# 2006 (February), Issue 1

# **Adult Services: A South Australian Perspective**

by Katharine Annear

Katharine is a Program and Services Officer with Autism SA and has Asperger syndrome. She has a long standing history as a disability advocate and has served on numerous boards and committees in the disability and community sectors. As a board member of Autism SA she is also a nominated director of the Autism Council of Australia.

It is with great dismay that we must read over and over again media coverage portraying Autism as a childhood condition with little if no recognition for the needs of the increasing adult population diagnosed with ASD. Whilst the need for access to early diagnosis and intervention services remains an issue the growing number of adults with autism spectrum disorder will require an unprecedented level of service in the very near future.

As of July 2005 there were over 400 adult clients and 1167 clients aged between 8 and 17, registered for services with Autism

SA. It goes without saying that in ten years time these clients will all be adults. In South Australia the diagnosed Asperger adult population will effectively triple in the next ten years (Michaelsen 2004). Michaelsen's (2004) small scale study in to the service needs of Adults with Asperger's syndrome demonstrates this effective tripling of the population and warns that his does not take into account the 30 new ASD diagnoses made in a month at Autism SA. Autism SA's client base is growing at rate of approximately 15% per year and the service, whilst expanding to accommodate this growth, must be cognisant of the need to plan proactively so that it will not struggle to meet the needs of adults. Recently Autism SA, in association with IDSC, carried out a year long pilot study into tenancy support for adults with Asperger syndrome and plans further research into models of support for adults with autism spectrum disorder

Reports from Michaelsen (2004) (Service Needs) and Alexander (2005) (Tenancy

### Inside this Issue

Adult Services: A South Australian Perspective Convenor's message

Victoria: Disability Bill exposure draft Role of GPs in services for people with ASD Early Childhood Intervention Coordination in NSW

Autism Tasmania Services

ASD and mental illness

Individuality, Diversity, Equality, Achievement 11

Letters / Emails

A4 Contacts

#### **Disclaimer**

- While we have made every effort to ensure that information is free from error, A4 does not warrant the accuracy, adequacy or completeness of the
- accuracy, adequacy or completeness of the information, graphics and materials in the A4 Update.
- 4 A4 does not guarantee that A4 Updates will be free from viruses.
- A4 is not responsible for the results of any action taken or not taken on the basis of any information in
- the A4 Update, nor for any error or omission in that information. A4 expressly disclaims all and any
- 8 liability and responsibility in respect of anything done
- onsequent on the whole or any part of the
- information in the A4 Update. A4 shall not be liable for any loss, damage, liability, expense, cost or personal
- injury, whether direct or indirect, consequential or incidental, which you suffer, incur or are liable for,
- 12 howsoever caused (whether due to A4's negligence or otherwise), arising from or in connection with your use of A4 Updates.



1

Support) outline the following service needs for adults:

### **\*** Life skills training

- Communication
- Social skills
- Sexuality
- Budgeting
- ➤ Household chores
- Safety and security
- Personal hygiene and medication
- > Transport

### **Social support**

- Group
- Individual
- Family

### Counselling

- Relationships
- Sexuality
- Self esteem
- Depression
- Anxiety
- > Isolation
- Assistance in dealing with government agencies and services
- **\*** Assistance in dealing with the law
- **\*** Employment Services

Both Michaelsen (2004) and Alexander (2005) make recommendations that clearly

warrant immediate action. Both stress the need for proactive measures to address the service needs outlined. Both highlight the need for community awareness of autism spectrum disorder. Alexander proposes a comprehensive case management system effective across the life span addressing the biopsychosocial needs of the client. Michaelsen recommends the training of peer supporters and further training for health and allied health professionals in autism spectrum disorders particularly in the area of counselling for individuals and families. Also proposed is a crisis hotline for adults and families of adults with ASD.

The future of services for adults is in the hands of service providers now and the statistics clearly point to the extent of the need for services and for proactive planning. It is incumbent upon the current autism services, autism advocates and peak bodies to recognise this need and lobby for appropriate funding and policy direction to support adults with autism spectrum disorder living in our communities.

#### References:

Michaelsen, K. (2004). Now we're all grow'd up: A small scale study into the services

and service needs of adults with Asperger syndrome. Autism SA & The School of Social Administration and Social Work, Flinders University.

Alexander, V. (2005). The path of the pioneers: Developing a model of tenancy support for people with an autism spectrum disorder (no intellectual disability). Autism SA.

# Wanted: Articles and letters for the next two issues of A4 Updates.

Please send letters to <a href="mailto:edit@a4.org.au">edit@a4.org.au</a>. Letters sent to the editor may be published unless they are clearly marked "not for publication". Normally, they will appear with your full name and state unless you mark them clearly "anonymous" or "first name only".

In the next two editions we are looking for articles and letters on:

- Respite
- Challenging/problem behaviour

Please send all contributions to the editors.



# Convenor's message

Dear A4 member,

Welcome to 2006. The year started with reports that ...

Prime Minister John Howard is promising to take mental health to the next meeting of the Council of Australian Governments (COAG) in February and has proposed a plan for boosting early intervention, residential care and counselling.

SMH, 2 Jan 2006 Mental health service set for boost

#### And

Parliamentary Secretary for Health Christopher Pyne said yesterday Mr Howard would push for a new deal with the states on mental health at COAG talks next month. ...

"The Government recognise that there is a need for substantial reform of mental health and in relation to the delivery of services in the community," Mr Pyne said.

"We are particularly concerned about the lack of accommodation for the mentally ill."

The Government is also being urged to consider a radical overhaul of commonwealth and state funding of services for the disabled and the mentally ill.

The Australian PM to act on mental health Samantha Maiden January 02, 2006

A4 will be trying to ensure governments include issues of ASD and mental health in the discussion and outcomes.

According to the federal Department of Health and Ageing website and its 2004-05 Annual Report, Mr Christopher Pyne MP has responsibility for matters relating to autism<sup>1</sup>. This clears up the issue of who in government is responsible for autism, at least at the federal level.

A4 will be doing our best to talk with Mr Pyne MP about autism/ASD in 2006. The issues we wish to raise immediately include:

- his plans associated with his responsibility for autism
- outcomes from the national autism forum and the subsequent joint (A4 & ACA) submission.
- progress in the use of the \$50,000 research commitment made at the time of the National Autism Forum.
- concerns that the government may have handed back to treasury at least \$63 million allocated for Better Outcomes in Mental Health when this money might have helped people with ASD have much better outcomes than they currently experience.

Every five years, the Australian Bureau of Statistics (ABS) conducts its Survey of Disability, Ageing and Carers (SDAC). The last survey was in 2003. The ABS does not publish results for "autism and related disorders" but gave A4 its results when asked for them.

The ABS estimates, from the SDAC 2003, that there are 6,100 male and 100 female adults (20 years of age and over) in Australia who report having autism or a related disorder. This turns out to be 4.3 per 10,000 adults, which is less than half what was expected. The number of females is very low and the male-to-female ratio is surprising.

<sup>&</sup>lt;sup>1</sup> see <a href="http://www.health.gov.au/internet/ministers/publishing.nsf/content/portfolioresponsibilities-3">http://www.health.gov.au/internet/ministers/publishing.nsf/content/portfolioresponsibilities-3</a>



This low level of reporting among adults suggests that at least half the adults who have ASD do not yet have a diagnosis — or if they were given a diagnosis they do not admit it. This means they do not get the services and support they need for their disabilities.

Children are now being diagnosed with ASD at much higher rates than in the past. Currently, at least 60 per 10,000 (1 in 166) school-leavers have received an ASD diagnosis.

The Victorian Department of Human Services is responsible for planning disability services. Its **Fact Sheets For Health Professionals** (see <u>their webpage</u>) misquotes outdated information saying ...

"autism occurs in 2.5 in every 10,000 children" and "Autism spectrum disorders have more recently been suggested to be 10 in every 10,000."

It seem unlikely to me that a government Department can plan services properly for people with ASD when it does not know how many there are. Unless it does not plan to provide any services.

The Victorian government cancelled my holiday this year. They ran their public consultation for their draft Disability Bill over Christmas. So several of us have been busy working on a response from A4 (see the item above). Then in the New Year, A4 found out at the last moment that the United Nations is working on a new convention on the Rights of people with a Disability. As our government did not consult us, or any ASD representatives that we are aware of — and time was limited, we wrote a quick letter directly to the UN committee to provide our input. Please take a look at our letter (download it from <a href="https://www.a4.org.au/documents/UNDisabilityRightsfinal.doc">www.a4.org.au/documents/UNDisabilityRightsfinal.doc</a>).

best regards Bob Buckley

# Victoria: Disability Bill exposure draft

The Victorian Government is reviewing its disability legislation. The Minister for Children and Minister for Community Services, the Hon. Sherryl Garbutt MP, released an exposure draft of the Bill for public consideration. This is an opportunity for the public to comment on the proposed changes prior to the Bill being introduced into Parliament.

The proposed changes to Victoria's Disability legislation raise concerns.

A very brief, and perhaps harsh, summary follows. The legislation creates a Disability Commissioner and complaints process where the main outcome of a successful complaint is that the service provider, if it does not mind, will be named in the Commissioner's Annual Report. The purpose of the draft Bill is to "strengthen responsibilities" for people with a disability. The draft Bill's Objectives include giving "due regard ... to the limited resources available to provide disability services"; in other words, the draft Bill ensures the Victorian Government will under-fund disability services. The draft Bill introduces formal systems for "Restrictive Interventions" and "Compulsory Treatment" for people with a disability. It proposes to formalise the Disability Advisory Council (that has no ASD representative on it).

Among other things, "restrictive intervention" could deny children with ASD their right to receive education. A4 is concerned that if adopted the Victorian draft Disability Bill will provide a legal framework for excluding from schools some of the 8,500 Victorian school students said to have challenging or problem behaviour (1/3 of them with Asperger's syndrome/disorder).

A stated purpose of the draft Bill is to protect the rights of people with a disability. Children with ASD should have Rights, but Australia is in breech of its international obligations under the <u>UN Convention on the Rights of the Child</u> in refusing to

• ensure children who are (mentally and/or physically) disabled "enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's



active participation in the community." [see Article 23(1)] Limiting resources does not ensure such an outcome.

- recognise "the right of the disabled child to special care" [see Article 23(2)] at a sufficient level when the child has ASD.
- address "the special needs of a disabled child, [the special care] shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development." [see Article 23(3)].

The rights of a child who is disabled by ASD go beyond ensuring the child "has effective access to" services. The UN Convention says the child has the right to receive … and that the state is responsible for ensuring the child actually receives "education, training, health care services, rehabilitation services, preparation for employment" and more. The **right to receive a service** means more than "inclusion"; that is, just being in the same room/setting does not ensure an "equal opportunity to access" a service/benefit. Many Australian children who are severely disabled by ASD cannot access and do not receive effective education, rehabilitation, etc. when they are included in mainstream settings unless they also receive effective preparation and the specialised support they need.

The draft Bill is mostly about support services for adults. It should also address children with a disability, early intervention, treatment/rehabilitation and special education.

Victoria's draft Disability Bill is a national issue because other states are watching. For example, the ACT is well into its review of its Disability Services Act and is closely observing the Victorian process.

If you like reading draft legislation ©, you can download the Exposure Draft of the Disability Bill (220 pages). If you want an overview of the draft Bill, you can download it from:

- Victorian Disability Bill 2005 Overview (PDF, 157 KB) (54 pages)
- Victorian Disability Bill 2005 Overview (Word, 372 KB) (41 pages)

The government provided 9 Information Sheets that present its view:

- 1. The Victorian Disability Bill moving forward
- 2. Government Leading Change
- 3. Access to disability services
- 4. Planning
- 5. Strengthening rights in residential services
- 6. Enhancing the accountability of disability service providers
- 7. Strengthening quality assurance and standards
- 8. Building strong complaint systems
- 9. <u>Protecting the rights of people subject to restrictive interventions and compulsory treatment</u>

The government's Information Sheets present a particularly rosy picture of the draft Bill. If you are interested, A4 recommends you read more widely. You can read A4's developing response (click here to download).

Wendy Kiefel made a huge effort helping get this submission into the best shape we could in the available time. Geraldine Robertson and Vern Hughes made very valuable contributions.



You can see comments from some other groups at ...

- http://www.valid.org.au/
- <a href="http://www.acrod.org.au/divisions/vic/BillResponseDec05.pdf">http://www.acrod.org.au/divisions/vic/BillResponseDec05.pdf</a> (peak body for service providers).
- www.makemcmillanmatter.com.au/news/default.asp?action=article&ID=3513
- you could contact Autism Victoria and ask for a copy of their submission.

If you feel strongly, please send your views as feedback to the community consultation process (<a href="legislative.review@dhs.vic.gov.au">legislative.review@dhs.vic.gov.au</a>), the Minister (see <a href="http://www.premier.vic.gov.au/ministers/list\_item.asp?id=25">http://www.premier.vic.gov.au/ministers/list\_item.asp?id=25</a>), the Shadow Minister (see <a href="http://www.parliament.vic.gov.au/shadow.html">http://www.parliament.vic.gov.au/shadow.html</a> and try to figure out who may be relevant) and your local politicians.

# Role of GPs in services for people with ASD

As we have previously reported, the Department of Health and Ageing suggests people with ASD and their family access treatment and health services for ASD through Medicare EPC Program Planning items with their GP. Medicare is funded federally.

While there are a few exceptions, GPs generally are not an effective path to the services people with ASD need. GPs have a history of dismissing family concerns over development delays in children and fail quite often to refer a child for assessment and diagnosis. For example, in relation to children who need early intervention in NSW, the <a href="Early Childhood Intervention">Early Childhood Intervention</a> <a href="Coordination Program">Coordination Program (ECICP)</a> Review Report says

... Families commonly reported that it had been difficult to have their early concerns about their child taken seriously by GPs and many had to be consistently assertive over a period of time in order to have their GP refer them to a specialist.

Page 42

In short, most GPs are reluctant (at best) to listen and respond to parents about their child's developmental delays. Many families are not assertive with their GP. In this way, GPs are often a barrier to children with ASD accessing crucial early intervention.

Adults are also affected. According to the College of GPs own website (see <a href="http://www.racgp.org.au/afp/downloads/pdf/august2004/20040803lennox.pdf">http://www.racgp.org.au/afp/downloads/pdf/august2004/20040803lennox.pdf</a>) adults with "intellectual disability" (apparently including autism) are

"at risk of undetected and undiagnosed physical and mental health conditions. Even when recognised, health problems may be poorly managed. Adults with intellectual disability on average have 5.2 conditions per person; half of these go unrecognised or are poorly managed."

Apparently, GPs fail to diagnose half of the health problems adults with such a disability experience. The article warns "Carers need to be aware that the GP is not paid for fact finding work outside the consultation." However, all professionals are required (and paid as part of their professional income) to maintain their current knowledge, expertise and skills as a prerequisite for their ongoing status as a professional.

Based on experience, many families distrust their GP on matters relating to ASD. Very few GPs have relevant expertise in treating ASD. And many GPs are sources of misinformation about ASD.

Problems with GPs will take some time to fix. In the meantime, it makes little sense that GPs control the pathway to autism treatment. Few GPs can plan treatment for autism. Effective

<sup>&</sup>lt;sup>2</sup> Update 4, May 2005, *Enhanced Primary Care Program*, p1 and again in Update 8, October 2005, *Enhanced Primary Care Program*, p1



planning and service delivery depends on professionals with ASD-specific knowledge and experience. Governments need to act to ensure suitable services are available.

Officials in the Department of Health and Ageing decided ASD services should be accessed through GPs without consulting the ASD community, without referring to research and (the FOI process reveals) without any discernible basis for such a decision.

# **Early Childhood Intervention Coordination in NSW**

In NSW, the Early Childhood Intervention Coordination Program (ECICP, see <a href="http://www.ecicp.com/Resources.html">http://www.ecicp.com/Resources.html</a>) started in 1991. ECICP can be contacted on 1300 65 68 65. Its goals are:

- To coordinate planning and service delivery
- To foster collaborative practice
- To improve early identification of children requiring early childhood intervention
- To improve access to and participation in early childhood intervention services
- To promote and support the development of quality family-centred services based on best practice standards
- To promote smooth transitions between services
- To raise the profile of Early Childhood Intervention

The Early Childhood Intervention Coordination Program (ECICP) Review Report says ...

#### Benefits of coordination

**Findings** 

- ...
- Where coordination of services is achieved for families, particularly through Individual Family Service Plans (IFSPs), this is of significant benefit and families value it highly. However, the extent to which coordination is undertaken for families is variable.
- The capacity of the ECICP to improve coordination of early childhood intervention services for families is somewhat limited because this is dependent on multiple factors, many of which are beyond the scope of the ECIP to control or change. Coordination by the ECICP at a system level is perceived to be particularly limited.

Page 6

Families of children with ASD seem unaware of or unable to access the ECICP or an Individual Family Service Plans (IFSPs). Coordination for families with a child with ASD seems to be absent, rather than variable.

In particular, ECICP is unable to refer to ASD-specific early intervention at the intensity recommended for child diagnosed with autism. Overseas and local experts advice that a child diagnosed with autism receive an extended period with a minimum of 15 to 25 hours of ASD-specific intervention<sup>3</sup> starting as soon after diagnosis as possible. We would certainly agree with the Review Report that coordination at a system level of early intervention services for children with ASD is perceived and observed "to be particularly limited" to the point of non-existence.

Do you have a young child with ASD? Do you live in NSW? Have you written to the ECICP lately asking for 20 hours of ASD-specific early intervention for you child? They need to know you want it! If you don't ask you won't get

The ECICP Review says ...

Key initiatives at a statewide level that have contributed towards the intended outcomes are:

<sup>&</sup>lt;sup>3</sup> Wray J., Silove N. & Knott H. (April 2005) Language disorders and autism MJA; 182 (7): pp354-360, see http://www.mja.com.au/public/issues/182\_07\_040405/wra10330\_fm.html



- The establishment of a Network of committees throughout the state that aim to involve key stakeholders in early childhood intervention in improving coordination of services.
- The development of Best Practice Standards for Early Intervention.
- Contribution to enhancing Family Centred practice in NSW through the development of "Recommended Practices in Family Centred Early Intervention" a manual which provides early childhood intervention workers with a description of the way in which family-centred early childhood intervention programs are best implemented. Area and Local Network Committees promote the uptake of recommended practices outlined in the Manual.

Page 16

Unfortunately, I was unable to find either *Best Practice Standards for Early Intervention* or *Recommended Practices in Family Centred Early Intervention* on the DADHC website. The ECICP review document is the only reference found by a search for these publications of the NSW DADHC website.

The Review mentions ECICP's role to identifying gaps. The case of Jason Dawes showed there are chronic gaps in services for children who are severely affected by their autism. There is no sign the ECICP has identified chronic gaps in services of children with ASD, or that the ECICP reported gaps relating to services for ASD to the NSW government.

In any case, others have reported the service gaps for children with ASD to the NSW government. There no point to identifying services gaps in NSW while the government refuses to do anything about them.

A4 would be interested to hear about experiences from anyone in NSW who has encountered an Area or Local Network Committee or any services related to the ECICP.

### **Autism Tasmania Services**

There is very little support available for adults on the spectrum in Tasmania, access to an experienced diagnostician is virtually nonexistent and the best we have at the moment is that an interstate diagnostician is considering visiting Tasmania twice a year. This will be a much needed service; however the cost may be prohibitive for many. Similarly there are no specialized counseling services. While generic services are available, they are often not suitable and sometimes inspire further conflict or difficulty in people's lives.

With regard to employment, once again there are no specialized services. Generic service providers try hard but may have little specialized knowledge of autism; try as they may it may not be understood that a person who is sensitive to noise needs a quiet work environment. It is rare for a person to be supported within the workplace once he/she has a job.

While progress is being made in the field of education, once again, service providers are learning. TAFE is probably most accessible to students with ASD's as there are regional TAFE providers. This is probably a good option for school leavers.

Supported accommodation is provided via generic services. Some individuals are well suited by this arrangement however many others struggle. Many adults who require supported accommodation stay at home.

There are adult support groups in two regions. Participants are encouraged to run the support groups themselves by rotating the chair or having participants follow up on other organization tasks.

As you can see, there is a long way to go before autistic adults are well catered for in Tasmania.



## **ASD** and mental illness

**Bob Buckley** 

Recently, the Prime Minister put mental health on the national agenda. In a previous A4 Update I raised the possibility that people with "treatment resistant" or "incomplete recovery" schizophrenia might have undiagnosed ASD. Several correspondents said professionals are unlikely to confuse ASD and schizophrenia. The following presents a case for considering diagnostic review ahead of pharmacological treatment.

In May 2003, the Medical Journal of Australia published a <u>Schizophrenia Supplement</u>. In the supplement, Pantelis & Lambert<sup>4</sup> describe and discuss people with "treatment resistant" or "incomplete recovery" schizophrenia. They say illness factors relating or contributing to "incomplete recovery" include the "poor prognosis of patients, who are typically single men with:

- Intellectual disability
- Marked cognitive impairment
- Poor premorbid adjustment
- Early and/or insidious onset of disorder
- Longer duration of prodrome
- Longer duration of untreated psychosis
- Negative symptoms at first admission".

The term "longer duration of prodrome" means that these symptoms were present well before the patient's schizophrenia was diagnosed.

"Negative symptoms" mean avolition, apathy, anhedonia, affective blunting, poverty of speech. Another article<sup>5</sup> gives meanings for these various "Negative symptoms":

- Affective blunting (restricted emotional experience and expression).
- Anhedonia/asociality (loss of capacity for pleasure, impoverished social drive).
- Alogia (decreased amount of speech, loss of fluency of speech).
- Avolition/apathy (lack of motivation/drive).
- Attentional impairment (inability to focus/sustain attention

These lists of symptoms use different language from that used to describe autism, but they still describe characteristics of autism. Particularly, "early and insidious onset", "cognitive impairment", "impoverished social drive" (asociality), "decreased amount of speech" and "loss of fluency of speech" (alogia) are among the diagnostic criteria for autism. The lists include characteristics commonly associated with autism include "intellectual disability", "untreated psychosis", "restricted emotional experience and expression" and "inability to focus/sustain attention"

According to the article, "negative symptoms" are "symptoms that reflect functions and behaviours that have been lost due to the illness." The articles do not show that clients had these functions and behaviours at a prior time. Possibly, the authors of the articles assumed but did not establish that these functions and behaviours were once present and subsequently "lost due to the illness".

<sup>&</sup>lt;sup>5</sup> T.J.R. Lambert, D.J. Castle (May 2003) <u>Pharmacological approaches to the management of schizophrenia</u>, MJA; 178 (9) Suppl: pp57-61.



<sup>&</sup>lt;sup>4</sup> C. Pantelis, T.J.R. Lambert (May 2003), *Managing patients with "treatment-resistant" schizophrenia*, MJA; 178 (9) Suppl: pp62-66

A patient with a history of having the symptoms in the lists from an early age may have an autism spectrum disorder. A person with such a history born before 1985 and fitting this "treatment resistant" or "incomplete recovery" category may have undiagnosed autism. Currently in Australia, fewer than half the expected number of adults report having an ASD diagnosis. Undiagnosed ASD has happened before (see for example, Wendy Lawson's website).

"For several decades after the initial description of autism, research on this and related conditions was impeded by a lack of consensus on aspects of syndrome definition, as well as by assumptions of continuity between these conditions and severe forms of mental illness in adults, particularly schizophrenia. The idea that autism was the earliest form of schizophrenia reflected an awareness of the severity of both conditions, the then-current extremely broad views of schizophrenia, and Kanner's use of the word autism, which had previously been used to describe the self-centered quality of thinking in schizophrenia, not a relative absence of social relatedness. It took many years before researchers and clinicians could be sure that autism and schizophrenia were indeed different conditions."6

#### Dosseter warns

"in the pre-pubertal, psychiatric referral for a miss-attributed diagnosis is much commoner than VEOS [very early onset schizophrenia]. ... Hallucinations and delusions have to be distinguished from pretend/imaginary friends, relationships with a "transitional object", stereotypic preoccupations, concrete externalisation of thoughts or conscience and pseudo hallucinations. Passivity phenomena may also occur in this context. The difficulty arises where the presenting young person has problems of social relating and in consequence problems of accurately identifying feelings and perspective taking. It is particularly in the context of anxiety or anger that such young people have difficulty recognising their ownership of the experiences they describe."7

#### Clinicians in Victoria describe ...

"a group of 25 adults who had been receiving treatment for psychotic disorders but with a less than optimal treatment response. After assessment by the Victorian Dual Disability Service (a clinical service specializing in intellectual disability and mental illness) it was found that they had diagnoses within the autism spectrum that had not been previously identified."8

Edwards and Bennett (in a frenzy of multiple negatives) conclude

"In our experience it is not uncommon for people with a mild intellectual disability and a diagnosis of schizophrenia who are not responding to treatment to have an unidentified Autistic spectrum disorder."9

Pantelis & Lambert<sup>10</sup> advise mental health practitioners that

"Although pharmacological treatment is a necessary first step in managing incompletely recovered patients, adjunctive psychosocial interventions are needed to optimise treatment success."

Possibly, the first step should be to review of the diagnosis before moving to "pharmacological treatment". A patient with ASD in the mental health system may not have an ASD diagnosis.

<sup>10</sup> C. Pantelis, T.J.R. Lambert (May 2003), Managing patients with "treatment-resistant" schizophrenia, MJA; 178 (9) Suppl: pp62-66

<sup>6</sup> http://info.med.vale.edu/chldstdv/autism/autism.html

<sup>&</sup>lt;sup>7</sup> D. Dossetor (Nov 2002) All that glitters is not gold: Misdiagnosis of Schizophrenia in Asperger's Syndrome Proceedings of Inaugural World Autism Congress, Melbourne, Australia.

<sup>&</sup>lt;sup>8</sup> S. Edwards & C. Bennett (Nov 2002) *Dual Diagnosis* Proceedings of Inaugural World Autism Congress, Melbourne, Australia.

<sup>&</sup>lt;sup>9</sup> ibid

So far, "pharmacological treatment" (drugs) has not been especially effective in treating autism.

To date, drug treatments act on symptoms of ASDs and not the core difficulties of social, communication and imagination functions.

p4

It is widely recognised, however, that although current drug treatments can improve some behavioural abnormalities in ASDs, the core symptomatology is relatively resistant to successful pharmacological intervention and that drug actions may be relatively non-specific.

MRC Review of Autism Research, p41.

Drugs will not help patients with ASD to "recover" from their ASD. While these patients may benefit from treatment for specific "behavioural abnormalities", mental health practitioners must understand patients with ASD will experience incomplete recovery from the symptoms associated with psychosis due to their ASD.

Few people would be surprised to find that drugs are ineffective in treating people with the same symptoms but who do not have a diagnosis.

### **Treatment Approaches in Autism**

Treatment is multifactorial and relies heavily on educational and behavioral interventions for the autistic child as well as family education. Physical, occupational and speech therapy are also often needed. Pharmacological therapy is used as adjunctive treatment for targeted symptoms that interfere with the autistic person's functioning. The most common targeted symptoms include hyperactivity, impulsivity, aggression toward self/others/property, and interfering repetitive thoughts/behaviors. No available drug treatment is curative in autistic disorder.

• • •

<sup>13</sup> McDougle CJ, Stigler KA and Posey D. Treatment of aggression in children and adolescents with autism and conduct disorder. J Clin Psychiatry 2003;64[suppl 4]:16-25.

See <a href="http://www.bcmhs.bc.ca/pdfs/Inpharmation/2003\_Oct\_Nov\_Autism.pdf">http://www.bcmhs.bc.ca/pdfs/Inpharmation/2003\_Oct\_Nov\_Autism.pdf</a>

So a first step in treating a patient with "incomplete recovery" schizophrenia could be to consider whether the patient has an autism spectrum disorder.

It makes sense, in the presence of ASD, to review a patient's symptoms and outcomes. Subsequent treatment might not rely on a pharmacological approach. Possibly, the patient's treatment should include immediately behavioural and/or psychosocial interventions appropriate for ASD.

Unfortunately, services providing effective and appropriate behavioural and/or psychosocial interventions for ASD are rare or may not exist in Australia.

# Individuality, Diversity, Equality, Achievement

Donna Williams

Auties.org is for people on the Autistic Spectrum who are ready to dare reach out, open the doors to the community and market their abilities directly to the public and for those interested in supporting these pioneers.

So if you are on the Autistic Spectrum and stagnating whilst waiting for society to create something for you, why not go ahead and look at what you CAN do and CAN manage, what you ARE interested in and ARE doing now, and begin creating your own opportunities. Even more, if you haven't got a clue where to start, take a look at what others on the Autistic Spectrum are doing in their own self employment and employable hobbies/skills and see if it inspires you to dare such things with your own unique style, in your own unique way.



All you need is a website or an email and the desire to take that leap. They say the greatest risk in life is taking no risks at all.

Auties.org has two sides to it, the entrepreneurial/self-employment/work-seeking side, and the 'autie-friendly' establishments side where you can check out all kinds of places, spaces, faces and activities that are advertising themselves for one reason or another as 'autie-friendly'... who knows they might even respect us enough to give us jobs if they have any! From accommodation and eating spaces, to entertainments, travel, social opportunities, goods and therapies, we hope, in time you may find these things here.

By using Auties.org and Autie-Friendly establishments you are supporting a vision of equality regardless of difference, celebration of diversity, ability within disABILITY, and of active empowerment of one of the most disempowered and also underemployed communities in society.

http://www.auties.org/home.0.html

### **Letters / Emails**

Please send letters to <a href="mailto:edit@a4.org.au">edit@a4.org.au</a>. Letters sent to the editor may be published unless they are clearly marked "not for publication". Normally, they will appear with your full name and state unless you mark them clearly "anonymous" or "first name only".

In the next two editions we are looking for articles and letters on:

- Respite
- Challenging/problem behaviour

# **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.

Update team: edit@a4.org.au

Editing team: Vicki McKay & Juanita

Dawson

Reporting team: we currently have vacancies

in all states

Production team:

Helen Curtin – proof-reading (Qld), Bob Buckley – distribution (ACT).

### Steering Committee

**A4 Convenor**: Bob Buckley, ACT convenor@a4.org.au

**Treasurer** (donations): Cathy Ryan, Vic. treasurer@a4.org.au

#### **Members:**

Alistair Campbell, Dr Andrew Brien, Geraldine Robertson, Dr Guy Hibbins, Judy Brewer Fischer, Karen Mackie, Kelley Harris, Lionel Evans, Mary Gebert, Meredith Ward, Michael Miles, Paul Davies, Stephen Courbet, Vern Hughes, Wendy Kiefel

