A4 Update
Autism Aspergers Advocacy Australia

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Report: ASD in English adults

In September, the NHS Information Centre in England published a report:

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

You can download the report 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

This report includes the following …

Summary

- Autism Spectrum Disorders (ASDs) are developmental disorders characterised by impaired social interaction and communication, severely restricted interests and highly repetitive behaviours.
- This chapter presents data on the prevalence and correlates of ASD among adults living in the English general population. This is the first time such data have been collected in any country.
- In the phase one interview ASD was screened for using a 20 item version of the Autism Quotient (AQ-20). In the phase two interview, assessments were carried out by clinically trained interviewers using the Autism Diagnostic Observation Schedule (ADOS) with a subset of respondents with medium to high AQ-20 scores. The results were weighted to generate a prevalence rate for the population as a whole.
- The recommended threshold of a score of 10 or more on the phase two ADOS assessment was used to indicate a case of ASD.
- Using this recommended threshold score on the ADOS, 1.0%of the adult population had ASD. The rate was higher in men (1.8%) than women (0.2%), which fits with the profile found in childhood population studies.
- 19 cases were identified in the phase two sample. Only a subset of phase one respondents was selected to take part in a phase two interview. Had all respondents completed a phase two interview, we estimate that 72 cases would have been identified in the sample as a whole. The small unweighted base size means caution with interpretation is required. Rates are shown for all adults and separately for men, but not separately for women due to small numbers.
- People who were single were more likely to be assessed with ASD than people of other marital statuses combined. This was evident among men: 4.5%of single men were assessed with ASD.
- ASD was associated with educational qualification. The rate was lowest among those with a degree level qualification (0.2%) and highest among those with no qualifications (2.1%).

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- Likelihood of a positive assessment for ASD varied with tenure and the level of deprivation in the local area. Those living in accommodation rented from a social landlord were the most likely to have ASD. This was strongly evident among men: 8.0% of men in social housing were identified with ASD.
- Being of low predicted verbal IQ was also associated with presence of ASD.
- There was no indication of any increased use of treatment or services for mental or emotional problems among people with ASD.

Some of these points deserve translation into normal language and/or comment on their significance.

The finding that 1% of adults have ASD is noteworthy new information. This result should be replicated as soon as possible.

The outcomes indicators are disappointing at least … some would say these outcomes are an outrage:

- Many adults with ASD are undiagnosed;
- Education outcomes for people with ASD are distinctly poor;
- The higher rate of single men suggests strongly that social outcomes for people with ASD are particularly poor;
- People with ASD appear to experience poor accommodation situations; and
- Adults with ASD do not get treatment and support for their ASD or for other health issues.

On the latter point, the report says …

> *If anything, it appears that rates of treatment and service use for a mental health reason may be lower for this group, although it must be emphasised that the treatment data can only be considered as, at best, indicative. (page 21)*

Probably, very similar outcomes could be observed in Australia.

See http://www.ic.nhs.uk/news-and-events/press-office/press-releases/one-in-a-hundred-adults-have-an-autism-spectrum-disorder-says-pioneering-new-study

Convenor's message

Dear A4 member,

I am sorry I have not written to you lately. I could offer excuses such as being very busy writing submissions for an ACT special education inquiry or for the ACT Government budget. But truthfully, I had a bit of what I assume is "writer's block".

There is no lack of things to write about.

For the moment my biggest concern is that Bill Shorten, Parliamentary Secretary for Disability, seems to get rather limited support from his fellow politicians, especially those on his side of politics, for his desire to improve disability outcomes. The Hon. Mr Shorten displays a passion for improving outcomes for people with ASD and generally for people with a disability.

I do not see much evidence of support from relevant ministers for continuing efforts for better outcomes for Australians with ASD.

Google finds Minister Macklin intent on cracking down on disability support pension applicants and recipients after their numbers appear to have risen during the Global Financial Crisis/Disaster … while her Government protects the banks and institutions that caused it.

When John Howard announced the Helping Children with Autism (HCWA) package he said HCWA was just the beginning. He recognised that HCWA does little for at least 30,000 Australians already diagnosed with ASD, a life-long disability. Nor does it help the unknown number of Australian adults who have ASD but do not have a diagnosis.

Instead of recognising this need and getting on with the task of improving outcomes for students and adults with ASD, Minister Macklin created yet another disability advisory group, its **National People with Disabilities and Carer Council** (see http://workingcarers.org.au/options/899-new-council-will-advise-on-the-national-disability-strategy). Preferably, the Council[1] would include a recognisable representative of the ASD community.

In November 2009, the Government announced it will develop another National Disability Strategy. As part of its process "the Australian Government has commissioned the Productivity Commission to undertake a feasibility study into long-term care and support for people with disability in Australia" (see http://www.fahcsia.gov.au/sa/disability/progserv/govtint/Pages/nds.aspx). The study will start in April 2010 and report by July 2011 (see http://www.fahcsia.gov.au/sa/disability/progserv/govtint/Pages/feasibility_study.aspx).

While the terms of reference for the "feasibility study" allow the report to address issues relating to ASD, experience shows that the Productivity Commission will regard ASD as part of or similar to other intellectual disabilities … so we can anticipate either an assumption or conclusion that people with ASD have similar needs to people with other disabilities … and on this basis Government can largely ignore particular needs of people with ASD and persist with existing services that are known to fall short of what people with ASD need.

This Government process sticks to the principal method of *mediocre management*, that is to delay or prevent decisions. Conducting a feasibility study certainly avoids action

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[1] see https://www.govdex.gov.au/confluence/display/NPDCC/Member+profiles

and the associated expense in the immediate aftermath of the Global Financial Crisis/Disaster.

In the meantime, FaHCSIA's shrunk[2] its ASD Branch and merged it with its Mental Health Branch. Much of FaHCSIA's administration of the HCWA package is being distributed to FaHCSIA's state offices which makes further development of national ASD policy (best done centrally) significantly more difficult.

What about the other Ministers? Apparently

- "An Australian study involving more than 20,000 students undertaken by ECU researchers has revealed that one in six high school students experience covert bullying on a regular basis." (see http://www.sciencealert.com.au/news/20090206-19246.html, http://www.deewr.gov.au/Ministers/Gillard/Media/Releases/Pages/Article_090603_080556.aspx and http://www.deewr.gov.au/Schooling/NationalSafeSchools/Pages/research.aspx)
- "Bullying is rife, with a quarter of Australian students saying they are bullied 'every few weeks or more'" (see http://au.news.yahoo.com/thewest/lifestyle/a/-/health/6704287/cyber-bullying-questions-and-answers).
- "When asked 'have you ever been victim of cyber bullying?' 20 per cent responded with a 'maybe', compared to 20 per cent who said yes and 60 per cent who said no." (see http://www.abc.net.au/local/stories/2009/10/02/2703218.htm)
- "There is bullying in every school in Victoria. That's the fact. Up to 60 per cent of Victorian school kids are bullied at some stage." (see http://www.heraldsun.com.au/opinion/bullying-is-cruel-not-cool/story-e6frfifo-1111113346039)

Of course reports are not consistent …

> "'Whereas rates of up to 50 per cent of [students] being cyber bullied have been reported among young people in the US and Europe, prevalence rates in Australia are much lower (less than 10 percent)', the report reads."
>
> see http://www.computerworld.com.au/article/318263/cyber_safety_data_hard_come_by_report

We hear from the education context that students with ASD are 4 times more likely to be bullied than other students. "Around 62% of students with Autism Spectrum disorder report being bullied once a week or more" (see http://www.bullyingnoway.com.au/pdfs/facts-bullying-stats.pdf and http://www.cheri.com.au/documents/bottroff.pdf).

Reports suggest (see http://a4.org.au/a4/node/147) students with disabilities, especially ASD, are likely to be excluded from school when their frustration with being bullied (then misinterpreted) boils over. There is no consequence for the school … only for the student and his/her family.

Long-term outcomes for students with ASD are very poor. The education system fails them and their employment prospects are minimal. We need much more from Minister Gillard on these issues.

Evidence both here in Australia and overseas shows over 1% of children are now being diagnosed with ASD. The Health system has done little or nothing to address or even

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[2] closer to 'annihilated' than 'decimated' … 'decimated' is just a 10% reduction.

understand this epidemic, this doubling in ASD prevalence every 4-5 years. Minister Roxon has not acted to ensure health professionals recognise and appreciate the needs of people with ASD. The Health Department published its Best Practice guidelines for Early Intervention, but it has not ensured allied health professionals are trained and experienced in how to deliver best practice.

It seems Health officials are ignoring the concerns of client advocates such as A4 and leaving issues of service standards up to the various professional bodies … who seem to me to have even less knowledge of what is needed than the bureaucrats[3].

I am not aware of Commonwealth Government efforts that will develop a health sector workforce with training, experience and expertise in ASD treatment & rehabilitation; that is the creation of a health sector in Australia that can tackle credibly the challenges of exponentially growing ASD numbers in the community.

Yes, it remains a disappointing picture.

Yes, you can do something about it. You may not feel like you can do much on your own, but when a few of us act together, it makes a difference. I suggest you contact your federal member (if you don't know who it is, use the Federal Electorate search on the AEC website http://apps.aec.gov.au/esearch/ then lookup your electorate here http://www.aph.gov.au/house/members/mi-elctr.asp … there are instructions at http://www.actnow.com.au/Tool/How_to_find_out_which_politician_represents_you.aspx).

You can write a short letter to your representative. I suggest you raise some of the following points briefly and in your own words.

1. The Government said Helping Children with Autism was just a beginning … so now that it is up and running what does the Government plan to do next to improve outcomes for people with ASD? You may want to ask specifically about older age groups or specific issues that you are particularly concerned about.
2. What is the Government doing to train allied health professionals to deliver ASD-specific treatment and rehabilitation that the ASD-community recognises as best practice for people with ASD? Notice, that tertiary students will still get the same amount of training, so there should be no real cost to the Government in tackling this issue.
3. What is the Government doing to (a) protect students with ASD from bullying, and (b) ensure teachers do not exclude students with ASD thereby denying them equitable access to education? Again, the amount of training teachers (4 years) get will be the same as before so such a measure should not cost more. If you are interested in people with ASD beyond school-age, you could ask what the Government is doing to improve employment for people with ASD … and especially to promote employment of people with ASD in their preferred areas of expertise.
4. If the Government is unsure what it should do about ASD, why not hold an Inquiry into ASD? ASD needs a distinct Inquiry because of the seriously increased prevalence and the particularly poor outcomes being experienced … and the failure of generic disability approaches to meet the needs of people with ASD.
5. How will the Government monitor and measure outcomes for people with ASD so they can see real improvement in the lives of people with ASD?

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[3] I am happy to explain this claim if I am challenged.

6. Would your representative
    a. join a *Parliamentary Friends of ASD* group if one were formed?
    b. attend a *Parliamentary Breakfast for ASD* (like that held in 2008 .. see http://a4.org.au/a4/node/29) sometime around April 2010 (which is Autism Awareness Month)?

If you can, ask for a meeting to discuss the issues you raise in your letter. You can meet them on your own or join up with a small group of friends and relatives (maximum 5 people). You should not be afraid … it is their job to meet you and hear what you have to say. Just remember to approach them asking for their help: do not go there to criticise or to tell them what to do.

Keep your letter under 2 pages. It is best if it is about 1 page long. You can provide a longer briefing at the meeting.

Be aware that politicians want to make things better. Typically, they are not close to all the issues and do not know how best to fix them. They need information. They know their resources are limited. They need to find solutions that will work and that the community will accept.

If they ask what you want them to do, you could suggest that they could ask your questions of the relevant Minsters … and get back to you with the Minister's response. They could ask their "party machine" will it address ASD-specific issues in its policy for the next election … perhaps mention that with 1% of children diagnosed with ASD, relevant policy could influence electoral outcomes.

If you can, please send your letter to the Senators in your state/territory. If any of your Senators have their office where you could meet them, please ask to meet them as well.

If your local politician responds, please scan their response and email it to us (convenor@a4.org.au). If you get a helpful response, please make the effort to thank them. In many cases, their answer will not be especially helpful, usually because they underestimate the ASD challenge and/or your existing expertise. Try to keep going: write an unemotional response back asking if could you further discuss the issues.

The next federal election is on its way. Now is a good time for us to focus the minds of politicians on the challenges people with ASD face and the need for all of us to contribute to better outcomes. We can all contribute. Together, we are an awesome team, so let's get moving.

Regards
Bob Buckley

30/1/2010

The Shorten Curlies

As yet, we have received no correspondence about the Shorten Curlies published so far. We are holding off publishing more of these while the Government catches up.

Carers of Disabled Welcome New National Companion Card

Media Release - 3/12/09

Jane Salmon, mother of two boys diagnosed with autism, says the new National Companion Card for Carers of Disabled promotes inclusion. It is a relatively easy thing to do, it requires good citizenship by corporations. It is one of many constructive initiatives from Shorten and Macklin.

But this Sydney carer adds, "We would like bread with those circuses, thanks. More access to vital therapy, less red tape, equal educational opportunity, appropriate respite and a choice of types of supported accommodation for adult disabled is a need that has been neglected by both the Howard and Rudd governments".

Parliamentary Secretary for Disabilities, Bill Shorten, MP is to launch a new National Companion Card for Carers of the Disabled in Melbourne this week.

The official launch of the National Companion Card Scheme at the Players Lounge, Rod Laver Stadium, Melbourne, 10:00am on Thursday 3rd of December 2009.

Bill Shorten asserts that the Companion Card Scheme is part of an integrated 'whole of government' response to support greater social inclusion for people with disability and their attendant carers.

A Companion Card, as piloted by the Department of Community Services in the state of Victoria, enables eligible people with disability dependent on full time care to take a carer with them on transport and to sporting and entertainment events for the price of a single ticket.

Ms Salmon continues, "Caring for a loved with a serious disability of any type is very, very stressful and economically isolating. The Companion Card will offer carers dignity and respect in cinema ticket queues and elsewhere. It will reduce struggle and make getting about easier and less expensive".

"The Companion Card is an inspired and generous initiative. It is one of several steps the Rudd Labor government has taken in two swift years to improve the quality of life for those of us who are working as carers or carees. It reduces the marginalisation and suffering of being 'Shut Out'.

"Bill Shorten has shown what insight and care can do when accompanied by political talent. He has done much for parents of autistic kids. Do-nothing dinosaurs of the Howard Ministry should watch and learn," said Ms Salmon.

"A Companion Card will also enhance quality of life for parents and carers of those whose differences are intellectual rather than physical.

Even superficially 'invisible" disabilities such as autism can be as draining to manage as physical disabilities. Families may be flat out funding very intensive and costly therapies and support to address challenging behaviours and needs. The demand for supervision 24/7 may prevent a parent from working.

"When a child's behaviour is inappropriate, members of the public frequently presume that is a result of poor parenting rather than an intellectual difference.

"Families working with intellectually different offspring who are physically whole don't usually qualify for a 'disabled parking sticker', for example. Yet moving their caree through car parks, streets and shops can be hard, simply because cooperation is difficult to secure.

"Most parents prefer to view fewer G-rated movies, for example, once their children are older than 12. However, many parents of adult offspring with learning difficulties have been paying for the privilege of doing just that until they are in their 80s and their child is 50.

"The Companion Card is recognition of the ordeal that ordinary life can be. It is also a part of the solution," said Ms Salmon.

Carers have been offered substantial hope that the National Disability Insurance Scheme will help families provide families with the "bread" of choices about appropriate accommodation, therapies and care.

With enough corporate support, the card can give greater freedom to circulate in the wider community, to access the release of laughter and culture. It can, as Mr Shorten claims, improve social inclusion.

Jane A Salmon

Mother to 2 young boys with autism, cancer patient, daughter of a person with cortico-basal degeneration.

Executive Committee member Association for Children with a Disability NSW
Executive member Carers Alliance
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Productivity Commission Inquiry into a National Disability Long-term Care and Support Scheme

Background

The Australian Government is committed to developing a National Disability Strategy to enhance the quality of life and increase economic and social participation for people with disability and their carers.

The Commonwealth, along with the States and Territories, has a major investment in disability specific support. However, there remains a significant level of unmet demand for disability services which impacts upon the lives of people with disability, their families and carers. Demographic change and the anticipated decline in the availability of informal care are expected to place further pressure on the existing system over the coming decades.

While Australia's social security and universal health care systems provide an entitlement to services based on need, there is currently no equivalent entitlement to disability care and support services.

The Government is committed to finding the best solutions to improve care and support services for people with disability. An exploration of alternative approaches to funding and delivering disability services with a focus on early intervention and long-term care will be an important contribution to the National Disability Strategy.

Scope of the review

The Productivity Commission is requested to undertake an inquiry into a National Disability Long-term Care and Support Scheme. The inquiry should assess the costs, cost effectiveness, benefits, and feasibility of an approach which:

- provides long-term essential care and support for eligible people with a severe or profound disability, on an entitlement basis and taking account the desired outcomes for each person over a lifetime;

- is intended to cover people with disability not acquired as part of the natural process of ageing;
- calculates and manages the costs of long-term care and support for people with severe and profound disability;
- replaces the existing system funding for the eligible population;
- ensures a range of support options is available, including individualised approaches;
- includes a coordinated package of care services which could include accommodation support, aids and equipment, respite, transport and a range of community participation and day programs available for a person's lifetime;
- assists the person with disability to make decisions about their support; and
- provides support for people to participate in employment where possible.

In undertaking the inquiry, the Commission is to:

1. Examine a range of options and approaches, including international examples, for the provision of long-term care and support for people with severe or profound disability.

   The Commission is to include an examination of a social insurance model on a no-fault basis, reflecting the shared risk of disability across the population. The Commission should also examine other options that provide incentives to focus investment on early intervention, as an adjunct to, or substitute for, an insurance model.

2. The Commission is to consider the following specific design issues of any proposed scheme:
   - eligibility criteria for the scheme, including appropriate age limits, assessment and review processes;
   - coverage and entitlements (benefits);
   - the choice of care providers including from the public, private and not-for-profit sectors;
   - contribution of, and impact on, informal care;
   - the implications for the health and aged care systems;
   - the interaction with, or inclusion of, employment services and income support; and
   - where appropriate, the interaction with:
     - national and state-based traumatic injury schemes, with particular consideration of the implications for existing compensation arrangements; and
     - medical indemnity insurance schemes.

3. Consider governance and administrative arrangements for any proposed scheme including:
   - the governance model for overseeing a scheme and prudential arrangements;
   - administrative arrangements, including consideration of national, state and/or regional administrative models;
   - implications for Commonwealth and State and Territory responsibilities;
   - the legislative basis for a scheme including consideration of head of power; and
   - appeal and review processes for scheme claimants and participants.

4. Consider costs and financing of any proposed scheme, including:
    - the costs in the transition phase and when fully operational, considering the likely demand for, and utilisation under different demographic and economic assumptions;
    - the likely offsets and/or cost pressures on government expenditure in other systems as a result of a scheme including income support, health, aged care, disability support system, judicial and crisis accommodation systems;
    - models for financing including: general revenue; hypothecated levy on personal taxation, a future fund approach with investment guidelines to generate income;
    - contributions of Commonwealth and State and Territory governments; and
    - options for private contributions including copayments, fees or contributions to enhance services.
5. Consider implementation issues of any proposed scheme, including:
    - changes that would be required to existing service systems;
    - workforce capacity; and
    - lead times, implementation phasing and transition arrangements to introduce a scheme with consideration to service and workforce issues, fiscal outlook, and state and territory transitions.

The Government will establish an Independent Panel of persons with relevant expertise to act in an advisory capacity to the Productivity Commission and the Government, and report to Government throughout the inquiry.

The Commission is to seek public submissions and to consult as necessary with the Independent Panel, State and Territory governments, government agencies, the disability sector and other relevant experts and stakeholders, and to produce a final report by 31 July 2011.

See http://www.fahcsia.gov.au/sa/disability/progserv/govtint/Pages/tor.aspx

Social Group for young adults with ASD

Autism Advisory and Support Service (AASS) proudly announce the launch of their Social Group for young adults with ASD. This unique social group involves neuro typical (NT) peers/mentors handpicked by our organization.

The aim of this group is to:

- Provide a social setting that will allow those affected by ASD to interact with NT peers of a similar age.
- Promoting and nurturing self confidence in young adults with ASD
- Encourage and give hope to their families that they are learning new social skills
- Teaching the participants skills that will take them one step closer towards their independence.
- Break down barriers between mainstream youth and youth with additional needs.
- Promote acceptance and awareness of ASD in the community.

This social group will meet once a month at AASS House. The minimum age of participants is 16 years of age. Participants from all areas on the spectrum are welcome, however we require a family member present for those participants who require personal care.

The first group will meet on Sunday 29th November 2009 from 2pm to 4pm. AASS House is at 88 Memorial Ave Liverpool.

Participants will need to fill out a form before the day.
Please feel free to call us if you have any further enquiries.

Autistic boy, 8, saves little girl from drowning at The Entrance

A BOY, 8, has been hailed a hero for saving a little girl from drowning.

What is even more remarkable is that rescuer Matthew Kennedy is autistic.

But he leapt into The Entrance pool on Sunday afternoon to save Emily Gold, 3, of Killarney Vale.

Matthew had just arrived at the pool, otherwise known as the Ocean Baths, about 4.30pm with his parents John and Karen and his two brothers and sister.

He was the first in the water and saw Emily struggling and kicking to stay above the water.

“I could see she was in trouble and that I had to help,” Matthew said.

“I jumped in the pool, grabbed her arms, lifted her head above the water and pulled her out of the pool,” he said.

Emily, who was not wearing any flotation device at the time, was unconscious and foaming at the mouth.

“There was no response from her and people at the pool were frantic and screaming,” Mrs Kennedy said.

Mr Kennedy and the pool lifeguard immediately began performing CPR.

After a few minutes, Emily began to breathe again. The Entrance lifeguards arrived soon after followed by an ambulance, which took Emily to Gosford Hospital’s emergency ward.

Surf Life Saving Central Coast director Stuart Harvey said if it was not for Matthew’s immediate actions, Emily would be dead.

Emily stayed in hospital on Sunday and was allowed home on Monday.

Matthew Kennedy is autistic and suffers from a severe speech impediment and learning difficulties. He is a year 2 student at the Central Coast School for Children with Autism called Aspect at Terrigal. “Matthew struggles with the most simple of tasks and it is just incredible that he knew exactly what to do when it mattered most,” Mrs Kennedy said.

John Kennedy was a lifeguard at The Entrance for 25 years.

About a month ago, he began training his children of what to do in an emergency situation.

“We come down to the pool once a week and I run through what to do if they see someone in trouble,” he said.

“Matthew did exactly that in a real life emergency and saved Emily’s life.” Mr Kennedy said the whole family was quite traumatised by what they had witnessed.

“I couldn’t sleep on Sunday night because I wasn’t sure if Emily was all right,” he said. “We are relieved to hear she is home.”

See http://express-advocate-gosford.whereilive.com.au/news/story/autistic-boy-8-saves-little-girl-from-drowning-at-the-entrance/

DSM-5: The Future of Psychiatric Diagnosis

Publication of the fifth edition of *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) in May 2013 will mark one the most anticipated events in the mental health field. As part of the development process, the preliminary draft revisions to the current diagnostic criteria for psychiatric diagnoses are now available for public review and comment. We thank you for your interest in DSM-5 and hope that you use this opportunity not only to learn more about the proposed changes in DSM-5, but also about its history, its impact, and its developers. Please continue to check this site for updates to criteria and for more information about the development process.

From http://www.dsm5.org/Pages/Default.aspx

Note: Links for Autistic Disorder (Autism Spectrum Disorder) and Asperger’s Disorder are:

- *http://www.dsm5.org/ProposedRevisions/Pages/proposedrevision.aspx?rid=94*
- *http://www.dsm5.org/ProposedRevisions/Pages/proposedrevision.aspx?rid=97*

Following is some of the commentary that has appeared in the press …

A Powerful Identity, a Vanishing Diagnosis

It is one of the most intriguing labels in psychiatry. Children with Asperger’s syndrome, a mild form of autism, are socially awkward and often physically clumsy, but many are verbal prodigies, speaking in complex sentences at early ages, reading newspapers fluently by age 5 or 6 and acquiring expertise in some preferred topic — stegosaurs, clipper ships, Interstate highways — that will astonish adults and bore their playmates to tears.

In recent years, this once obscure diagnosis, given to more than four times as many boys as girls, has become increasingly common.

Much of the growing prevalence of autism, which now affects about 1 percent of American children, according to federal data, can be attributed to Asperger’s and other mild forms of the disorder. And Asperger’s has exploded into popular culture through books and films depicting it as the realm of brilliant nerds and savantlike geniuses.

But no sooner has Asperger consciousness awakened than the disorder seems headed for psychiatric obsolescence. Though it became an official part of the medical lexicon only in 1994, the experts who are revising psychiatry’s diagnostic manual have proposed to eliminate it from the new edition, due out in 2012.

If these experts have their way, Asperger’s syndrome and another mild form of autism, pervasive developmental disorder not otherwise specified (P.D.D.-N.O.S. for short), will be folded into a single broad diagnosis, autism spectrum disorder — a category that encompasses autism’s entire range, or spectrum, from high-functioning to profoundly disabling.

“Nobody has been able to show consistent differences between what clinicians diagnose as Asperger’s syndrome and what they diagnose as mild autistic disorder,” said Catherine Lord, director of the Autism and Communication Disorders Centers at the

University of Michigan, one of 13 members of a group evaluating autism and other neurodevelopmental disorders for the manual.

“Asperger’s means a lot of different things to different people,” Dr. Lord said. “It’s confusing and not terribly useful.”

Taking Asperger’s out of the manual, known as D.S.M.-V for the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders, does not mean the term will disappear. “We don’t want to say that no one can ever use this word,” Dr. Lord said, adding: “It’s not an evidence-based term. It may be something people would like to use to describe how they see themselves fitting into the spectrum.”

But the change, if approved by the manual’s editors and consultants, is likely to be controversial. The Asperger’s diagnosis is used by health insurers, researchers, state agencies and schools — not to mention people with the disorder, many of whom proudly call themselves Aspies.

Some experts worry that the loss of the label will inhibit mildly affected people from being assessed for autism. “The general public has either a neutral or fairly positive view of the term Asperger’s syndrome,” said Tony Attwood, a psychologist based in Australia who wrote “The Complete Guide to Asperger’s Syndrome” (Jessica Kingsley Publishers, 2006). But if people are told they should be evaluated for autism, he went on, “they will say: ‘No, no, no. I can talk. I have a friend. What a ridiculous suggestion!’ So we will miss the opportunity to assess people.”

The proposed changes to the autism category are part of a bigger overhaul that will largely replace the old “you have it or you don’t” model of mental illness with a more modern view — that psychiatric disorders should be seen as a continuum, with many degrees of severity. The goal is to develop “severity measures within each diagnosis,” said Dr. Darrel A. Regier, research director at the American Psychiatric Association and vice chairman of the diagnostic manual’s task force.

Another broad change is to better recognize that psychiatric patients often have many health problems affecting mind and body and that clinicians need to evaluate and treat the whole patient.

Historically, Dr. Regier said, the diagnostic manual was used to sort hospital patients based on what was judged to be their most serious problem. A patient with a primary diagnosis of major depression would not be evaluated for anxiety, for example, even though the two disorders often go hand in hand.

Similarly, a child with the autism label could not also have a diagnosis of attention deficit hyperactivity disorder, because attention problems are considered secondary to the autism. Thus, they might go untreated, or the treatment would not be covered by insurance.

The new edition, by contrast, will list not only the core issues that characterize a given diagnosis but also an array of other health problems that commonly accompany the disorder. For autism, this would most likely include anxiety, attention disorders, gastrointestinal problems, seizures and sensory differences like extreme sensitivity to noise.

Parents and advocates have been clamoring for an approach that addresses the multiple health problems that plague many children with autism. “Our kids will do much better if medical conditions like gut issues or allergies are treated,” said Lee Grossman, president of the Autism Society of America, a leading advocacy group.

The new diagnostic approach addresses another source of confusion: the current labels may change over time. “A child can look like they have P.D.D.-N.O.S., then Asperger’s, then back to autism," Dr. Lord said. The inconsistent use of these labels has been a problem for researchers recruiting subjects for studies of autism spectrum disorder.

And it can be a problem for people seeking help. In some states, California and Texas, for example, people with traditional autistic disorder qualify for state services, while those with Asperger's and pervasive developmental disorder do not.

A big challenge for the diagnostic manual team working on autism is how to measure severity in a condition that often causes a very uneven profile of abilities and disabilities. Mr. Grossman gives the example of a woman who serves on an advisory panel to his organization. She is nonverbal and depends on an electronic device to communicate, is prone to self-injury and relies on a personal aide. And yet "she's absolutely brilliant, she runs a newsletter, and she's up on all the science," he said, adding, "Where would somebody like that come out on the rating scale?"

Recent books by people with Asperger's give insights into the workings of some oddly beautiful minds. In "Embracing the Wide Sky" (Free Press, 2009), Daniel Tammet, a shy British math and linguistic savant, tells how he was able to learn enough Icelandic in a week to manage a television interview and how he could recite the value of pi to 22,514 decimal places by envisioning the digits "as a rolling numerical panorama" of colors, shapes and textures.

In "Look Me in the Eye" (Crown, 2007), John Elder Robison describes a painfully lonely childhood and an ability to look at a circuit design and imagine how it will transform sound — a talent he used to invent audio effects and exploding guitars for the rock band Kiss.

Not all people with Asperger's have such extraordinary abilities, and some who do are so crippled by anxiety and social limitations that they cannot hold down a job or live on their own.

Dr. Susan E. Swedo, a senior investigator at the National Institute of Mental Health who heads the diagnostic manual group working on autism, acknowledges the difficulty of describing such a variable disorder. Dr. Swedo said the plan was to define autism by two core elements — impaired social communication and repetitive behaviors or fixated interests — and to score each of those elements for severity.

The trick is to "walk the tightrope of truth," Dr. Swedo said, between providing clear, easily used diagnostic guidance to clinicians and capturing the individual variation that is relevant to treatment. "People say that in autism, everybody is a snowflake," she said. "It's the perfect analogy."

The proposed elimination of autism subtypes comes at the very moment when research suggests that the disorder may have scores of varieties. Investigators have already identified more than a dozen gene patterns associated with autism, but Dr. Lord, of Michigan, said the genetic markers "don't seem to map at all into what people currently call Asperger's or P.D.D."

Nor have many of these genes been linked to distinct sets of symptoms. Until research can identify reliable biological markers for autism subtypes, Dr. Lord and other experts say, it is better to have no subtypes than the wrong ones.

In interviews, people with Asperger's and mild autism were divided on the prospect of losing the label. Temple Grandin, a Colorado State University animal scientist who is perhaps the best-known autistic American, said Asperger's was too well established to be thrown overboard. "The Asperger community is a big vocal community," Dr. Grandin said, "a reason in itself" to leave the diagnosis in place.

"P.D.D.-N.O.S., I'd throw in the garbage can," she added. "But I'd keep Asperger's."

But some younger people involved in the growing autism self-advocacy movement see things differently.

"My identity is attached to being on the autism spectrum, not some superior Asperger's identity," said Ari Ne'eman, 21, an activist who founded the Autistic Self-Advocacy Network, a 15-chapter organization he has built while in college, adding, "I think the consolidation to one category of autism spectrum diagnosis will lead to better services."

All interested parties will have an opportunity to weigh in on the proposed changes. The American Psychiatric Association is expected to post the working group's final proposal on autism diagnostic criteria on the diagnostic manual's Web site in January and invite comment from the public. Dr. Swedo and company are bracing for an earful.

From http://www.nytimes.com/2009/11/03/health/03asperger.html

The Short Life of a Diagnosis

By Simon Baron-Cohen
Published: November 9, 2009 Cambridge, England

THE Diagnostic and Statistical Manual of Mental Disorders, published by the American Psychiatric Association, is the bible of diagnosis in psychiatry, and is used not just by doctors around the world but also by health insurers.

Changing any such central document is complicated. It should therefore come as no surprise that a committee of experts charged with revising the manual has caused consternation by considering removing Asperger syndrome from the next edition, scheduled to appear in 2012. The committee argues that the syndrome should be deleted because there is no clear separation between it and its close neighbor, autism.

The experts propose that both conditions should be subsumed under the term "autism spectrum disorder," with individuals differentiated by levels of severity. It may be true that there is no hard and fast separation between Asperger syndrome and classic autism, since they are currently differentiated only by intelligence and onset of language. Both classic autism and Asperger syndrome involve difficulties with social interaction and communication, alongside unusually narrow interests and a strong desire for repetition, but in Asperger syndrome, the person has good intelligence and language acquisition.

The question of whether Asperger syndrome should be included or excluded is the latest example of dramatic changes in history of the diagnostic manual. The first manual, published in 1952, listed 106 "mental disorders." The second (1968), listed 182, and famously removed homosexuality as a disorder in a later printing. The third (1980) listed 265 disorders, taking out "neurosis." The revised third version (1987) listed 292 disorders, while the current fourth version cut the list of disorders back to 283.

This history reminds us that psychiatric diagnoses are not set in stone. They are "manmade," and different generations of doctors sit around the committee table and change how we think about "mental disorders."

This in turn reminds us to set aside any assumption that the diagnostic manual is a taxonomic system. Maybe one day it will achieve this scientific value, but a classification system that can be changed so freely and so frequently can't be close to following Plato's recommendation of "carving nature at its joints."

Part of the reason the diagnostic manual can move the boundaries and add or remove "mental disorders" so easily is that it focuses on surface appearances or behavior (symptoms) and is silent about causes. Symptoms can be arranged into groups in many ways, and there is no single right way to cluster them. Psychiatry is not at the stage of other branches of medicine, where a diagnostic category depends on a known biological mechanism. An example of where this does occur is Down syndrome, where surface appearances are irrelevant. Instead the cause — an extra copy of Chromosome 21 — is the sole determinant to obtain a diagnosis. Psychiatry, in contrast, does not yet have any diagnostic blood tests with which to reveal a biological mechanism.

So what should we do about Asperger syndrome? Although originally described in German in 1944, the first article about it in English was published in 1981, and Asperger syndrome made it only into the fourth version of the manual, in 1994. That is, the international medical community took 50 years to acknowledge it. In the last decade thousands of people have been given the diagnosis. Seen through this historical lens, it seems a very short time frame to be considering removing Asperger syndrome from the manual.

We also need to be aware of the consequences of removing it. First, what happens to those people and their families who waited so long for a diagnostic label that does a good job of describing their profile? Will they have to go back to the clinics to get their diagnoses changed? The likelihood of causing them confusion and upset seems high.

Second, science hasn't had a proper chance to test if there is a biological difference between Asperger syndrome and classic autism. My colleagues and I recently published the first candidate gene study of Asperger syndrome, which identified 14 genes associated with the condition.

We don't yet know if Asperger syndrome is genetically identical or distinct from classic autism, but surely it makes scientific sense to wait until these two subgroups have been thoroughly tested before lumping them together in the diagnostic manual. I am the first to agree with the concept of an autistic spectrum, but there may be important differences between subgroups that the psychiatric association should not blur too hastily.

Simon Baron-Cohen, the director of the Autism Research Center at Cambridge University, is the author of "The Essential Difference."

See *http://www.nytimes.com/2009/11/10/opinion/10baron-cohen.html*

Autism treatments: Risky alternative therapies have little basis in science

Alternative therapies amount to uncontrolled experimentation on children, investigation finds

By Trine Tsouderos and Patricia Callahan, Tribune reporters, November 22, 2009

James Coman's son has an unusual skill. The 7-year-old, his father says, can swallow six pills at once.

Diagnosed with autism as a toddler, the Chicago boy had been placed on an intense regimen of supplements and medications aimed at treating the disorder.

Besides taking many pills, the boy was injected with vitamin B12 and received intravenous infusions of a drug used to leach mercury and other metals from the body. He took megadoses of vitamin C, a hormone and a drug that suppresses testosterone.

This complex treatment regimen -- documented in court records as part of a bitter custody battle between Coman, who opposes the therapies, and his wife -- may sound unusual, but it isn't.

Thousands of U.S. children undergo these therapies and many more at the urging of physicians who say they can successfully treat, or "recover," children with autism, a disorder most physicians and scientists say they cannot yet explain or cure.

But after reviewing thousands of pages of court documents and scientific studies and interviewing top researchers in the field, the Tribune found that many of these treatments amount to uncontrolled experiments on vulnerable children.

The therapies often go beyond harmless New Age folly, the investigation found. Many are unproven and risky, based on scientific research that is flawed, preliminary or misconstrued.

Laboratory tests used to justify therapies are often misleading and misinterpreted. And though some parents fervently believe their children have benefited, the Tribune found a trail of disappointing results from the few clinical trials to evaluate the treatments objectively.

…

More … see http://www.chicagotribune.com/health/chi-autism-treatments-nov22,0,3049622,print.story

Early Intervention for Toddlers With Autism Highly Effective, Study Finds

ScienceDaily (Nov. 30, 2009) — A novel early intervention program for very young children with autism -- some as young as 18 months -- is effective for improving IQ, language ability and social interaction, a comprehensive new study has found.

"This is the first controlled study of an intensive early intervention that is appropriate for children with autism who are less than 2 1/2 years of age. Given that the American Academy of Pediatrics recommends that all 18- and 24-month-old children be screened for autism, it is crucial that we can offer parents effective therapies for children in this age range," said Geraldine Dawson, chief science officer of Autism Speaks and the study's lead author. "By starting as soon as the toddler is diagnosed, we hope to maximize the positive impact of the intervention."

The study, published online in the journal *Pediatrics*, examined an intervention called the Early Start Denver Model, which combines applied behavioral analysis teaching methods with developmental relationship-based approaches. This approach was novel because it blended the rigor of applied behavioral analysis with play-based routines that focused on building a relationship with the child. While the youngest children in the study were 18 months old, the intervention is designed to be appropriate for children as young as 12 months of age with autism. Although previous studies have found that early intervention can be helpful for preschool-aged children, interventions for children who are toddlers are just now being tested. Autism is a lifelong neurodevelopmental disorder characterized by repetitive behaviors and impairment in verbal communication and social interaction. It is reported to affect one in 100 children in the United States.

"Infant brains are quite malleable so with this therapy we're trying to capitalize on the potential of learning that an infant brain has in order to limit autism's deleterious effects, to help children lead better lives," said Sally Rogers, a professor of psychiatry and behavioral sciences, a study co-author and a researcher at the University of California, Davis, MIND Institute in Sacramento, Calif.

The five-year study took place at the University of Washington Seattle and was led by Dawson, then a professor of psychology and director of the university's Autism Center, in partnership with Rogers. It involved therapy for 48 18- to 30-month-old children with autism and no other health problems. Milani Smith, who oversees the UW Autism Center's clinical programs, provided day-to-day oversight.

The children were separated into two groups, one that received 20 hours a week of the intervention -- two two-hour sessions five days a week -- from UW specialists. They also received five hours a week of parent-delivered therapy. Children in the second group were referred to community-based programs for therapy. Both groups' progress was monitored by UW researchers. At the beginning of the study there was no substantial difference in functioning between the two groups.

At the conclusion of the study, the IQs of the children in the intervention group had improved by an average of approximately 18 points, compared to a little more than four points in the comparison group. The intervention group also had a nearly 18-point improvement in receptive language (listening and understanding) compared to approximately 10 points in the comparison group. Seven of the children in the intervention group had enough improvement in overall skills to warrant a change in diagnosis from autism to the milder condition known as pervasive developmental disorder not otherwise specified. Only one child in the community-based intervention group had an improved diagnosis.

"We believe that the intervention group made much more progress because it involved carefully structured teaching and a relationship-based approach to learning with many, many learning opportunities embedded in the play," Rogers said.

"Parental involvement and use of these strategies at home during routine and daily activities are likely important ingredients of the success of the outcomes and their child's progress. The study strongly affirms the positive outcomes of early intervention and the need for the earliest possible start," Dawson said.

In this study, the intervention was provided in a toddler's natural environment (the home) and delivered by trained therapists and parents who received instruction and training as part of the model.

"Parents and therapists both carried out the intervention toward individualized goals for each child, and worked collaboratively to improve how the children were responding socially, playing with toys, and communicating," said Smith, associate director of the UW Autism Center and a study co-author. "Parents are taught strategies for capturing their children's attention and promoting communication. By using these strategies throughout the day, the children were offered many opportunities to learn to interact with others."

Other study authors include Jeffrey Munson, Jamie Winter, Jessica Greenson, and Jennifer Varley, all of UW Autism Center or the department of psychiatry and behavioral sciences, and Amy Donaldson of the department of speech and hearing science, Portland State University, Portland, Ore.

The study was funded by a grant from the National Institute of Mental Health. The Institute has also funded a multi-site trial of the Early Start Denver Model that is currently being conducted at the University of Washington, UC Davis and the University of Michigan.

From http://www.sciencedaily.com/releases/2009/11/091130084720.htm

See also http://www.medpagetoday.com/Neurology/Autism/17216

ACER report for National Council for Special Education (Ireland) released

Today the Republic of Ireland's National Council for Special Education (NCSE) will publish an international evaluation of strategies used in educating children and young people with autism. Prepared by researchers from the Autism Centre for Education and Research (ACER) at the University of Birmingham and St. Patrick's College Dublin, the report used a set of rigorous guidelines to evaluate the latest studies from around the world published between 2002 and 2008. It also includes data from policy and best practice guidelines from the United Kingdom and Ireland.

The report's four major findings are:

- There is no one best approach to education for all children on the autism spectrum
- The evidence base for current interventions is patchy
- There is a particular lack of research regarding good provision for secondary students and those in post-compulsory education
- The evidence base for good practice in transition between settings and stages of schooling needs improvement

The new report will be relevant to practitioners, policymakers and families worldwide on the NCSE Web site (http://www.ncse.ie) from today.

Research requests

Dear Bob Buckley

I am a researcher from Monash University in Melbourne, based at The Alfred Hospital. Our team are currently conducting research into the brain basis of autism and Asperger’s disorder. This research is funded by the National Health and Medical Research Council (NHMRC). I am writing to ask whether you would allow us to advertise for research participants in one of the A4 newsletters.

This research involves the use of transcranial magnetic stimulation (TMS). TMS is a safe and non-invasive neuroscience technique that, similar to MRI, involves the use of magnetic fields to investigate the brain. With TMS, a magnetic pulse is used to briefly stimulate a small area of the brain. It has been used extensively to investigate depression and schizophrenia. We believe that it will be similarly effective in improving our understanding of autism and Asperger’s disorder, which will assist with both diagnosis and the development of new treatments. This research has been approved by the ethics committees of Monash University and The Alfred Hospital.

We would be very grateful if you were able to support this research by including in your A4 Update an advertisement inviting people with high-functioning autism or Asperger’s disorder to be involved in this study. We would also be happy to provide brochures for distributing to your members.

Our team are very happy to answer any questions that you may have about this research. You can contact me, Dr. Peter Enticott, or Ms. Hayley Rhook, on (03) 9076 6564, or via email (peter.enticott@med.monash.edu.au).

I hope to hear from you soon.

Yours sincerely,
Dr. Peter Enticott

> *Editor's note: we apologise for the delay in getting this A4 Update out. In the interest of expediency we printed this letter as we received it.*

To whom it may concern,

I am a registered psychologist, but am also completing my Doctor of Clinical Psychology/PhD at the University of Sydney. Our research team is currently conducting a research project examining the experience of friendship in children and adolescents with high-functioning Autism Spectrum Disorders (ASD), as well examining parental perceptions and understanding of their child?s friendship experience. Current research in this area is considerably lacking and we hope this research will contribute to current intervention programs.

I am writing to ask whether A4 would be interested in advertising this study. It is currently taking place at the University of Sydney, NSW and involves a one-off assessment with a parent and child/adolescent with a previous diagnosis of an ASD. For your information, I have attached the information sheet which contains a more detailed outline of what is involved for families. If you are interested in advertising I can forward on the ethics approved advert as well. You can contact me via email or on 0413327728.

Thank you in advance,
Sandy Vickerstaff
Doctor of Clinical Psychology/PhD student
The University of Sydney

contact Sandy Vickerstaff on (02) 9351 8476 (svic4915@mail.usyd.edu.au) or Dr Sandra Heriot on 0408280220

Dear Families
Please assist Autism Advisory and Support Service (AASS) gather important statistics on schooling for our beautiful children with Autism by completing this quick survey. It will only take one or two minutes of your time and will help us lobby the Government.

Please feel free to pass this on to anyone else you know who has a child with Autism in school.

Thanks and kindest regards
Grace
www.aass.org.au

http://www.surveymonkey.com/s/K5DLKQC

Letters

A suggestion

Hi just a suggestion, is there any documents to hand that describe exactly what is available within the autism reform. I have read several documents and can't seem to exactly see what is available. My son in particular is 13, is there still nothing available for that age bracket.

He needs social skills training and i can't seem to find anywhere in Qld that are experts in that field.

By the way your newsletters are a doing a great job for autism.

Many Thanks,
A4 Member.

Blood tests and mercury

Hi Bob,

Quote …

> Mercury levels similar in autistic, normal kids
>
> 20 October 2009 By David Morgan
>
> WASHINGTON (Reuters) - Children with autism have mercury levels similar to those of other kids, suggesting the mysterious disorder is caused by a range of factors rather than "a single smoking gun," researchers said on Monday.
>
> The researchers at the University of California, Davis, initially found that children aged 2 to 5 with autism had mercury levels lower than other children because the autistic kids ate less fish, the biggest source of mercury that shows up in the blood................etc (page 18)

I find this sort of lying tedious so will be brief. Although blood tests are "gold standard" in the minds of traditional MDs, they are close to useless for testing mercury in our kids.

Blood levels show acute exposure only and do not represent tissue levels of mercury in the body.

http://www.wellsphere.com/autism-autism-spectrum-article/mark-blaxill-and-boyd-haley-respond-to-pichichero-et-al-thimerosal-mercury-excretion-study/175737

Also see Dr Blaylock's excellent exegesis on the "science" of studies such as this one

http://www.whale.to/v/blaylock7.html

cheers
Kerrie

P.S. see also http://articles.mercola.com/sites/articles/archive/2009/11/14/Expert-Pediatrician-Exposes-Vaccine-Myths.aspx

Almost identical twins

Hi Bob

It was great to meet you last Wednesday night following the monthly AAACT Support Group meeting.

As mentioned I am looking for any other parents of identical twins where only one has autism.

I would be extremely grateful if you could send a query along the following lines to your many contacts:

Canberra parents of 2 ½ year old identical twin boys seeking to make contact with other parents in the same situation.

Contact c/- cnvnr@a4.org.au

Many thanks
Liz

Warning … getting old with Aspergers

I'd like to warn those of you what its like getting old with Aspergers.

The man haters go into the schools and they tell the kids - who we all know have an excess of imagination - that there's paedophiles everywhere. And I have mild Aspergers. So I'm not good with people. And I live by myself next to a park. And I'm a bit odd. So they've decided I must be the local paedophile. If I walk down the street the kids shout abuse at me. They throw rocks at my house and break the windows. They tell their parents and they shun me. It doesn't matter that I have nothing to do with the kids. That I'm totally uninterested in them. Its like with Saddam's WMDs, we know you're got them, if we can't find them it must be that you've got them so well hidden. You can see the way they think: we know you're a paedophile, the nasty over-imaginative bullies we've raised are telling us you are, so you must be hiding it really well so you can leap out from behind a bush and attack them. I'm a bit odd and clumsy with people as people with Aspergers are, I'm a loner, so there must be something wrong with me, and everyone knows there's paedophiles everywhere, they are told there are, and they can't find any others, so I must be one.

Try living with that every day.

Gordon Drennan
e-dress: gordon.drennan@three.com.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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