A4 Autism Aspergers Advocacy Australia

Update

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Study by Flinders University detects signs of autism in first weeks

Verity Edwards, The Australian, 14 September 2009

A world-first study on siblings of children with autism is showing that signs associated with the behavioural disorder appear in babies in their first weeks of life.

The Flinders University research is the first of its kind to study the behaviour of infants who have an increased risk of developing autism from as young as 10 days, and to revisit the children every second month until they are 18 months old.

The ability to diagnose children with an Autistic Spectrum Disorder within the first months could lead to significant improvements in a child's quality of life, because it would enable parents to seek early intervention therapies for their children and to circumvent the formation of specific behavioural patterns.

Study co-ordinator Danielle Robson told The Australian preliminary results were showing children in an at-risk group - with an older sibling with an ASD including Asperger's syndrome - were developing different behavioural patterns to children from families with no history of autism.

"Many of the at-risk infants are showing early patterns of behaviour that's consistent with autism even if they don't go on to develop autism," Ms Robson said yesterday. "Even if they didn't develop autism, their development is different to infants with no family history of autism and what it should be, suggesting there may be a broader spectrum of the disorder among family members."

The plight of parents with autistic children was highlighted last week when national rugby league star Mat Rogers and his wife Chloe Maxwell revealed that their son Max had been diagnosed with the behavioural disorder.

The family has been working with a therapist four hours a day and they have noticed the three-year-old now engages with them.

Autism affects up to 16 children per 10,000, with wider spectrum disorders affecting up to 60 children per 10,000. The assessments measured a wide range of developmental areas, including traits associated with autism such as responding to people, sensory perceptions and pictures. During her assessments, Ms Robson used toys, pictures, noises and other items to gauge the child's attention and watch how they responded.

Differences between the groups included noticeable autism-related behaviours such as their ability to pay attention, respond to their own name, early language development and cognitive abilities, temperament and sensory processing.

As well as using four internationally recognised behavioural measures to identify ASDs, Ms Robson and Flinders University psychologist Robyn Young created an early detection tool to assess traits thought to develop atypically in autistic infants from birth.

Autistic traits are not generally detected in children until they are at least three years old, and many not until school.

Ms Robson said early detection enabled parents to seek intervention therapy for the child as soon as possible, which could significantly alter the formation of behaviour patterns.

"Early intervention seems to improve their prognosis; there's anecdotal evidence that starting intervention early can lead to better outcomes," she said.

Early intervention involves behaviour-modifying therapy, such as working repetitively with children to improve their understanding of verbal instructions, play skills and teaching children how to respond to others.

Of the 39 children assessed, including 15 not at risk, Ms Robson was able to tell the parents of three children there were definite signs of an ASD before their first birthday.

"Three of those families started doing some behaviour modifications and all of those children at 18 months old didn't have autism," she said.

The aim of the study is to investigate whether autism could be detected at a younger age than with present diagnoses.

From http://www.theaustralian.news.com.au/story/0,25197,26068823-23289,00.htm

Also see http://www.abc.net.au/worldtoday/content/2009/s2685193.htm

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Convenor's message

Dear A4 members,

I was one of the people lucky enough to attend APAC '09. It is a big conference and I only saw a small part of it.

Some of the material presented was especially impressive. If you are interested, you could take a look at the program on the website, http://www.apac09.org/full-program.php. Decide which sessions most interest you, then contact your state association and ask if you can see a DVD of the sessions that interest you.

I thought the research into very early behavioural signs of autism spectrum disorders was exciting. It seems to me that very early detection of behavioural signs followed by appropriate intervention could inhibit the emergence of the more disabling behavioural aspects of ASD.

The Honourable Bill Shorten MP, Parliamentary Secretary for Disability, was there to represent the Prime Minister. In his speech, he announced there is activity funded through FaHCSIA to develop a national Register of people with ASD. There has been relatively little media interest. You can find some on A4's website (see http://a4.org.au/a4/node/144) and there is a copy of the press release in this Update.

He also mentioned the need for people diagnosed with ASD to access case management to help with the complex set of services that they typically need. I will be interested to see how and when this concern is manifest in government policy and service delivery.

My role in the conference included delivery of a paper showing the number of Australians getting Carer Allowance relating to their Autistic Disorder or Asperger's Disorder from 2004 to 2009. FaHCSIA kindly shared this data with us. The data shows the number of children diagnosed with ASD and receiving Carer Allowance has more than doubled in the last 5 years, continuing an alarming trend that has been observed — both here in Australia and overseas — for around twenty years.

The Australian Advisory Board on Autism Spectrum Disorders (AABASD) report in 2007, using data from 2003 to 2005, said that ASD was at a level of 1 in 160 for children aged 6-12 years. On the same basis, ASD is 1 in 90 in mid-2009. That is, 1.1% of children aged 6-12 years are diagnosed with an ASD.

Most services for people with ASD are delivered through the state disability systems. To my knowledge, services for people with ASD that are offered at the state level have not doubled in any state in any 5 year period over the last twenty years. Nor has the capacity of allied health professionals to deliver services doubled in any 5 year period.

Twenty years ago, services for people with ASD were minimal (being polite). The ASD Community needs to make it clear to government at both state and federal level that funding services for people with ASD is not about *extra* services: it is at best *catch up* for people with ASD.

When approached, state disability ministers typically argue that they cannot just help people with ASD. Personally, I am happy for them to help all people with a disability. However, my role is to advocate for people with ASD.

State disability ministers do not ensure service availability and delivery keeps pace with demand from people with ASD. Their refusal to act significantly disadvantages people with ASD since the limited services are diluted among the increasing numbers of people diagnosed with ASD. This is a serious cut to services on an individual basis for people who mostly have severe or profound disability. To my knowledge, no other severe disability group is experiencing the growth observed in ASD, or the consequent reduction in essential services to the individuals in that group.

I get no reassurance from things like an ***Australian Charter of Healthcare Rights*** from the Commission on Safety and Quality in Health Care (see http://www.safetyandquality.gov.au/internet/safety/publishing.nsf/content/PriorityProgram-01). I doubt there is any **Right** in Australia to access anything like Best Practice in Early Intervention for children with ASD as documented by the Health Department. It would be dishonest for the Government to mislead people into believing such rights exist if they do not.

Students with ASD are supposed to have the right to equitable access to education. But children with ASD are frequently excluded from education settings (see http://a4.org.au/a4/node/147).

> **SCHOOLS are turning children with disabilities into part-time students by restricting their attendance hours in breach of anti-discrimination laws.**
>
> Some school principals are limiting the time disabled students are in class to match the hours a teacher's aide or other assistance is available, Macquarie and Sydney university researchers have found.

School principals have the legal backing of the High Court's *Purvis vs NSW* decision to allow them to exclude a student with a disability if they think they won't like some aspect of the student's potential behaviour.

A4 has a lot of advocacy to do. Thank you for your support.

Regards
Bob Buckley
September 2009

The Shorten Curlies

This is a new column in A4 Updates for describing possible or perceived challenges, anomalies, inequities and policy glitches that are ASD-related – in other words "curly" issues for our federal government. This column raises challenges and issues that A4 members feel the federal government could or should address. A4 will share these "curlies" with government and report the ensuing dialogue or outcomes as they emerge.

The column is named for The Hon. Bill Shorten MP, Parliamentary Secretary for Disability, who is a member of the Government likely to consider such issues.

If the title of this column gives you any discomfort, try seeing it as a metaphor: try to imagine a game of curling with the Parliamentary Secretary smoothing the way and improving the chances that our "spectrum coloured" curling stone (symbolising treatment, services and support for people with ASD) will reach its target (representing a goal of equitable outcomes for people with ASD). And if you like obscure sport metaphors, you might see ASD currently as a skeleton event in the Winter Olympics with participants speeding head-first down a slippery and twisting course … an event with far too few winners in the end.

SC#1. **ASD and accessing CSTDA-funded services**: A4 commends the federal government for supporting people with ASD through Carer's Allowance and through the CSTDA

(Commonwealth State/Territory Disability Agreement). A4 also appreciates the valuable data collection and reporting that is part of these schemes.

Table 1 below shows the number of Australians with autism spectrum disorders (ASD) using data collected both by the Australian Bureau of Statistics (ABS) through the 2003 Survey of Disability, Ageing and Carers (SDAC) and by Centrelink for the purpose of paying Carer's Allowance. These data show comparable ASD prevalence in their common age ranges even though the ABS data was collected 4 years previously.

In Australia, most disability services are provided through the Commonwealth State and Territory Disability Agreement (CSTDA). The Australian Institute of Health and Welfare (AIHW) reports on data collected by state and territory governments relating to disability services provided through the CSTDA. Table 1 shows the latest published data for younger Australians.

Table 1: People with ASD and people with ASD accessing disability services.

Ages (years)	ABS SDAC 2003	Carer Allowance 2006-7	CSTDA 2006-7	c.f. CSTDA and Carer Allowance
0-4	1200	2189 to 3515	1136	35% to 50%
5-9	8200	10071	3632	36%
10-14	10800	10055	2723	27%
15-19	3900	-	2552	-
20-24	-	-	1584	-
25-29	-	-	663	-

The right-most column of Table 1 compares the best available estimates of the number of Australians with ASD to those who receive disability services through the major disability service mechanism agreed between the levels of Government. These data show that fewer than half the people diagnosed with ASD access disability services funded through the CSTDA.

This issue arises from the following points:

a) ASD is highly disabling: the AIHW reports that 87% of people with ASD have severe or profound disability[1];
b) people with ASD usually need disability services that are substantial, complex/comprehensive and ASD-specific;
c) the bulk of disability services (apart from those services for people with ASD that are part of the Education and Health systems, and the recent federal HCWA early intervention and playgroups) are offered and provided as disability services via the CSTDA-related system; and
d) these data indicate that many people with ASD do not access the CSTDA-related disability service which are the very services intended to address their substantial disability-related needs;

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[1] AIHW Bulletin 42, 2006, page 11.

The low CSTDA numbers suggest that adults, as well as children, with ASD are not accessing disability services that they need.

CSTDA services are provided through state-based schemes yet the AIHW reporting on their website is national. We now know the number and age of people diagnosed with ASD in the different states and territories. The AIHW should at least show the number of people in each state and territory who access the disability services available in the state.

This problem goes beyond the issue that most families cannot access any disability services. Of those who access a disability service, many families suggest the disability services funded that they do access are neither adequate nor effective for their ASD. The services people access through the CSTDA should better address growing, specific and distinct needs associated with ASD.

SC#2. **PDD-NOS and Carer's Allowance**: As indicated above, A4 commends the federal government for supporting people with Pervasive Developmental Disorders (PDD), including ASD, through Carer's Allowance. However, A4 suggests there is an anomaly in the Carer's Allowance scheme relating to the Pervasive Developmental Disorder called "Pervasive Developmental Disorder not otherwise specified" (PDD-NOS).

Formal diagnosis of any type of Pervasive Developmental Disorder under the DSM-IV, including PDD-NOS, is a clinical diagnosis that requires the diagnosed person has "severe and pervasive impairment".

The qualifying conditions for Carer's Allowance recognise all disorders in the DSM-IV Pervasive Developmental Disorders category except PDD-NOS. This exclusion of PDD-NOS from Carer's Allowance appears inconsistent and discriminatory.

While it is possible that a child with PDD-NOS can qualify for Carer's Allowance the nature of their disability may not be reflected clearly in Centrelink's client database.

In other schemes, such as its HCWA package, government recognises and supports all the ASD diagnostic types in the DSM-IV Pervasive Developmental Disorders category, including PDD-NOS.

SC#3. **Disability discrimination in Australian Law**: Australia is among the first countries to ratify international law. Australia is signatory to international law that disallows disability-related discrimination, especially in relation to children.

Australia could complete processes required under these agreements so that Australian Law protects children with a disability from discrimination such as that suggested in SC#2 above.

A4 recognises that the government departments responsible for Australian Law do not answer to the Parliamentary Secretary for Disability – though our members would appreciate any influence exerted in that direction.

SC#4. **Nature and cost of Best Practice early intervention for ASD**: The federal government's Helping Children with Autism (HCWA) package is Australia's biggest assistance initiative ever offered for people with autism spectrum disorders.

The nature of "best practice early intervention for ASD" is a subject of dispute among alleged experts in the field. The Department of Health and Ageing (DoHA) advises that Best Practice for young children with autism is "20+ hours per week of intensive ASD-specific early intervention for a minimum of 2 years".

Intensive means one-on-one delivery or delivery processes that use very low staff/client ratios.

Using advice from an academic and clinical “expert reference group”, FaHCSIA created a Provider Panel and the HCWA early intervention component is essentially face-to-face clinical interventions. The cost of a HCWA Panel Provider is at least $100 per hour so the cost of best practice using services from Panel Providers is at least 20x$100 per week for 48 weeks per year – a minimum annual cost of at least $96,000.

The HCWA package can provide a family with up to $6,000 per year so families would have to find $90,000 from other sources or find complementary and compatible services. Very few families can find this level of funding.

In contrast, families advise that they expect programs providing 30+ hours per week “intensive ASD-specific early intervention”, exceeding DoHA’s “best practice” recommendation for children with autism, can be provided practically for $40,000 to $60,000 per year. But even at this lower cost, few families can afford such a program. They need help from government and/or from their community to get early intervention for their child.

Families recognise that

- There are insufficient clinicians with the required expertise in ASD to deliver anything like best practice on a face-to-face basis for all the young children diagnosed with ASD in Australia.
- The cost of a clinician model using face-to-face delivery for 20+ hours per week over at least 2 years is excessive, and challenging politically
- Practical and affordable service models for ASD early intervention are essential
- The $6,000 per year that HCWA provides needs to be augmented so that effective early intervention is provided for as many Australian children with ASD as possible.

One practical approach is for clinicians to supervise less experienced staff to provide “intensive” face-to-face intervention for young children with autism. This approach has been shown to be capable of delivering outcomes among the best known for children with ASD. But Australian graduates in allied health areas do not get adequate ASD-specific training, and they are not taught to supervise delivery using junior staff and assistants. Very few allied health graduates are employed after graduation in situations where they develop these skills.

But the HCWA package does not fund early intervention services using this model: a model recognised as having the strongest evidence for its effectiveness.

In some areas, such as the Australian Capital Territory, early intervention services funded through the CSTDA are not compatible with services available through the HCWA Panel. Families of children newly diagnosed with ASD have to choose between extremely inadequate service models.

Families are also concerned that many clinicians lack the skills they need through their careers to interpret and adopt methods from quality research. Some clinicians appear rigid and inflexible in their approach, becoming increasingly out-of-date in their methods in relation to ASD.

Some people argue that the families themselves can be trained to provide most of the 20 hours per week of early intervention. While there is evidence that family involvement can benefit an effective program of early intervention, there is no real evidence that families can meet the clinical needs of a child with ASD.

> Nor is there evidence that anyone benefits from making families responsible for meeting their child's ASD-related clinical needs. Demonstrably, there are many families where the child's needs are not met through this model. The extra burden on a family can contribute substantial additional family dysfunction. This "parent is clinician" model is considered completely inappropriate for most clinical disorders – why are children with ASD and their families singled out for this (lawful) discrimination/injustice?

A4 members are encouraged to use this forum to raise further challenges for the federal government. Please send your suggestions for this column to editor@a4.org.au.

Rotary Club of Dapto and Australian Rotary Health fund $35,684 autism research grant

When the members of the Rotary Club of Dapto learnt about the many challenges that people face with autism they decided it was time to discover more about autism. The Club teamed up with Australian Rotary Health to fund a Funding Partner Grant for autism research. The club raised $20,000.00 dollars through book stalls, garage sales, chocolate sales, raffles, BBQs and donations from local organizations like the Dapto RSL Sub Branch and the students from St John's Catholic Primary School.

With additional money from Australian Rotary Health they were able fund a one year autism research grant of $35,684. This particular grant broke the record for having the most applications for a Funding Partners Grant, double the previous record holder which was for breast cancer research.

Dr Michael Sorich from the University of South Australia was the successful applicant. Along with his team, they will be investigating the role gastrointestinal disturbances have in the cause of autism.

Contribution from Peter

Government announcements

Extending eligibility for PDD Early Intervention

A recent media release (see *Autism services expanded across Australia* below) from the federal government extended the eligibility criteria for its Helping Children with Autism Early Intervention scheme. Under newly extended conditions, children who are diagnosed formally with a Pervasive Developmental Disorder, which includes autism spectrum disorders (ASD), before they turn 6 years old, are now able to access funding for early intervention until they turn 7 years of age.

Extending access to early intervention means services for many children can continue while they start school. Many children with ASD need clinical support to develop key learning skills for success in school. This is a clear step in the right direction and acknowledges that school is not sufficient to meet the clinical needs of many children with ASD.

Increased access to ASD-specific early intervention will help many families whose child has an ASD and who did not access essential early intervention when their child was younger.

Autism Advisors around the country are busy contacting families they know about in relation to these changes in eligibility. But there is no need to wait: you can contact the Autism Advisors in your state if you think this could affect your child.

The Government also changed the criteria for its provider Panel. Allied health professionals may now qualify in their own right. They may not need to form (or join) a consortium to be listed on the Panel.

This change makes it easier for small service providers to be included on the panel. It could help providers with a smaller population base.

The ASD community welcomes these changes and refinements to this central element of the Federal Government's *Helping Children with Autism* package.

Bob Buckley
Sept 2009

Autism services expanded across Australia

Media Release from The Honourable Jenny Macklin, MP, Minister for Families, Housing, Community Services and The Honourable Bill Shorten MP, Parliamentary Secretary for Disabilities and Children's Services

22 September 2009

Around 1400 children with Autism Spectrum Disorders will have easier access to early intervention services, following changes to the Helping Children with Autism package.

The changes will increase the number of service providers and allow families more time to use the $12,000 over two years available under this package.

This funding gives children with Autism Spectrum Disorders the chance to benefit from a range of early interventions, including one-on-one intensive activities and tailored group and individual programs.

From 19 October 2009, new arrangements will allow additional speech pathologists, occupational therapists and psychologists to participate in the autism program, subject to quality requirements.

Under the previous requirements, individual professionals could only be approved if they formed or joined consortia and operated as part of a team. Now these providers can join the program, increasing the number of service providers families can access across Australia.

Under the changes, families with children approved for early intervention funding will also be able to access early intervention funds until the child's seventh birthday.

This has been increased from six years, and will give families an extra year to access autism services.

Families will still need to have their child diagnosed with Autism before their sixth birthday and see an Autism Advisor to access early intervention funding.

Parents who have since lost access to their approved early intervention funding because their child turned six, will be given an additional 12 months to use the funding.

Due to significant demand, some families have experienced waiting lists and have been unable to utilise their full funding package before their child had their sixth birthday.

Since October 2008, more than 3700 children have accessed services under the $190 million Helping Children with Autism package, the first national initiative to help families deal with this challenging disorder.

Currently there are almost 350 service organisations delivering early intervention in 536 locations across Australia.

Helping Children with Autism is making it easier for parents to access early intervention services for children with autism.

From http://www.billshorten.com.au/press/index.cfm?Fuseaction=pressreleases_full&ID=2018

Government announces Autism Spectrum Disorder register

Media Release from the Honourable Bill Shorten MP, Parliamentary Secretary for Disabilities and Children's Services

20 August 2009

The Australian Government has given its support to a National Autism Spectrum Disorder (ASD) Register to better track the incidence of the condition in Australia.

Bill Shorten, Parliamentary Secretary for Disabilities and Children's Services, today announced the Register at the Asia Pacific Autism Conference 2009.

Mr Shorten said the register would bring much-needed data to the autism and allow governments to work more effectively to help people with autism.

"The autism community has been advocating for a comprehensive approach to national data collection for many years," Mr Shorten said.

"We need to know the extent of autism in Australia so we can properly support people with ASDs."

"This register will give us a better idea of the number of Australians with ASDs, where they live and what services they need."

The register was a recommendation from the report, The Prevalence of Autism in Australia, commissioned by the Australian Advisory Board on Autism Spectrum Disorders (AABASD) in 2007.

"The report aimed to estimate the current prevalence rates for ASD in Australia from existing data, but was hamstrung by the lack of available data and recommended that more data systems be established," Mr Shorten said.

"There is widespread support for good quality national data on autism from researchers and indeed from families and service providers.

"It is an important first step in undertaking epidemiological research into autism."

The AABASD, the WA Autism Register and other key experts will report to the Department of Families, Housing, Community Services and Indigenous Affairs by September 30 with options for the operation of a National ASD Register.

"The Government will consider the range of options in the report, before making progress to develop the Register," Mr Shorten said.

Last year the Rudd Government announced the landmark $190 million Helping Children with Autism Package, which will provide early intervention services to thousands of families who have a child with an ASD.

From http://www.billshorten.com.au/press/index.cfm?Fuseaction=pressreleases_full&ID=2008

ASD in the news

Australia signs UN disability protocol

30 July 2009

People with disabilities now have another avenue to complain about being discriminated against under an agreement ratified by 40 nations.

Australia has signed up to the UN's Convention on the Rights of Persons with Disabilities Optional Protocol.

The protocol, agreed to by 40 nation's, allows complaints to be lodged to the UN if all domestic remedies have been exhausted.

Disability Discrimination Commissioner Graeme Innes said it was crucial to get a new national disability strategy up and running.

"People with disability and their families want to have their human rights respected and fulfilled in practice rather than just the right to complain about it not happening," he said in a statement.

From http://news.smh.com.au/breaking-news-national/australia-signs-un-disability-protocol-20090730-e2oe.html

More links:

http://www.theage.com.au/national/australia-to-sign-un-disability-protocol-20090729-e1ky.html

http://www.news.com.au/perthnow/story/0,21598,25857649-5005361,00.html

http://tools.themercury.com.au/stories/25764241-national-news.php

http://news.ninemsn.com.au/article.aspx?id=843851

Autism Spectrum Disorders in adults living in households throughout England – report from the Adult Psychiatric Morbidity Survey 2007

The National Health Service (NHS) of the UK released a report on 22 September 2009 which found that the prevalence of autism for adults was 1.0 per cent of the population, which is the same as the prevalence for children. You can read the report in full here, http://www.ic.nhs.uk/webfiles/publications/mental%20health/mental%20health%20surveys/Autism_Spectrum_Disorders_in_adults_living_in_households_throughout_England_Report_from_the_Adult_Psychiatric_Morbidity_Survey_2007.pdf A summary of the main findings and key facts is below.

Summary

This report presents data on the presence of Autism Spectrum Disorders (ASD), based on the data collected at phases one and two of the Adult Psychiatric Morbidity Survey (APMS) 2007. These findings were not included in the initial survey report. Estimated disorder prevalence is presented by age, sex, ethnic group, marital status, highest educational qualification, equivalised household income, economic activity status, receipt of benefits, housing tenure, area level deprivation and predicted verbal IQ. The level and nature of treatment and service use is considered, although the sample size means that this cannot be explored in detail.

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.

From http://www.ic.nhs.uk/statistics-and-data-collections/mental-health/mental-health-surveys/autism-spectrum-disorders-in-adults-living-in-households-throughout-england--report-from-the-adult-psychiatric-morbidity-survey-2007

More links http://www.guardian.co.uk/society/2009/sep/22/autism-rate-mmr-vaccine

http://news.bbc.co.uk/2/hi/health/8268302.stm

How do autistic children survive as adults?

16 August 2009

Families complain there is not enough support and a postcode lottery syndrome for sufferers of autistic-spectrum disorder

Caroline Scott, The Sunday Times (UK)

Peter Griffin is 29, he has an IQ of 159, a degree in astrophysics, and a gallows humour about his Asperger's syndrome, an autistic-spectrum disorder that makes social interaction so difficult that his longest — indeed his only — stretch of paid work has been a Saturday job in Tesco, which he has had since he was 16. He is so wired after his shift that he is awake until 4am and it takes him the rest of the week to recover: "At the end of a day trying to be 'normal', acting the part, wearing the mask and reining myself in, I'm like a pressure cooker."

Very few people outside his family seem to understand Peter's needs. At 11, an educational psychologist said, "I'm happy to tell you that Peter is among the top 2% of the population," which, since Peter was unable to get anything down on paper, made his parents feel worse rather than better. "His teacher used to say, 'If only I could find the starter button.'" At secondary school, homework involved standing next to his mother, Ann, who would say, "Why? What? When?", then quickly type what he said. "He knew all the answers. But his thinking was, 'Why are they asking?' It made no sense to him."

[…]

Last year, as part of its I Exist campaign, the National Autistic Society (NAS) commissioned the largest ever UK survey on the experiences of adults with autism and their families. It identified a fundamental problem: nobody — not government nor health authorities nor primary care trusts — knows how many autistic adults there are in England. No wonder, then, that so many don't have access to the services they need. The National Audit Office, crunching the figures it has on children, estimates that there are half a million people with autistic-spectrum disorders in the UK, of whom around 400,000 are adults, ranging from the mildly affected to those who will need lifelong care. A recent study suggests that autistic adults cost the economy around £25.5 billion a year, 36% of which is accounted for by lost employment. The government is now committed to developing a national adult-autism strategy, which includes the appointment of a full-time autism specialist within the Department of Health, and training for social and healthcare professionals. Every parent has his or her own professional horror story, from the GP who thought Asperger's was a childhood syndrome — "Do they think kids magically shed ASD when they're 18?" asked one parent incredulously — to the social workers who repeatedly lump young adults with ASD (autism-spectrum disorder) together with those who have mental-health or severe learning difficulties.

Dedicated teams within local authorities will now be tasked to ensure that every 14-year-old with a statement has a transition plan. This is a statutory requirement set out in the SEN (special education needs) code of practice, yet at present only 34% of children with ASD have them. The consequences of getting things so badly wrong are huge. Currently, only 15% of adults with ASD are in full-time employment, and they report that their experiences at work are marred by misunderstandings and inadequate support.

[…]

There are pockets of good practice: local authorities in Liverpool, Newham and Oldham have dedicated teams to support autistic adults. And in Sunderland, Paul Shattock has established inspirational residential colleges for autistic adults. "In the right environment — low stress, low sensory stimulation — you've got a chance to make a real difference," he says. ESPA colleges, which take a mix of long-term residential and day students and have a waiting list of hundreds, have their own charter of rights; paramount is "No decisions about us without us".

Paul points out that there's a lot of money to be made in autism. "Nightclub owners", as he calls them, "buy a house, fit it out and fill it with five or six autistic adults. That's not acceptable. But neither is the other option: the vast majority of autistic young people who end up stuck at home with ageing parents, doing nothing".

The NAS hopes that the national adult autism strategy, due at the end of this year, will "hold local authorities legally responsible for providing support for autistic adults and ensure they have clear routes to diagnosis, assessment and support". Which all sounds marvellous, but a plethora of legislation and statutory guidance already exists that is supposed to do the job. Unless local authorities are held to account, this new guidance may not be worth the paper it's printed on. Amanda Batten, the NAS's head of policy, says: "We do not underestimate the challenge. We'll keep a very close eye on it and we'll go to court if we have to."

[…]

One in three autistic adults suffer mental-health problems, and for each of those, not one but several lives are shattered. So many parents talk of the difficulties in securing a diagnosis, or of getting one — but much too late, when their child has dropped out of college or employment or suffered an emotional breakdown. Janette Robb's 30-year-old son, Danny, was only formally diagnosed two years ago. "My son has spent 75% of the past five years in psychiatric hospitals, much of it due to lack of support within the community."

Rosie Cousins, whose adult son has become addicted to prescription drugs, is filled with fury at the years of botched diagnoses and, ultimately, with grief over what might have been. Her plea is simple: “I love him dearly,” she writes. “I don’t want his life’s journey to be a worthless one.”

[…]

For the full article see http://women.timesonline.co.uk/tol/life_and_style/women/families/article6794806.ece

Family forced to head to UK for autistic son's sake

By Sharon O'Neill for the 7:30 Report 20 August 2009

A New South Wales family have made the gut-wrenching decision to leave the home and friends they love and move to the UK because they say Australia cannot provide the support and services they need for their autistic son.

It is estimated that 500,000 Australian families are affected by autism.

Many of them struggle not just with the needs of an autistic child or adult, but with the huge costs associated with the array of therapies required.

For the Maxwell family, that struggle came to an end last week when they decided Australia was not the place to provide the support and services needed for their autistic son.

"Our whole lives have just been packed up today and put into that truck and it's gone," father Kevin Maxwell said. "It's very surreal."

"This is really exciting for us because we really hope that we can get something better for Jonah. But the other side of the equation is it's sad.

"Things have to be pretty severe for us to give up that sort of a home base, that foundation, and go to the other side of the world."

[…]

For the full article see http://www.abc.net.au/news/stories/2009/08/20/2661233.htm?site=local

Also http://www.abc.net.au/7.30/content/2009/s2661082.htm

Mother just wants to hear son speak

Julia Medew, The Age, 22 August 2009

LILJANA Simonovska wants nothing more than to hear her son Filip speak. In recent years, her five-year-old boy has blurted out odd words here and there, but none of them have ever really made sense.

''He makes a lot of sounds but he can't connect them into words and speech,'' she said. ''He often communicates by taking my hand and showing me things instead. He also uses a picture exchange system to communicate sometimes too.''

Filip was diagnosed with autism, a development disorder characterised by impaired social interaction and communication skills, just before his third birthday. His parents were told that the sooner they could take him to a speech therapist, the better his chances of learning to talk.

But for Mrs Simonovska, finding the right help for Filip has been a constant battle. All of the speech therapists she contacted had waiting lists of up to two years, and to pay for private sessions was impossibly expensive.

Her sense of frustration was temporarily relieved by last year's Federal Government announcement that it would give parents $12,000 to spend on speech therapy for children under the age of six as part of its ''Helping Children with Autism Package''.

At the time, the Government's media release boasted that parents would be able to choose early intervention measures that best suited their children, and that the $190 million package would provide greater access for those in need.

But after qualifying for the program in June and contacting 32 listed providers, Mrs Simonovska has been given nothing but more huge waiting lists. ''It has made me feel so powerless. Filip's desperately trying to talk. He makes lots of sounds, especially when he is angry. I have all this money on paper to help him, but we can't do anything with it,'' she said.

Mrs Simonovska and her son are not alone. Autism Victoria chief executive Murray Dawson-Smith said many Victorian families had contacted him with similar complaints.

[…]

For the full article see *http://www.theage.com.au/national/mother-just-wants-to-hear-son-speak-20090821-etv9.html*

Autism Again

Transcript – Stateline Canberra. Reporter: Melissa Polimeni

CHRIS KIMBALL, PRESENTER: First, research indicates that autism or Asperger's Syndrome, may be affecting as many as 1 in 100 children.

If that's the case, it will touch most of us in some way, family members, friends, or our children's school-mates. We also know from the research that early intervention programs are crucial. So, if we know all of that, how is it that so little is still being done, even after 40 years of talking about it?

For more see http://www.abc.net.au/stateline/act/content/2006/s2657680.htm

My Name Is Jack

10 August 2009

As one half of famed media duo 'Jono & Dano', Ian 'Dano' Rogerson enjoyed a decade long run in the 1980s with top rating radio shows and a string of national television programs.

But while Jonathan 'Jono' Coleman went on to forge a career in Britain, Ian Rogerson all but disappeared from the media spotlight.

Why would you jettison a successful media career? In Ian Rogerson's case, it was because of his young son, Jack.

Diagnosed with autism as a toddler, Jack Rogerson was hyperactive, could barely speak and was unable to express ordinary affection. Like many parents of autistic children, Ian and his wife Nicole were left struggling to find their way.

Introduced by Therese Rein, the couple candidly discuss the highs and lows of life with Jack and explain how they've raised him to discover his full potential.

For the full transcript, see http://www.abc.net.au/austory/content/2007/s2652214.htm

Bizarre bullying strategy slammed

Kate Lemmon 16 September 2009

A MOTHER has condemned the anti-bullying policies of an Ipswich school after her autistic son was given a “stop” sign to wave at his tormentors.

The eight-year-old boy was armed with the sign by staff at Ipswich West State School after he said he had been pushed down a staircase by bullies and even dangled over a second-storey veranda.

Far from deterring the cruel attacks on her son, his mother said the sign only made him a target for more bullying.

“My son is terrified of going to school and no-one is helping him. He’s totally on his own,” she told The Queensland Times yesterday.

“The situation is atrocious and I think that giving my son a card to wave at these bullies is completely inappropriate.

“It made my son feel terrible. He told me he didn’t go back to school because he had been told carry this sign about.”

[…]

For the full article see http://www.qt.com.au/story/2009/09/16/schools-bizarre-bullying-strategy-slammed/

Also see http://www.brisbanetimes.com.au/queensland/school-gives-bullied-boy-stop-sign-20090916-fq1i.html

http://www.qt.com.au/story/2009/09/17/schools-bullied-kids-anti-depressants/

Schools telling disabled children to stay at home

Justine Ferrari, Education writer, The Australian 26 August 2009

SCHOOLS are turning children with disabilities into part-time students by restricting their attendance hours in breach of anti-discrimination laws.

Some school principals are limiting the time disabled students are in class to match the hours a teacher's aide or other assistance is available, Macquarie and Sydney university researchers have found.

The study, based on surveys with principals in mainstream schools in city and rural areas of NSW, identified several practices that breach education and anti-discrimination laws.

The breaches included negotiating with parents to limit a child's attendance, sending children directly to doctors to obtain a diagnosis without parental approval and pressuring parents to enrol their children in other schools or support classes.

The study also highlights the subjective nature of labelling children with behavioural problems -- responsible for a rise in the number of students with disabilities. One principal was quoted as saying: "Well, a behaviour problem at (this school) would be a child who just doesn't do what he's told."

[..]

For the full article see http://www.theaustralian.news.com.au/story/0,,25982712-13881,00.html

Capped funds for pupils with disabilities

Anna Patty Education Editor, The Sydney Morning Herald 14 August 2009

School funding for students with special needs will be capped and no longer distributed according to the number of individual students, under NSW Department of Education proposals.

Principals and teachers are concerned that funding for students with autism and mental health disorders will be capped for the next three years at 2009 levels. The State Government plans to allocate grants based on the prevalence of disorders in the wider community.

Schools attract funding of up to $6000 for each child with a low-level of special needs. Children with severe needs will continue to attract at least $6000 each.

Cheryl McBride, the head of the independent Public Schools Principals Forum, said schools would receive a fixed amount of funding regardless of any fluctuations in the number of students with disabilities.

This would contain costs and prevent budgets increasing with an expected rise in the number of children being diagnosed with special needs.

''The need is growing, but the pot of money isn't,'' she said.

Under the Department of Education proposals, teachers will no longer specialise in reading and language, autism or behavioural difficulties. They will be expected to cover a broader range of special needs after undergoing 110 hours of online learning.

''We are diluting the skills of those experts and putting them into a melting pot,'' Ms McBride said. However, the president of the Primary Principals Association, Geoff Scott, said many teachers had no formal training in the area and would benefit from the online course. He said the Department of Education would consult all principals about the new proposals in the next few weeks.

''We think the current model has the potential to be better,'' he said.

The Department proposes to allocate all schools with a learning support teacher for half a day to two days a week.

Gary Zadkovich, the deputy president of the NSW Teachers Federation, said the Government's decision to cap funding meant it would not have to accommodate any increase in autism and health disorders.

''By changing from a diagnosis-based identification of students, governments avoid their obligation to increase funding proportionate to actual student need,'' he said. ''The proposal to make teachers an expert in every learning disability and behaviour disorder is ridiculous.''

The Greens MP John Kaye said the motivation was ''to contain the budget''. The Opposition's acting spokesman on education, Andrew Stoner, said the Government needed to ''ensure no students with disabilities miss out''.

A spokeswoman for the NSW Minister for Education, Verity Firth, said: ''The proposal to allocate funding directly to schools would remove the need for teachers to complete paperwork or seek confirmation of a student's disability.''

From http://www.smh.com.au/news/national/capped-funds-for-pupils-with-disabilities/2009/08/14/1249756441911.html

2m Australians living with multiple disabilities: study

Stuart Rintoul, The Australian, 9 September 2009

An estimated 10 per cent of Australians, or two million people, suffered from two or more disabilities, according to the Australian Institute of Health and Welfare.

While the institute's report includes the infirmities of old age, it found that half of all children aged under 15 years with psychiatric disability (42,300) or acquired brain injury (11,500) had three or more disabilities, followed by over one-third of children with sensory-speech (48,100) or intellectual disability (55,100).

More than half of people aged 15 to 44 with acquired brain injury (more than 85,000 people) or intellectual disability (over 95,000 people) had three or more disabilities.

The report, “Disability in Australia: multiple disabilities and need for assistance”, found that a “substantial proportion” of care for people with multiple disabilities is provided by their family members and friends.

Saying the prevalence of multiple disabilities made policy development “complex”, report author Xingyan Wen found that people with multiple disabilities who needed very frequent assistance with daily activities were “much less likely to have their needs fully met than people with less frequent need for assistance”.

Of the one million people who needed help with core activities, three-quarters had their needs fully met, and one in six had their needs partially met.

People with three or more disabilities who needed help with health care were less likely to have their health care needs fully met than people with one or two disabilities. The unmet need was particularly high among adults with four or five disabilities.

Dr Wen said dementia, autism, Parkinson's disease, schizophrenia, speech problems, and stroke were commonly associated with multiple disabilities, increasing with age, with 35 per cent of people aged 65 or over suffering from multiple disabilities.

As an indication of how multiple disabilities occur, 91 per cent of people with dementia also had some form of physical disability, 82 per cent had intellectual disability, and 68 per cent had sensory-speech disability and 15 per cent had acquired brain injury.

Based on a 2003 survey of disability, ageing and carers by the Australia Bureau of Statistics, the report found the proportion of all people with disability who had two or more disabilities was 49 per cent for children aged 15 or younger, 45 per cent for people aged 15 to 64 and 62 per cent for people over 65.

The highest proportions of people with three or more disabilities were people with disabilities related to acquired brain injury (64 per cent) and intellectual disability (61 per cent), followed by people with psychiatric (49 per cent) and sensory/speech (33 per cent) disabilities.

Unsurprisingly, people aged 15 to 64 years with a mix of psychiatric, physical disabilities, and other disability were more likely than others to have employment restrictions. More than one-third of people with three disabilities and almost half of people with four or five disabilities had profound employment problems.

From http://www.theaustralian.news.com.au/story/0,,26048368-23289,00.html

Special education reform put on hold

18 September 2009

The New South Wales Government has deferred the reform of special education in public schools for allow time for further consultation.

It has been proposed that teachers be trained to cover a broader range of needs instead of specialising in areas such as autism, language or behavioural difficulties.

The Education Minister, Verity Firth, says a decision on the plan now will not be taken until the middle of next year - but trials at schools will go ahead.

The Green's Education Spokesman, John Kaye, has welcomed the decision, but still harbours concerns.

"The idea of using online training for just 110 hours and put teachers infront of students with diverse special needs was always absurd," he said.

"It's great that it's been deferred. But there's a sting in the tail.

"We're very concerned about the trials the department is going to conduct next year. We don't want to see kids in those schools disadvantaged."

The Education Minister, Verity Firth, says she does not believe specialisations will be lost, or that training will be inadequate.

"I think that their 110 hours of additional specialist training is something that most teachers that I've talked to have actually jumped at the chance to do." she said.

"Teachers love professional learning and they love to be able to give more to their students, especially students with special needs."

From http://www.abc.net.au/news/stories/2009/09/18/2689698.htm

Letters

Hi Bob

Autism Services Expanded Across Australia:
http://www.jennymacklin.fahcsia.gov.au/internet/jennymacklin.nsf/content/autism_services_22sept09.htm

It seems that our persistent lobbying [badgering] of Bill Shorten has paid off.

This is a terrific outcome for children like our son Joshua (who is 6yo and lost his autism early intervention funding when he started school this year):

'... Under the changes, families with children approved for early intervention funding will also be able to access early intervention funds until the child's seventh birthday ...'

Cheers
Andrew & Janet McLean
parents of Joshua (aged 6yo) and A4 members, WA

> *Hi Andrew*
> *Great to hear from you.*
> *Perhaps this is a lesson for people. People need to let governments know when things do not work for them.*
>
> *Bob Buckley*
> *A4 Convenor*

Notice

Announcing the Olga Tennison Autism PhD Scholarship to be undertaken at any University or affiliated research centre in Australia

In 2008 La Trobe University established The Olga Tennison Autism Research Centre. The Centre is offering a competitive PhD research scholarship to be awarded to the best candidate-supervisor team with an innovative research proposal in the area of autism.

The scholarship which includes a yearly stipend of $21,000 (approx.) for 3-years will commence in 2010, and is only available to Australian citizens. For full application packs, including information on candidature, eligibility, etc., please contact:

Ms Lisbeth Wilks
Olga Tennison Autism Research Centre
School of Psychological Sciences
T 61 3 9479 2497
E otarc@latrobe.edu.au

A4 Contacts

A4 is a grassroots organisation. All A4 activity, such as publishing the Updates (newsletters), is done by volunteers. Please understand that A4 volunteers may have no training or qualifications for their various roles. They do the best they can for people with ASD, their families and associates. A4 welcomes assistance and constructive criticism.

Anti-spam: change -at- to @ in email addresses.

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