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Inclusion debate continues

Bob Buckley

Recent news reports in Britain show that the Inclusion debate has reactivated. An article in The Guardian (see <http://education.guardian.co.uk/schools/story/0,5500,1517312,00.html>) says ...

Baroness Warnock, who chaired an inquiry into the education of "handicapped" children in the 1970s, will today call for a new inquiry into how best to provide for pupils with a range of learning difficulties ranging from dyslexia to autism.

She will suggest that rather than teaching all children in mainstream schools, more special schools should be established.

Her apparent u-turn on inclusion has drawn fire from charities representing children with special educational needs, which have accused her of betraying the principals of promoting tolerance through teaching all pupils together.

...

She goes on to argue that the "worthy ideal" of inclusion can be "carried too far".

"Children are also different, and it is essential to acknowledge this, since refusal to address genuine differences can wholly undermine our attempts to meet children's needs. This, I believe, is what we are seeing today, and the way forward is for the government to set up another commission to review the situation."

And she suggests that new special schools should be set up to make pupils who struggle in mainstream school, such as those with autism, feel at home.

There are a number of links to "Related Articles" at the end. For example, the Ofsted Report¹ subtitled Special educational needs and disability: towards inclusive schools, in its main findings says:

- Most mainstream schools are now committed to meeting special needs. A few are happy to admit pupils with complex needs. The admission and retention of pupils with social and behavioural difficulties continue to test the inclusion policy.
- A minority of mainstream schools meets special needs very well, and others are becoming better at doing so. High expectations, effective whole-school planning seen through by committed managers, close attention on the part of skilled teachers and support staff, and rigorous evaluation remain the keys to effective practice.

...

¹ The Ofsted Report can be downloaded from <http://image.guardian.co.uk/sys-files/Education/documents/2004/10/12/Ofsted.pdf> or <http://www.ofsted.gov.uk/publications/index.cfm?fuseaction=pubs.displayfile&iid=3737&type=pdf>

- Effective partnership work between mainstream schools and special schools on curriculum and teaching is the exception rather than the rule.
- Over half the schools visited had no disability access plans and, of those plans that did exist, the majority focused only on accommodation.

There has been no such review of Australian schools ... but discussions with teachers and parents who have been recently immersed in the UK system indicate the situation in Australia is no better than in the United Kingdom. Children with high and/or complex education needs cannot wait while deficits in mainstream education settings are rectified. Particularly, given how long it has taken already ... there has to be significant doubt that the required standard can ever be achieved.

Choosing the “right” setting for a child with ASD can be incredibly difficult. Generally, it seems best to aim for a “least restrictive setting”. But major deficiencies in all the available settings make the basis for choice depend most on the individuals involved. The quality of your child’s education depends on your input.

Convenor’s message

Dear A4 member,

Thanks for the positive response to the last Update and the national forum.

Congratulation to Caroline Franks for completing her petition that asks for a National Autism Register and DNA Database. And let me also thank all those who supported this project. See Caroline’s letter below.

The May 2005 Update #4 mentioned Peter Hill’s project to raise funds for autism/ASD research. This project needs support from people all over the country. Please join in if you possibly can. There is more on this below.

We need help with the A4 Updates. We didn’t get much information on Autism Awareness Week from the states and the regions.

We’d really appreciate some help from people in getting information together for the Update. It would be great if someone in each state would download their state budget papers and write a short article on what they got in their state budget for autism in their 2005-06 budgets. Huge thanks to Soraya for collecting all the Victorian Hansard references to autism. You can download her collection from www.a4.org.au/documents/Hansard-Victoria.doc .

The March 2005 Update #3 mentioned that A4 was preparing a submission to the [Inquiry into Teacher Education](#), conducted by [Standing Committee on Education and Vocational Training](#) ... The Committee published A4’s submission on its website at <http://www.aph.gov.au/house/committee/evt/teachereduc/subs/sub115.pdf>. Please take a look if you are interested. You can download other submissions from the Committee webpage to see what they say about teacher education in general.

If you support what A4 says in our submission to the Committee, you can send a short email or fax saying something like “I am disappointed with the education provided in <your state> for my child who has an Autism Spectrum Disorder. I read Submission 115 and endorse what Autism Aspergers Advocacy Australia (A4) says.” The Committee can be reached at ...

Committee Secretary
 Standing Committee on Education and Vocational Training
 House of Representatives
 Parliament House
 CANBERRA ACT 2600

Phone: 61 2 6277 4573

Fax: 61 2 6277 4427

Email: evt.reps@aph.gov.au

This is a broad-ranging inquiry so we need to cut through all the other issues to make an impact. Every voice helps.

Regards,
Bob Buckley
3rd June 2005

The Clinician: coming edition on ASD

Several A4 members wrote asking about the progress of this publication (see <http://www.camhsnet.org/editLevel3.asp?subsectionID=26&SectionID=7&SectionName=Publications&SubSectionTitle=The+Clinician> for previous issues).

A4 contacted the publishers of The Clinician on 8/7/2005. They told us that the edition on Autism or ASD "is in the final stages of editing ... we are not sure when it will be going to print". We will try to let you know of any developments when we hear more.

Lists of Recognized Disabilities

Roger Barson, FaCS Branch Manager for Disability and Carers Branch, wrote to A4 on the 8th June 2005. He thanked us for our submission to the Review of the Carer Allowance (child) Lists of Recognised Disabilities. He said "It was determined that Autism and Aspergers Disorder did meet the criteria and have been included on the Lists of Recognised Disabilities when diagnosed by a psychiatrist, developmental paediatrician, or a psychologist experienced in the assessment of Pervasive Developmental Disorders using the current Diagnostic and Statistical Manual of Mental Disorders. Pervasive Developmental Disorder (not otherwise specified) is not included as the condition was deemed to be variable in its effects and therefore did not meet the criteria for inclusion."

He points out that the carer of a child with PDD-NOS may still be eligible through an assessment using the Child Disability Assessment Tool (CDAT).

The Lists include Rett's syndrome (in 4. Chromosomal or syndromic conditions ...) and Child Disintegrative Disorder (12... diagnosed by a psychiatrist using the current DSM).

He says "The amendments to the Lists of Recognised Disabilities will be introduced on 1 July 2005".

Please let us know if you have any trouble having CentreLink recognise Aspergers Disorder from the Lists for Carer Allowance (child) now that 1 July 2005 has passed.

Fundraising for Research

Peter Hill, a member of A4, started a project to raise funds for autism research. Rotary will double the funds contributed to the project.

Please join in this project if you possibly can. Could you contact a Rotary Club in your area and make a simple presentation about autism? Peter will provide you with information and help on how to do it. For most of you, this is something you can do relatively easily. Rotary Clubs are very sympathetic and supportive. They want to hear what you have to say and are keen to help. Peter has prepared the material so you have relatively little preparation to do.

As well as possibly raising funds for research, this project increases community awareness of autism and ASD. You may get some community contacts and local support. All you need to do is:

1. Contact a Rotary Club in your area. *This may be the hardest part.*
2. Ask the relevant person (the President, Secretary or Program Organizer) to let you talk to the club about autism and the research funding project.
3. Get the presentation materials from Peter Hill and prepare for your talk.

4. Deliver your talk (if you are naturally shy, expect to be nervous but remember the audience wants to hear you and are sympathetic).
5. Follow up to see how it went and whether they will contribute anything. They may also offer help for local support groups.

Please check out the website (<http://www.a4.org.au/research>) and take a look at the materials.

Give it a go. Our kids can't afford to wait for governments. They depend on us for a better future.

Petition Outcome

For all those people (704 of you) who signed the autism petition for a National Autism Register and Voluntary DNA Database, here is some news.

The petition has gone from Tony Abbott's office to Christopher Pine, Parliamentary Secretary for the Department of Health & Aging. His office rang me today and said that on Thursday 2nd June, Tony Abbott will be talking about the petition in the House of Representatives. The discussion will be going into Hansard records and within 24hours will be available on the Parliamentary internet site.

Frankly I don't expect much given the appalling low amount of resources and funding currently available for families with any disabled member but I am trying to remain optimistic. Please keep your fingers crossed that our pleas for help will be heard and answered with action and most importantly, funding for that action.

Thank you again for signing the petition and for the many heart felt and detailed suggestions that you filled in the comments section of the petition.

Yours sincerely, Caroline Franks

Page 82 of the House Hansard for June 2 shows:

DOCUMENTS

Mr. ABBOTT (Warringah—Leader of the House) (3.06 pm)—I present documents on the following subjects, being petitions which are not in accordance with the standing and sessional orders of the House.

...

Seeking a national registry and data base for sufferers of autism—from the member for Sturt—700 Petitioners

Autism research in Australia

The government has mentioned the total funding for autism-related research it supports in press releases and questions in parliament. The figure is the level of funding that the National Health and Medical Research Council (NHMRC) provided in various years.

There are two aspects to research. Firstly, we need to get people to develop research ideas. This may be the major problem in Australia. We need to get more researchers thinking about autism/ASD research.

Then the researchers need to apply for funding.

Finally, the funds need to be available. The indications are that NHMRC will fund good autism/ASD research. More good research proposals are needed.

Does A4 have a role in this? Can we promote autism/ASD research to relevant academics and other researchers? Should we do this? If so, how can we do this effectively?

The amounts for various projects in recent years are shown in the following table:

Grant Id	CIA	2000	2001	2002	2003	2004	2005
987570	Dr C Ellaway	\$12,850					
991230	A/Pr J Hallmayer	\$122,681	\$148,679	\$6,630			
113844	Prof S L Einfeld	\$150,000	\$150,420	\$158,556	\$158,556	\$144,258	
124303	Prof B J Tonge	\$94,043	\$102,020	\$109,611			
141107	Prof M J Dyck		\$60,190	\$97,914	\$105,207		
185202	Prof J Christodoulou			\$145,770	\$145,770	\$145,770	
194238	Prof B J Tonge			\$65,220	\$55,000		
206522	Mr. G J Pelka			\$19,214	\$64,239	\$10,158	
211058	A/Pr E Whitelaw			\$101,100	\$95,990	\$95,990	
236834	Prof B J Tonge				\$92,750	\$87,750	\$87,750
268905	Dr S El-Osta					\$84,750	\$84,750
284303	Prof B J Tonge					\$145,500	\$145,500
303189	Dr H Leonard					\$157,550	\$45,000
346603	Prof J Christodoulou						\$156,250
		\$379,574	\$461,309	\$704,015	\$717,512	\$871,726	\$519,250

Grant Id	CIA	Simplified Title	Admin Institution
987570	Dr Carolyn Ellaway	Rett syndrome diagnostic evaluation and therapeutic strategies	The Children's Hospital at Westmead
991230	A/Pr J F Hallmayer	Identifying a genetic marker of autism	University of Western Australia
113844	Prof Stewart L Einfeld	BEHAVIOUR PROBLEMS OF YOUNG PEOPLE WITH INTELLECTUAL DISABILITIES	University of New South Wales
124303	Prof Bruce J Tonge	Helping parents manage their child with autism	Monash University
141107	Prof Murray J Dyck	Understanding the patterns of ability deficits that define different developmental disorders	Curtin University of Technology
185202	Prof J Christodoulou	Understanding the Biology of Rett Syndrome	Children's Medical Research Institute
194238	Prof Bruce J Tonge	Motor functioning in autism and Aspergers disorder	Monash University
206522	Mr. Gregory J Pelka	Development of mouse models of Rett syndrome	University of Sydney
211058	A/Pr Emma Whitelaw	Understanding phenotypic variation which is not caused by genetic or environmental factors	University of Sydney
236834	Prof Bruce J Tonge	Identifying children with autism as early as possible	Monash University
268905	Dr Sam El-Osta	Chromatin and transcription	Baker Heart Research Institute

284303	Prof Bruce J Tonge	Education and training for parents of adolescents with autism	Monash University
303189	Dr Helen Leonard	Investigating the burden for girls and their families in Rett syndrome, a severe neurological disorder	University of Western Australia
346603	Prof J Christodoulou	STK9, a new gene that can cause Rett syndrome	The Children's Hospital at Westmead

The NHMRC is not funding a lot of research into autism or Aspergers Disorder. Rett's Syndrome currently receives quite a bit of research attention. Some of the research listed is not especially related to autism/ASD (e.g. 113844, 141107, 211058 and 268905). There may be some autism research funded through ARC Grants and much smaller projects from University internal funding.

Accommodation and Teaching Facility for Adults with Aspergers Syndrome

I am looking for people who would be interested in forming a group to push the government to establish an accommodation and teaching facility for adults with Aspergers Syndrome. It would be based on a service which has been operating successfully for many years in England. Please see www.nas.org.uk/hayes

This unit is an alternative for people who have been in trouble with the law and face going to gaol. As we know, people with ASD need intensive autism-specific treatment for their condition, which they will not receive in gaol.

I live in the Coffs Harbour area in NSW and we have a son living in Newcastle, so for ease of meeting if you live anywhere between these areas it may be easier, but with e-mail communication maybe it doesn't matter.

Robyn Kirkwood
sweetpea.woopi@aaccess.net
 02 6654 7099

Letters

Dear Bob,

Thanks for your comprehensive update on the forum. I am pleased to hear that A4 is doing so much as I feel some state organisations are not.

I have been through early intervention for one of my girls — I have 3, 2 with high functioning ASD/Aspergers syndrome — and I agree it is sadly lacking. I was appalled by what we received as I have a health professional background (OT), not in paediatrics mind, but to not be offered any individual therapy was unthinkable. We accessed what we could afford privately.

My oldest daughter was not diagnosed until she was at school and I would like to know what lobbying is being done for those on the higher functioning end who may not necessarily be diagnosed before school age.

The education dept in Victoria certainly doesn't want to be responsible and I have had to fight hard to get funding. How that is being used is another matter. There should be much greater accountability placed on to schools to demonstrate that our hard won funding is being used appropriately instead of the advocacy being left to the exhausted parent once again!!!!!!!

These are some of the issues I see need addressing:

- Clear guidelines for allocating funds for those on the higher functioning end of the spectrum that do not fit into the current system but are still being denied access to an education.
- Equitable resources for teachers within state education departments across the nation. I am aware that some states have Autism units to consult with teachers. In Victoria, apart from a few Autism schools, the resources for mainstream education are extremely poor for students with Autism.
- What about some performance standards for teachers who have a child with ASD in their classroom. It would be great to know that they were expected to undertake some kind of professional development to be accredited to do this? There are some amazing teachers who are doing great things without training and resources but I think we can do better.
- Accountability for how funds allocated to a child are spent. As far as I can see, if funds are obtained in Victoria, a school does not have to account for what they do with it. I have known of cases where children with other disorders have died and the school did not then have to return the funds to be reallocated and no one came asking. Likewise when a family has relocated for 6-9 months. The schools consider this extended leave and keep the money to prop up inadequate budgets. Not fair in either case. There does not need to be a formula for how funds are spent, just someone other than a parent, that a school has to be accountable to after they have written an IEP. I would not like to see a formula because the needs of each student can be so different. I currently have some skilled professionals who advise the school but should any teacher wish, they are free to disregard anything that is suggested without discussion and there is not much a parent can do about it. Perhaps classroom observation could be part of an accountability/auditing process.
- Integration assistants - I see they did crop up in your discussion as being underpaid and unskilled. There was no mention of downright inappropriate or detrimental to the student. I have experienced this and had to write to the school to request that they do not act inappropriately. If they continue to, there is not much I can do in terms of anyone having to be accountable. It comes back to me advocating once again. There is no clear appeal process. Fortunately for me, I have a great state MP who is very supportive and understands the complex issues involved.

Keep up the good work and I hope some of this is useful.

Yours Sincerely,
Kaye Shanks - 1/7/2005

Convenor's response

Hi Kaye

Thanks for your feedback. It is great for all those involved to be acknowledged and appreciated. In Victoria, you have some great advocates working at the state level: at least in that respect you are much better off than most other states. Getting the message out to the wider community takes considerable effort on the part of an organisation. For example, writing the description of the national forum was a major task that took a couple of weeks of my effort. But communication with members is crucial to the success of an organisation. Members must know and support what an organisation does. State organisations could do more to tell everyone what they do.

Yes, A4 is very concerned about education issues, too. Some of what we said on this subject appears in A4's submission to the federal government's Inquiry into Teacher Training (see the information in the Convenor's Message).

A4's Submission does not cover all the issues you raise. Education, especially inclusion, is an emotive issue. Expect to hear a lot more about it from A4 in the near future.

A4 could collect advice and suggestions from parents on how to improve education for children with ASD in each type of setting, and at all levels of functioning.

You raise the issue of resource allocation and accountability. While systems vary between states, this is a common problem. In Victoria, Families in Partnership have created a scheme where families can manage some of their support funds. I suggest you contact their **Integration Funding in Schools - Family Control of Funds** scheme (see <http://www.partnerships.org.au/FIP.htm> or contact Vern Hughes on 03 9326 4481 or vern@partnerships.org.au). In the ACT, resource allocation in Education is completely opaque and the system is designed to ensure accountability is impossible. The Minister refuses to acknowledge parent concerns over the issue.

I am keen to see A4 develop firm positions on education for students with ASD. This is a big task and could draw on the knowledge, experience, support and inspiration of lots of our members. I need help getting this project going. Even constructing a plan is a major undertaking. This has to be one of our highest priorities.

Again, thanks for your input.

Best regards,
Bob Buckley - 8/7/2005

Southern Suburbs Autism Support Group

***In conjunction with Sutherland Shire Learning Difficulties Support Group Inc.
Autism and Aspergers Syndrome Information Forum and Expo***

Wednesday 10th August 2005

9.30am - 4.00pm (*registration from 8.45am*)

Sutherland United Services Club - 7 East Parade, Sutherland

Registration: \$15 members ~ \$20 non-members ~ concessions available ~

Special Guest Speaker: Wendy Lawson Bss, Bsw(Hons), GDip(Psychstud), GDip(Psychology)

Enquiries and requests for registration forms to SSLDSG on 9545 1505 or email to autismgroup@optusnet.com.au

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