

March 2005

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Falling between the cracks

By Julie Robotham

March 12, 2005

When parents can no longer afford private treatment, or a child's difficulties are so complex they may require a team of specialists to nut out a solution, the public system is the backstop.

There, where children's development problems are most extreme and they stand to gain most from intervention, the limited services available to help them are stretched further than ever before.

"There has been an attenuation of resources ... the system is unethical," says Dr Clare Cunningham, the director of the Tumbatin developmental clinic and the learning difficulties clinic at Sydney Children's Hospital in Randwick.

In the late 1980s, Cunningham was involved in a NSW pilot program to screen preschool children for developmental delays. But it was abandoned because there were not enough speech pathologists to treat the number of language problems identified; a central tenet of medical practice is that you should not screen for conditions that you cannot treat.

And yet, says Cunningham, more than a decade later the children with the greatest need still wait longest for assessment or treatment. "In the public sector they're waiting 12, 24, 36 months [for speech pathology]. By the time their turn comes up they're about to go to school and the service says, 'We don't see school-aged children.'"

"There's a big push for the early identification of autism," she continues. "What is the point of diagnosing autism in an 18-month-old when they're not going to get services until they're three?"

Children whose development is at the margins of expected norms are even further disenfranchised. Until they fail in a more spectacular fashion, they receive no extra resources.

"People are talking about how many children are leaving school with low literacy skills. But they entered school with low literacy skills," Cunningham says. Reading recovery programs - the education system's solution to getting six-year-olds' literacy back on track, may just defer the inevitable. "There is always going to be a group of children with a true reading disability who are going to need ongoing support," she says.

With intensive support, Cunningham says, "slow learners can also acquire good literacy skills." But in a competitive and individualistic world, children who fall through the academic cracks attract little sympathy. "Many of these problems are organically based. But there's a lot of blaming of the child, and blaming of the teachers." And the standard advice - to read to children each night to foster an interest in the printed word - is like asking parents to fly to Mars if they themselves have barely learned to read.

On the other side of the city, at the Children's Hospital at Westmead, Dr Paul Hutchins is suffering similar frustrations.

"The system that provides help demands a diagnosis to divide up the dollars," says Hutchins, the head of the hospital's child development unit. "If you have a diagnosis of [Asperger's syndrome] you get three hours' help rather than 30 minutes."

The problem is that the degree of disability and distress that a child suffers rarely correlates directly with a diagnostic label. "Most social impairments are determined by society's demands and lack of understanding. It matters, it messes your life up," Hutchins says.

One in 10 people with autism will eventually do well enough to live independently as adults, Hutchins says. But that presents another dilemma: "If I undiagnose their autism they will lose their support at school," he says. "A pre-schooler with autism needs 15 hours of autism-specific intervention [a week]. You're very lucky to get two to three hours."

Community health centres, which are supposed to manage the complex care needs for people in their local areas, are often unable to bring together the necessary skills.

"Yesterday a child was seen here by four professionals who cumulatively have 100 years of child development experience," says Hutchins. "That team assessment would cost \$2000 [if done privately]. In reality we're having to do a lot of that work in a tertiary centre."

Convenor's message

Dear A4 member

We have some very good news.

Aspergers syndrome has been added to the FaCS List of Recognised Disabilities for Carer Allowance. I am proud to point out that A4 played its part in the process. More on this appears elsewhere in this Update.

Early in February, I met with Tony Abbott MP, federal Minister for Health and Ageing. The meeting resulted from the work in 2004 of the A4 policy group asking the Minister for a summit or conference to develop plans for treatment and therapy services for young children with autism spectrum disorders.

The letter/email appearing elsewhere in this newsletter shows the Minister agreed to try and hold a "stakeholder conference" to develop a federal position on health issues relating to ASD in early childhood. We will let you know what happens next.

We continue to remind the government that their so called Medicare Safety Net is no such thing for families who need intensive early intervention, therapy or treatment.

The government is changing arrangements for the Disability Support Pension (DSP). Many people with ASD depend on the DSP once they leave school. The Australian Federation of Disability Organisations (see www.afdo.org.au) organised a forum on the issue.

Two A4 Steering Committee members, Geraldine Robertson and Vern Hughes, attended the forum on A4's behalf. A4 owes them HUGE thanks for representing A4 and ASD. When the organisers spoke after the forum — they expressed their appreciation for A4's presence at the forum.

More than 30 disability, welfare and employment services agencies (is A4 any of these?) attended the People with Disability: Participation & Payments Forum held in Melbourne on Thursday, 3 February to consider options for the reform of income support and employment policies for people with disability and ways that the community sector can contribute to it. Documents relating to the forum can be downloaded from links on the web page www.afdo.org.au/People%20with%20Disabilities:%20Participation%20&%20Payments%20Forum.

Following the forum, A4 was invited to contribute to consultation with the Department of Employment and Workplace Relations (DEWR) about proposed changes to the DSP. Please send your concerns about the proposed changes to convenor@a4.org.au. And if you can, please also write directly to government.

Now my bit of self-indulgence ... Recently my work involved me in some bioinformatics research. One thing led to another and the John Curtin School of Medicine at the ANU invited me to join them as a Visiting Fellow. I accepted. And I will use every chance I get to raise autism awareness with medical researchers.

Finally, let me write a big **THANK YOU** to the people who send us supportive and encouraging emails. It helps a lot to know our efforts are appreciated. I have a small request ... please send your accolades and feedback about the A4 Updates directly to the A4 Update editor; use the address edit@a4.org.au rather than emailing me or the membership address. My role in the A4 Updates is limited. I just write my message for each update and whatever other articles I can manage. Anita Harvey, our hardworking editor, and her team produce the newsletter. They deserve the credit for their A4 Updates.

Regards

Bob Buckley — A4 Convenor

State News

Queensland

HAVE YOUR SAY: on improving disability services in Queensland

The period of community consultation has commenced!

Did you know that you are invited to participate and contribute your views?

Please circulate this information to as many parents of people with a disability, and to those people with a disability who are able to speak for themselves. Thankyou!

Dept of Communities (Qld) are facilitating the "**Have Your Say: On improving disability services in Qld**" process.

<http://www.communities.qld.gov.au/community/disabilityconsultation/>

Your Regional Disability Councils (RDC) (10 in Qld) are involved. Check the website out to see who is in your local area to find out how they can assist you in having your say.

<http://www.communities.qld.gov.au/community/disabilitycouncils/rdc/members.html>

Information from the small DL flyer (DSQ & Dept of Communities) says:

The Qld Government wants to hear what you think on proposed improvements to:

- Assessment
- Prioritisation
- Services
- funding.

Get involved - you choose how:

- complete the discussion paper response booklet (blue cover booklet)
- provide your feedback to a person who will represent our views
- participate online: www.getinvolved.qld.gov.au

Alternate format discussion papers are available.

Find out more:

- Ph 1800 102 225
- Ph DIAL 1800 177 120 or 1800 010 222 (TTY)
- download a discussion paper at www.communities.qld.gov.au

You can provide comments and feedback up until 15 April 2005.

And

There are many other ways you can provide your feedback. You can:

- <http://www.communities.qld.gov.au/community/disabilityconsultation/response/index.html>
- download a full version of the [discussion paper](#)
- access a [response booklet](#) to record your feedback
- write down your feedback in the [response booklet](#) and send your booklet to:
Department of Communities
Disability Engagement Project
GPO Box 806
BRISBANE QLD 4001
- email your feedback to disability.engagement@communities.qld.gov.au
- respond to the questions online via the [ConsultQLD website](#):
<http://www.getinvolved.qld.gov.au/consultqld/index.cfm?go=consultonline.viewIssue&issueID=83>
- fax your feedback to 07 3239 3678
- telephone the 1800 102 225 number on 13, 14 or 15 April 2005 and speak directly with a person from the Department of Communities who will record your views
- provide your feedback to a person or group who can represent your views

Another way that is also being used is a community forum process facilitated by the Dept of Communities. These meetings will be small to enable people to voice their ideas, concerns and any solutions. Who attends these meetings I am unable to clarify, but it would be important that there be a range of people who can collectively represent the broad issues of families - not just service providers doing it for us. Support groups and other parent groups may like to check with their local RDC members to find out how to attend such face-to-face gatherings.

To contribute your own personal information to the "Have Your Say..." your best way is to complete the booklet, either completing it online, downloading it, or having it sent to you.

If the government is to hear about our needs in the area of Autism-Aspergers, then we have to contribute in whatever way we can as a community. Please share this with other parents, parent-groups, your school community, and other families with people with disabilities, and of course with the people who have a disability.

Finally, together we can make a difference in the lives of people with Autism-Aspergers.

Cheers,

Helen Steinhardt
Secretary/Coordinator
Gold Coast ASD Support Group
[AH] 5578 3558 [M] 0417 700190
[Gold Coast Regional Disability Council member]

National News

Disability Support Pensions (DSP) the facts revealed

The Australian Council of Social Service (ACOSS) today released new research about the Disability Support Pension in order to counter misinformation in public debate.

"Many arguments used to justify a crackdown on disability pensions are false or misleading. It's not true that 'it's easy to get the DSP' or that 'governments put people on DSP to hide unemployment,'" said ACOSS President Andrew McCallum. "This research outlines the facts of who is on the DSP and why."

Findings revealed in *Ten Myths & Facts about the Disability Support Pension* (downloadable from www.acoss.org.au) include:

- Most Australians do not support a tough approach to people on DSP. A recent survey found that half felt it was reasonable to ask DSP recipients to retrain, participate in their community or improve their literacy skills but 2/3rds did not support requirements for people with disabilities to look for work. 75% did not support requirements for people with disabilities to participate in Work for the Dole.
- It's not easy to get the DSP. Recipients must have a serious medical condition independently assessed by doctors and vocational experts. The condition must prevent them within the next two years from working 30 hours a week or more.
- Disabilities of people on DSP are more diverse and serious than 'sore backs'. 33% of people on DSP have musculo-skeletal disabilities (loss of mobility & limbs), 25% have psychological & psychiatric conditions, and 11% have intellectual & learning disabilities, 5% circulatory system problems and 21% other conditions. The doubling of the number of DSP recipients over the past 15 years is due to:
 - Increased recognition of disabilities in society. The ABS estimates that the number of Australians of workforce age with a "core activity restriction" rose from 1.2 million in 1988 to 1.5 million in 1998.
 - Improved identification of disabilities such as mental illness and lower mortality rates after accidents account for this increase. The strongest growth was in severe and profound disabilities.
 - The closure of payments and pensions to older women. The fastest growing category of DSP recipients is not older men but mature aged women. The closure of payments such as the Wife Pension, Widow's Pension and the Age Pension for women 60-65 years old means that more women with disabilities applied for the DSP.
 - The decline in of number of low-skilled full time jobs and lack of employer support for people with disabilities. In the 1990s, all growth in fulltime permanent jobs was in higher skilled employment when people with disabilities on average have a low level of skills.

Ten Myths & Facts about the Disability Support Pension can be downloaded from: www.acoss.org.au

Family slams lack of care

By Natasha Wallace - SMH April 5, 2005

The day Craig Dawes discovered his wife had killed their severely autistic 10-year-old son Jason, he stood in the street outside their home and shouted repeatedly that the family had never got any government help.

It was a tragic end to a bitter and seemingly fruitless battle that he and his wife, Daniela Dawes, had fought with three state departments for eight years.

The family's cries for help were indeed loud, constant and far-reaching, a court heard yesterday.

Mrs Dawes, 40, had previously threatened in front of her teenage daughter to relieve the family of the "burden" of Jason's disability, and there had been notifications to the Department of Community Services for 10 years documenting domestic violence and severe depression in both parents, Ballina Coroner's Court heard.

And on the morning of Jason's death, on August 4, 2003, Mrs Dawes's mother, Carla Rios, contacted police concerned her daughter would harm herself.

But the investigating officer, Sergeant Stephen Dempsey, told the court it was "difficult" to conclude better support services may have saved Jason.

"There are several contributing factors relating to the tragic death of this child," Sergeant Dempsey said. "The family appeared unstable for many years, mainly associated with the mental health issues concerning Craig and Daniela Dawes. It appears to me they never totally accepted Jason's intellectual disabilities ...

"Both parents appeared to have an inability to cope at various stages of Jason's life."

Mrs Dawes admitted to suffocating Jason in their home, then tried to end her own life.

The deputy state coroner, Carl Milovanovich, said he hoped the absence yesterday of DOCS, the Education Department and the Department of Ageing, Disability and Home Care "is not indicative of the disinterest they showed 10 years ago".

The court also heard that it took two years before Jason received a place at Ballina Early Intervention Centre.

Outside court, Mrs Dawes said: "The only way of getting anything is when you're in absolute crisis. Well, how about helping people before they get to that point so that tragedy doesn't occur?"

The inquest continues.

The following is Bob's response to this article

Dear SMH Editor

Thank you for printing the story "Family slams lack of care" (SMH, April 5, 2005).

The investigating Sergeant told the court "It appears to me they never totally accepted Jason's intellectual disabilities ...". Jason was diagnosed with autism, a clinical disorder that requires clinical attention. Autism is not "intellectual disability" although many government representatives such as the Sergeant remain ignorant of the clear distinction between these conditions. Your article shows Jason's mother accepted his autism diagnosis to the extent that she "fought with three state departments for eight years" trying to get effective treatment.

Sergeant Dempsey should investigate whether DOCS, the Education Department and the Department of Ageing, Disability and Home Care accepted Jason's autism diagnosis and, if so, why they failed to offer the clinical attention he needed for his severe disorder. If the Sergeant's job is to investigate Jason's death, he should investigate why the NSW government ignores overwhelming evidence that children with autism need intensive autism-specific treatment for their condition; treatment that few families can provide without assistance and that the state refuses to provide. He should investigate whether Jason's untreated autism could have contributed his parents' mental health issues and family instability ... as it does in all the other families whose children suffer from untreated autism.

A child who is denied treatment for autism can become a burden their family cannot endure. It would be unjust and cruel to blame the family alone if the state failed them completely. The agencies' disinterest in Jason, even now including his premature death, is a complete disgrace. Hopefully the Coroner sees beyond the Sergeant's superficial investigation.

Sincerely,

Bob Buckley, Convenor - Autism Aspergers Advocacy Australia

Folks -

As you all know, the Commonwealth government has a list of recognised disabilities. The "Lists of Recognised Disabilities" identify those disabilities or medical conditions that automatically qualify a carer for payment of Carer Allowance (Child).

The "Lists of Recognised Disabilities" were introduced in 1998 to assess eligibility for Carer Allowance (Child) as part of the Child Disability Assessment Determination.

For some time, the ASD community in Australia has campaigned to have Aspergers' added to this list.

It appears from the Ministers Press Release, that this has now occurred.

See

http://www.facs.gov.au/internet/Minister1.nsf/content/changes_to_the_lists_of_recognised_disabilities_17mar05.htm

The addition of Aspergers to the list a small, but significant victory for our community. I was president of the ACA at the time and so I know the people who worked on the various submissions on this [in no particular order]-

- The ACA Board, most especially Adrian Ford who worked on the ACA's submission and shepherded the submission through the Council
- Autism NSW, especially, Anthony Warren - who wrote a submission and also worked on the ACA submission
- The Autism Association of the ACT which made a submission, and subsequently answered various questions from the Department
- Bob Buckley and A4 - for his work at the time and his continued lobbying on behalf of people on the spectrum.
- Judy Brewer-Fischer who worked so hard to ensure the ASD community's voice was and is heard.

Together these folks have made a significant improvement to the lives of people who have Aspergers and their family. It is a privilege on my part to have been associated with this.

If I might make a suggestion - this announcement of the addition of Aspergers to the list, represents an opportunity to write to the minister thanking her for this move - and gently suggesting one or two other, achievable things.

Well done all and best wishes. I hope to be able to catch up with you all soon.

Andrew.

Media Release

SENATOR THE HON KAY PATTERSON

Minister for Family and Community Services

Minister Assisting the Prime Minister for Women's Issues

Thursday, 17 March 2005

Changes to the Lists of Recognised Disabilities

Parents or carers of children with a disability or medical condition may find it easier to receive the Carer Allowance under changes to the Lists of Recognised Disabilities.

Minister for Family and Community Services, Senator Kay Patterson, announcing the changes, said the revised Lists include a number of new childhood disabilities and medical conditions that automatically qualify for payment of the Carer Allowance.

“A review of the Lists was held to determine whether they were providing a consistent and objective means of assessing eligibility for the Carer Allowance. The Government has adopted most of the recommendations by the independent review panel, which was made up of peak disability and carer organisations and specialists in childhood disability.”

The adopted recommendations included:

- adding some conditions to the Lists such as Asperger’s Disorder and Lamellar ichthyosis;
- modifying the descriptions of some existing conditions;
- developing new categories to simplify the Lists and allowing for the future inclusion of other conditions;
- increasing the flexibility and longevity of the Lists without compromising their integrity; and
- streamlining the assessment process for medical practitioners.

“I will also be seeking further additional expert medical advice regarding Diabetes Mellitus Type 1. I have asked my Department and the Reference Group to explore the prospect of this condition being added to the Lists of Recognised Disabilities in the future,” Senator Patterson said.

“If a child has a disability or medical condition on the Lists their parent or carer can be fast tracked on to Carer Allowance with no need for further medical assessment until the child’s 16th birthday.

“This benefits the customer and the Medical Practitioner as the revised Lists will reduce, in a number of cases, the volume, complexities and length of the Treating Doctors Report.

“These changes follow the recent Budget’s \$461 million increase in assistance for carers over four years in recognition of their important contribution to the community which included a one-off carer bonus and respite measures for both older and young carers. The Howard Government also supported carers by bringing forward the implementation date to extend eligibility of Carer Allowance from 1 April 2005 to 1 September 2004.

“As part of its election commitments the Howard Government will also increase the number of hours that a carer may work or study without losing qualification for Carer Payment, from 20 to 25 hours per week from 1 April 2005.

“The Australian Government’s ongoing programs and budget initiatives will continue to provide support for people with disabilities, their families and others who care for them,” said Senator Patterson.

**Media Contact: Nicole McKechnie, Media Adviser, 0433 219 423
Kate Walshe, Assistant Media Adviser, 0411 472 299**

Emails

Mr Bob Buckley
Convenor Autism Advocacy Australia
By email: convenor@a4.org.au

Dear Bob

It was good to meet you the other day. As discussed, I am keen to facilitate the stakeholder conference you have suggested and am working with officials of my Department to work out the best means of bringing this about.

I'm sorry the election, its aftermath and the Christmas break, delayed our meeting but appreciated hearing your point of view.

With all best wishes.

Yours sincerely,
(SIGNED)
Tony Abbott

Mr Tony Abbott MP
Minister for Health and Ageing
Parliament House

Dear Mr Abbott MP

Thank you for your letter/email (18/2/2005) confirming our meeting and your keen interest in facilitating a stakeholder conference on health services for young children with autism spectrum disorders.

Shortly after our meeting I wrote to Isobel Brown (12/2/2005) asking about progress and offering help. As yet, I have not received a reply.

During a conversation (14/2/2005) with Colleen Krestensen from the Department, we discussed the possibility that her section would be involved in a stakeholder conference. I understand she had been in contact with your office. I offered to brief her and other Department staff on what I could about the background for such a conference. I have not heard back from her yet.

I am keen to progress this matter. I would be happy to help in any way that I can. In particular, I am willing to contribute through:

- a briefing for Health Department staff (and any other interested parties) who would be involved in the proposed conference or might have an interest in issues relating to autism spectrum disorders
- discussion of terms of reference for the proposed conference
- helping identify stakeholders

yours sincerely,
Bob Buckley
Convenor - Autism Aspergers Advocacy Australia (A4)

From: Disability Rights Unit [<mailto:disabdis@humanrights.gov.au>]

Sent: Friday, 4 March 2005 8:39 AM

Subject: HREOC Lists: NATIONAL HUMAN RIGHTS INQUIRY INTO EMPLOYMENT AND DISABILITY

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HREOC Mailing List Service
.....

Disability Rights Update
.....

NATIONAL HUMAN RIGHTS INQUIRY INTO EMPLOYMENT AND DISABILITY
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The Human Rights and Equal Opportunity Commission (HREOC) today launched a national Inquiry into employment for people with disabilities in Australia.

Human Rights Commissioner and Acting Disability Discrimination Commissioner, Dr Sev Ozdowski, said equal opportunity for Australians with disabilities was a fundamental human rights concern as well as being a significant economic issue.

"A range of studies indicate that Australians with disabilities are missing out on opportunities to develop and use their skills and capabilities, and to earn a decent living for themselves and their families," said Dr Ozdowski.

"This national independent Inquiry will look at a broad range of barriers that face people with disabilities in seeking work, and issues for employers in recruiting, retaining or fully utilising employees with disabilities."

The Commissioner welcomed the current debate on how reform of the Disability Support Pension and related programs could contribute to improved employment outcomes, but stressed that this Inquiry was not a substitute for other review processes being conducted by government.

"Evidence suggests that like most other Australians, people with disabilities want to work and earn a good living. But they face barriers - in getting employment or keeping their jobs; physical difficulties; inflexible work practices and attitudes; and economic hurdles," said Commissioner Ozdowski.

"Employers also report that they face barriers - in getting access to information and advice on how to accommodate disability in the workplace; and in getting access to government support to make adjustments."

Around 20% of Australians have some sort of disability.

Only 53% of people with disabilities of working age are in the workforce, compared to 80% for other Australians. They have a higher unemployment rate than other Australian workers (8.6% compared to 5%) and lower incomes.

These numbers have not improved considerably over the last decade - and in some areas have actually got worse.

The Inquiry will seek to consult and cooperate with government agencies, employers, and people with disabilities, community groups, unions and employment service providers to put strategies in place to improve work opportunities for people with disabilities.

The Inquiry is now calling for public submissions and aims to publish its findings and recommendations in November 2005.

.....
Terms of Reference
.....

To:

- (a) Identify existing systemic barriers to equal employment opportunity for people with disabilities;
- (b) Examine data on employment outcomes for people with disabilities including workforce participation, unemployment and income levels; and
- (c) Examine policies, practices, services and special measures implemented to advance equal employment opportunities for people with disabilities.

.....
Further information on the National Inquiry (including a series of Issues Papers) is available online at www.humanrights.gov.au/disability_rights/employment_inquiry.
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World News

A short film on autism has been nominated for an Oscar. It is entitled: "Autism is a World"

FILM SYNOPSIS

Sue has autism. Its causes and cures are unknown. This is a journey inside autism to explain what Sue feels and does, and how she relates to others.
http://oscar.com/nominees/nom_34039.html

Info about the film can be found here: http://www.whittier.edu/Sue_Rubin.htm

25/01/2005

Short documentary about autism nominated for Oscar

LOS ANGELES, USA: The film "Autism Is a World" was nominated on January 24 for an Oscar in the Documentary Short Subject category.

The remarkable film was written by a 26-year-old woman with autism, Sue Rubin. It is narrated by Julianna Margulies and produced and directed by the Oscar-winning filmmaker, Gerardine Wurzburg.

Sue's unusual behaviour led to a diagnosis of autism when she was four. She was believed to be retarded until the age of 13. But then a controversial communication technique gave Sue the ability to connect with the world. Now, she is a junior at Whittier College in California, with a high IQ, works tirelessly as a disabled-rights activist and is an articulate guide into a complex disorder.

Like many people with autism, Sue still does not make eye contact or offer to shake your hand. Instead, she may fixate on the buttons of your shirt.

In "Autism is a World," the audience is lured into an understanding of what Sue feels and does. The film explains how she relates to others, why she clutches spoons or finds comfort in falling water, how she navigates her way through college and copes with the tasks of daily living.

Sue guides us through all that is special, and unusual about her life. From the racetrack, where she goes to unwind, to the classroom, where her intellect shines, from a presentation at an autism conference to the challenges of paying bills or cleaning house or shopping, Sue takes an admirably unflinching look at the world of autism.

The film is co-produced by Professor Douglas Biklen, of Syracuse University, California, who introduced the system known as facilitated communication into the United States from Australia.

"(Rubin) is a very articulate and intelligent person," Biklen said. "She forces us to question physical performance and ideas about smartness."

Wurzburg has said she waited 12 years to make a documentary about autism. During the filming of her Oscar-winning movie, "Educating Peter," Biklen introduced his keyboard-based system which would allow autistic users to communicate effectively. Wurzburg's company, State of the Art Inc., assisted Biklen by producing autism training films.

"What made it possible to make this film was Sue," Wurzburg said. "Many people with autism are now speaking through a keyboard, speaking independently."

Rubin is a history student at Whittier College. Wurzburg said that, although Rubin did not appear intellectually advanced at first glance, she had an IQ of 133. She also said that Rubin had a low IQ until she was introduced to facilitated communication at 13 and began to mature rapidly.

"In this film, you meet a woman who, if you walked into a room, you would think was mentally retarded," Wurzburg said. "She is smarter than (any) of us."

At the age of four, Rubin's parents took her to the University of California at Los Angeles to explore the possibility that she might have autistic tendencies. In fact, it turned out that Rubin was severely autistic.

However, people view her very differently now. "Sue is a very impressive person to get to know," Wurzburg said. "For me getting to know her personally was a transforming experience."

"Autism is a World" examines the complexities of the disorder and explains, quite rightly, that its causes and cures are still unknown. The film aims to show what it has been like for Rubin to go to college and run her own life.

"(Wurzburg) was taken with the Sue Rubin story," Biklen said. "What we really wanted to do was capture aspects of Sue's life and her interpretation on autism. I don't think there has ever been anything quite like it."

According to Biklen, the film was screened in Los Angeles and Vermont with very positive reactions. He said even people who knew nothing about autism had found it very engaging.

"For me, with films it is their ability to affect change," Wurzburg said. "Why waste the money and airtime if you are not moving the issue somewhere?"

Wurzburg won an Oscar in 1992 for her documentary short, "Educating Peter," which featured Peter Gwazdauskas - a young boy with Down's syndrome - and explored the inclusion of children with disabilities in mainstream schools.

(Source: Adam Feinstein, January 25, 2005)

Letters to the Editor/A4

Hello

In its story, "The Hidden Army", the ABC's *4 Corners* recently examined the impact on families and carers of caring for someone with high support needs.

This issue is something that is also of concern to the *National Family Carer's Voice*, a committee established by the Minister for Family and Community Services, Sen. Kay Patterson, to provide advice on issues affecting family carers.

The *National Family Carer's Voice* Issues Paper is now available online at http://abc.net.au/4corners/content/2005/20050328_hidden_army/family_carers_interim_report.pdf

The *National Family Carer's Voice* is keen to hear responses to the Interim Paper. These can be sent directly to the Minister or to one of the committee members for consideration. The *National Family Carer's Voice* contact details are

National Family Carers Voice Secretariat
C/- Disability and Carers Branch
Australian Government Department of Family and Community Services
Box 7788
Canberra Mail Centre ACT 2610
Ph: 1300 653 227
Email: nfcv@facsv.gov.au

I am writing to seek A4's support in a new initiative for parents/carers of children with ASD 0-18 years.

Called "A Recipe for Success", this project is funded by the NSW Dept of Health through the Autism Association's Behaviour Intervention Service to provide parent management training across NSW.

I have attached the project flyer and an expression of interest form for interested parents/carers. At this stage I am trying to develop a database of names so that a calendar of training can be developed. I am hoping that you may be able to put a link to this on your website as well as include it your next newsletter.

Please contact me or our website should you wish further information

Dr. Mark Clayton
Senior Practitioner
Behaviour Intervention Service
Autism Association NSW
PO Box 770 Seven Hills 1730
Ph: 8868-8509/8512 Fx: 9896-5266 Mo:0403-07-8450

http://www.autismnsw.com.au/our%20services/bis_recipeforsuccess.asp

[The information on Mark's flyer is all on the page (link given above) of the Autism NSW website. There is a link on the page for downloading the registration form.]

Hi Mark

I'll pass your material on to our newsletter team. However, I have a personal opinion on this issue that may be published in a coming A4 Update. I've attached a draft version of my article. I am happy to have constructive discussion of this issue.

Regards

Bob Buckley

Bob,

Thank you for your response. I appreciate your views on this matter.

Mark

Parent training versus actual treatment

Bob Buckley, A4 Convenor

18 March 2005

There is an epidemic of state governments catching the "parent training" bug for autism. Victoria and the ACT started down this track some time ago.

Now the New South Wales Health Department together with the Autism Association of NSW are working together on

"an innovative program for helping parents and carers of children with Autism Spectrum Disorder to manage challenging behaviour. The program will teach carers how poor behaviour is developed and maintained and how, by altering some of their own behaviours they can help to improve their child's behaviour."

See http://www.autismnsw.com.au/our%20services/bis_recipeforsuccess.asp

While these programs may be well-intentioned, their justification is unclear and outcomes are unknown. Where is the evidence that most parents do not already do all they can? Parents of children with autism demonstrate their enormous capacity for managing behaviour problems on a daily basis, often well beyond the ability of professionals the child encounters in community and service settings. For example:

families manage young children with autism in the family home when a childcare centre or preschool refuses to accept their untreated autistic behaviour

students with autism who exhibit challenging behaviours at school are sent home where usually their behaviour is managed far more effectively with far fewer staff and much less effort.

respite centres call families for relief from children with autism when it gets too hard

Life with autism for Daniella Dawes was so overwhelming that she took her son's life before trying to take her own. The judge in Regina v Daniella Dawes (District Court File Number 04/21/1041) described the situation facing Daniella Dawes and her son Jason saying ...

The practical reality is that the care in terms of daily responsibility to feed, toilet, bathe, educate, entertain and love fell to his mother

The parent training plan would add the development, provision and management of a complex treatment program for her son to her burden. It can increase the demonstratively overwhelming burden adding specialised treatment for communication, social and behavioural disorders and prevention of challenging behaviours. Parents of children with other clinical disorders are not expected to meet all their clinical needs. Why do Health Departments single out parents of children with autism to bear the unbearable?

Parent training programs:

- provide none of the intensive early intervention and specialised treatment that children need for their autism
- are not identified among best practice in any of the comprehensive research reviews conducted over the last decade
- lack evidence of their effectiveness.

These programs divert crucial professional attention away from much needed clinical work with children. Governments ignore the uniform recommendations of experts and the numerous research reviews, to provide evidence-based autism-specific intensive early intervention and services (except for the very limited support given to the Autism Association of NSW).

Of course parents want to know as much as they can. But this plan burdens parents with an onerous clinical role that few are adequately prepared for. And parents whose children subsequently develop challenging behaviours will be devastated.

Can the people who come up with these ideas reasonably expect parents to do much more? Are they so unaware of what life with autism is usually like? One has to wonder whether they know enough about life with autism to actually help parents.

Proper consultation with the community could have suggested better approaches. There are other options. Perhaps parents with intimate knowledge and close experience of autism could design and run effective information programs for parents of newly diagnosed children.

Children who are diagnosed with autism have a clinical disorder that requires clinical attention. These are their most urgent needs and they are not being met.

In the late 1980s, ... NSW [tried a] pilot program to screen preschool children for developmental delays. But it was abandoned because there were not enough speech pathologists to treat the number of language problems identified; a central tenet of medical practice is that you should not screen for conditions that you cannot treat.

And yet ... more than a decade later the children with the greatest need still wait longest for assessment or treatment. "In the public sector they're waiting 12, 24, 36 months [for speech pathology]. By the time their turn comes up they're about to go to school and the service says, "We don't see school-aged children."

"There's a big push for the early identification of autism," ... "What is the point of diagnosing autism in an 18-month-old when they're not going to get services until they're three?"

...

Community health centres, which are supposed to manage the complex care needs for people in their local areas, are often unable to bring together the necessary skills.

SMH, March 12, 2005, Falling between the cracks

Professionals should focus on providing the intensive and specialised treatment that children who are seriously affected by their autism need to give them their best chance to participate in their community and function independently. They should provide comprehensive case management for families whose support services fail to behave as an effective team.

CONGRATULATIONS A4 MEMBERS AND THANKS!

The response to our call for articles for the special ASD edition of The Clinician magazine has been fantastic. Over twenty A4 members have taken the time to sit down and share their own personal experiences of living with autism – and the stories are exactly what we hoped for. Honest, thoughtful, at times emotional but often also uplifting descriptions of our lives as they really are.

Just as no two people with autism spectrum disorder are alike, no two stories or experiences that we have received are similar or repetitive. Every family has a different story to tell, but sadly, the unifying factor seems to be the lack of understanding from others, and how hard families have had to fight for information, support, appropriate therapies and treatments.

All the submissions are now with the editorial team of The Clinician who are preparing this special magazine for release later in the year. Although we have little influence from this point on, we are very hopeful that many of our stories will be published, alongside contributions from various autism luminaries such as Tony Attwood, Carol Gray, and medical experts from the Westmead Children's Hospital and the John Hunter Hospital.

I am sure that it will be a 'breakthrough' publication in many ways – a true partnership between families and professionals. We will keep you updated as more information comes to hand, and we promise to circulate our stories to you when they are finalised.

On behalf of our families, a special big thank you to our budding authors for rising to this challenge!

Judy Brewer Fischer

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Managing the Social and Emotional Learning Needs of Children with an Autism Spectrum Disorder

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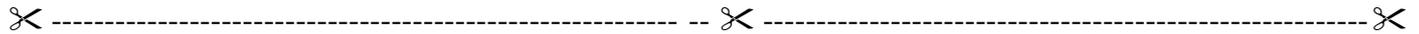
(Morning tea and lunch provided)

For further details and to register, please contact
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