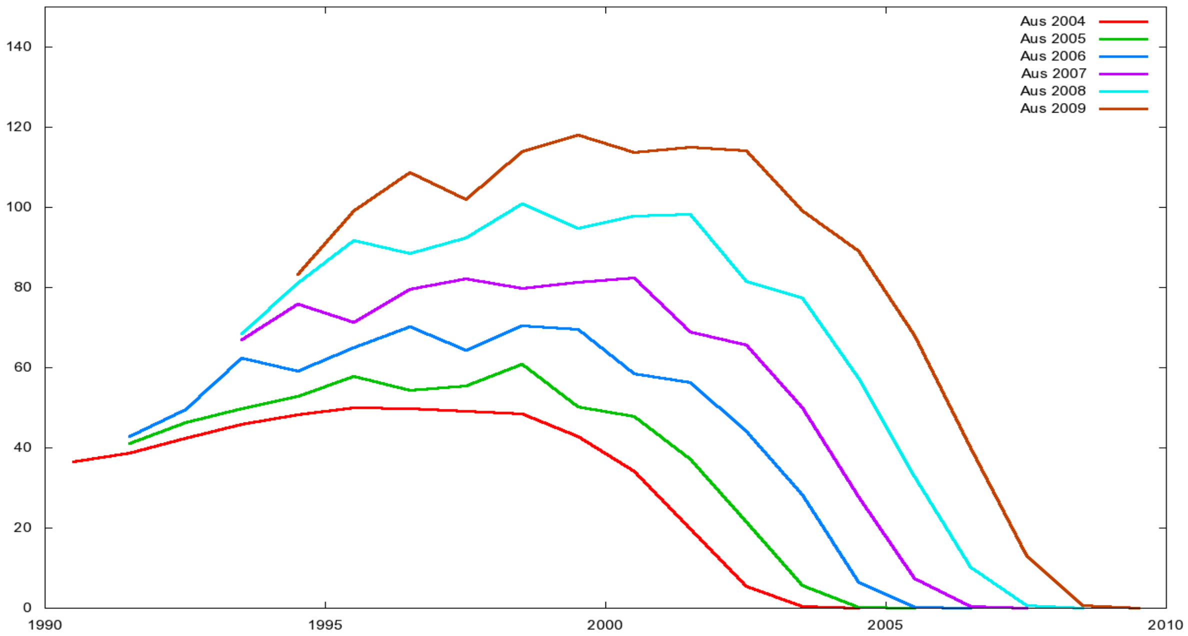

Illustration 1: Autistic and Asperger's Disorders in Australia from Carer Allowance

Other data sources confirm this growth including FOFMS for children with ASD aged 0-7 years, Autism SA client data and Qld Education Department enrolements.

Authoritative reports from both the UK and USA also show the number of children diagnosed with ASD now exceeds 1% of school-age children.

Four boys are diagnosed with ASD for every girl.

Universal Health and Education Schemes

Government's in Australia provide what they call “universal” education and health systems. These systems are complicated and involve components from both Commonwealth and state levels.

For people with ASD, Australia's so-called universal health system is not universal. It is not universal because it does not provide essential treatment and rehabilitation for people with ASD. People with ASD cannot get essential early intervention or behavioural intervention through Australia's health system.

Mental health services often refuse treatment to people with ASD even if they have mental illness.

Some health funding comes from the Medicare levy. As health funding provides minimal treatment and rehabilitation or other relevant services, I have not examined the detail of health funding.

Each state in Australia has its own education system. Each system is different.

Most students with ASD are enrolled in the public health system. While most students with ASD are enrolled in mainstream education, some are enrolled in segregated special education settings … and a few are in ASD specific settings.

Students with ASD experience extremely high levels of bullying in mainstream settings.

The High Court, in *Purvis vs NSW*, decided that schools can exclude a students whose behaviour they regard as inappropriate.

Neither the Health nor the Education systems in Australia is universal.

About the Author

Bob Buckley has a wife and two children. My 19 year old son has severe Autistic Disorder. He has been advocating for people with ASD since 1997. He is:

- Convenor of Autism Aspergers Advocacy Australia (known as A4)
- ACT representative and Director of Australian Advisory Board on Autism Spectrum Disorders
- Vice+president of Autism Asperger ACT Inc.

For most of his working life he was Consultant in systems analysis & engineering, operations research, computer-based modelling, computing & information technology, industrial relation and workforce planning.

As an academic, he published papers in all these areas as well as in his recent work in ASD prevalence.

He was a Visiting Fellow at John Curtin School of Medical Research following his work in bioinformatics in the early 2000s.

Currently, he works as a Data Analyst for elite sport at the Australian Institute of Sport.

Annex

Thursday, June 3, 2010 The Canberra Times News 5

Coroner to investigate death of disabled man

Mother to find out how autistic son died in care

By Phillip Thomson

INQUEST: Jack Sullivan, 18, had an average of three epileptic seizures a month.

The mother of a profoundly disabled Canberra man who died in care will finally have a coronial inquest into her son's death more than two years after it occurred.

The NSW Crown Solicitor's Office is collecting a brief of evidence for the NSW Coroner about the death of 18-year-old Jack Sullivan.

Jack's mother, Esther Woodbury, expects the inquest to expose weaknesses in the ACT Government's review systems for disability care.

Since her son's death Ms Woodbury has assumed that her autistic son drowned in a bath after an epileptic seizure, was brought back to life by a medical crew, fell into a coma and had his life support switched off at Canberra Hospital the next day on February 18, 2008.

But she is yet to find out the exact manner and cause of Jack's death.

A solicitor for the Crown, Jessica Murty, confirmed the manner and cause of Jack's death would be decided at an inquest at Queanbeyan Local Court starting in four months' time.

The woman caring for Jack at the time of the bath incident, a former professional carer who became a teacher of autistic children, Terri Carroll, said her respite care business was destroyed by the death.

Yesterday, Ms Carroll said the inquest should have been finished long ago so everybody involved could receive closure.

Ms Carroll said all organisations she had contracts with, including Disability ACT and NSW Department of Community Services, ceased contracts with her following the death.

"It was horrific for Jack's family, my family and myself, we were on the breadline the next day," Ms Carroll said.

She had lived with the stigma of Jack's death since, she said.

Ms Carroll, who had known Jack for many years, said the 18-year-old slipped below the water level of the bath because of an epileptic fit and that she had trouble getting him out.

Jack was known to have an average of three epileptic seizures a month, or about one every 10 days, according to his mother.

Ms Woodbury, who has been on a two-year campaign to find out exactly why and how Jack died, also wants to know why it has taken more than two years for an inquiry to be called into the death.

Opposition disability spokesman Steve Doszpot, who asked for an update on the case in an ACT budget estimates hearing last week, said Jack was placed in care at the Queanbeyan facility by Disability ACT.

Ms Woodbury said funding for the care came from the ACT Government via Community Connections.

A spokesman from Health Minister Joy Burch's office said the ACT Department of Disability, Housing and Community Services (of which Disability ACT is a part) had no formal funding agreements with the facility operated by Ms Carroll at the time of Jack's death.

Australian Government
Department of Education, Employment and Workplace Relations

Your Ref
Our Ref MC10-010373

Mr Bob Buckley
27 Fairbridge Cresent
AINSLIE ACT 2602

Dear Mr Buckley

Thank you for your email of 21 May 2010 to the Prime Minister, concerning Youthlinx funding for the Gungahlin Regional Community Service. Prime Minister Gillard has asked me to reply on her behalf.

The Australian Government has combined the funding from several programs for at risk young people, including Youthlinx, into the new Youth Connections program. The intent of the new program is to provide a nationally consistent safety net for young people at risk.

In the ACT, Youth Connections providers work with at risk young people aged 12-18 years to provide an improved safety net for young people who have disconnected from education or their community, or are at risk of disengaging. The services are flexible, offering a combination of case-managed support as well as linkages with wider community activities to help young people to re-connect with education or training and build resilience, skills and attributes that promote positive choices and wellbeing.

Anglicare Canberra and Goulburn has been contracted to provide Youth Connections in the ACT, and Gungahlin Regional Community Service has been sub-contracted by Anglicare to provide Youth Connections services in the Gungahlin region.

However, as you have observed, the afterschool care service will not be funded under this program. There are a number of afterschool care, holiday programs and support services for young people with mental disabilities, including autism, currently available in the ACT. The Autism Asperger ACT Association has compiled a list of all of the available services in the region. To register with Autism Asperger ACT visit their website www.autismaspergeract.com.au or call (02) 6140 1061 to speak to an Autism Advisor about the services available for your family.

I trust that this information is of assistance.

Yours sincerely

Helen McLaren
Branch Manager
Youth Attainment and Transitions Branch

30 June 2010