A4 UPDATE
Autism Aspergers Advocacy Australia

May 2005
Issue 4

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Enhanced Primary Care Program

Jo Heard for A4 Update

‘The Enhanced Primary Care (EPC) program was introduced to provide more preventative care for older Australians and improve coordination of care for people with chronic conditions and complex care needs’. The aim of the program is to provide a framework in which a multidisciplinary approach to health can be formulated.

Since July 2004, Medicare enables people with chronic conditions and complex care needs to claim for some allied health services. The claimant must have needs that are being managed by their General Practitioner under an EPC program, formulated for that purpose.

Some of the services that are eligible are Occupational Therapy, Speech Pathology and Physiotherapy. Under the EPC program five services can be rebated at 85 % of the schedule fee in any one year. The Medicare schedule fee for the allied health services is $52.85 – meaning that the benefit works out to be $44.95 for each service (to the maximum 5 per year).

In order to apply for the EPC program, the claimant must liaise with their GP and formulate a case/care plan. There is provision on the form to list all involved professionals such as paediatrician, occupational therapist, speech pathologist, physiotherapist and psychologist (these form the multidisciplinary team). The treatment plan detailed and the form is then sent to all members of the team for approval. The GP needs only to receive two approvals for the EPC to be functional.

The EPC plan (or copy) must then be taken to each of the 5 appointments to be completed by the servicing allied health professional, after which the benefit can be claimed through Medicare.

The EPC program does not provide access to services for many people as the benefit is below 50% of the amount that most allied health professionals charge. It does however enhance access by making 5 sessions more affordable for some.

Autism Spectrum Disorder is a chronic condition and people who are affected have complex care needs. Parents of children with Autism Spectrum Disorder are eligible to apply for the EPC program. It is an option worth considering for those able to afford some of the cost of such treatment.

Convenor's message

Dear A4 member

Please understand that we are not neglecting A4 members. Our recent focus has been on getting submissions from A4 to the Teacher Education, Mental Health and HREOC's employment inquiries in April. Hopefully, the submissions will be posted on the various Inquiry websites in the near future.

A4 welcomes Autism Spectrum Australia (Aspect), a big change in NSW. The former Autism Association renamed itself. It is now called ASPECT and is a service provider. While Aspect is based in NSW, its new constitution lets it operate outside the NSW borders. The creation of a major ASD-specific service provider has enormous potential. Check out their website … www.autismnsw.com.au. Does this leave an opening for an ASD advocacy group in NSW?

Recently, an article in the Medical Journal of Australia said

> "It is now widely accepted that between 15 and 25 hours of specific intervention is adequate, … Services available differ between areas, and in Australia there are no government-funded programs providing the recommended amounts of intervention. There is a need for increased government financial support for early intervention programs."[1]

Actually, the reference given for this information[2] says a minimum of 20 hours is required for children with autism 0–3 years of age. Pat Howlin said 20 hours is required when she last spoke in Melbourne.

The consensus of people expert in educating students with ASD is well known.

> "The [expert] committee recommends that educational services begin as soon as a child is suspected of having an autism spectrum disorder. Those services should include a minimum of 25 hours a week, 12 months a year, in which the child is engaged in systematically planned, and developmentally appropriate educational activity towards identified objectives. … Each child must receive sufficient individualized attention on a daily basis so that adequate implementation of objectives can be carried out effectively."[3]

The recent RHEF broadcast provided valuable information. But Anthony Warren presented and Bruce Tonge endorsed the NSW First Steps program as "an excellent program"[4]. The First Steps program provides just two hours of treatment per week. First Steps has no stated objects, or measured outcomes for children with ASD. The service level is 10% or less of the intervention international experts regard as a minimum for a child with autism.

Do Australian experts tell us that Aussie kids need 10% of a cancer treatment, or 10% of the recommended dose of antibiotics, or a small fraction of the education overseas students need? No, they do not. So why do these professionals suggest Aussie kids with autism be given utterly inadequate treatment?

The RHEF broadcast was critical of parents for getting treatments from the internet that are not evidence based. Yet it endorsed a program that is utterly unsupported by evidence.

Bob Buckley — A4 Convenor

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[1] 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

[2] New York State Department of Health. Clinical practice guideline. Early intervention program: report of the recommendations, autism/pervasive developmental disorders. Assessment and intervention for young children (age 0-3 years). New York: New York State Department of Health, 1999. Available at: www.health.state.ny.us/nysdoh/eip/autism.

[3] National Research Council (2003) *Educating Children with Autism*. Committee on Educational Intervention for Children with Autism, Catherine Lord & James P. McGee, eds. Division of Behavioural and Social Sciences and Education. Washington, DC: National Academy Press, p6. see http://www.nap.edu/openbook/0309072697/html/index.html

4 Open mms://bne002z.webcentral.com.au/bne_sm091/RH/2005/RH502/rh502_lo.wmv with Windows Media Player and move the slider to about 1 hour and 12 minutes into the program.

State News

New South Wales

New Aspect for Autism

Media Release April 7, 2005

Services for people with an Autism Spectrum Disorder took a big step forward today.

On 6 April 2005 at a Special General Meeting of the Autism Association of NSW, the largest autism-specific service provider in Australia, Members approved a new Constitution which, importantly, included a new name for the organisation.

From today, Autism Association of NSW will be known as **Autism Spectrum Australia** (or **Aspect** for short, where the "A" comes from Autism and the "spect" from Spectrum). The new name is very inclusive; acknowledging that autism is on a spectrum and that there is a range of diagnoses that make up the Autism Spectrum including Autistic Disorder, Aspergers Disorder and Atypical Autism.

The new name will build on the organisation's current service provision and give the organisation a voice at the national level, increasing options to seek funding for new programs from the federal government or national corporations. It also provides opportunities for collaborating with organisations to extend services to people with Autism Spectrum Disorders and their families.

According to Peter Werner, Chairman of the Board of Directors of **Autism Spectrum Australia (Aspect)**, "We are a service provider, and the new Constitution will help us do a better job. It says what we have become since being founded 40 years ago, and where we want to go in the future".

"At the same time", continued Mr Werner, "it is important to reassure all the people who currently receive services from the organisation that NSW remains our focus, and that we will continue to look at how we can better meet the need for more services for people with an Autism Spectrum Disorder and their families".

Adrian Ford, the Chief Executive Officer, said: "The new Constitution sets out the reason the organisation exists, which is to *provide services* to individuals with Autism Spectrum Disorders and their families, along with those with related communication disorders. Everything the organisation does relates to these *services*, whether it be actually providing these services, giving information about these services or undertaking research to find out what services work best. The new Constitution and the new name really clarify that the organisation wants to use every opportunity to extend services to people with autism, because the need is so great."

Autism Spectrum Australia (Aspect) currently works with over 6,000 people with an Autism Spectrum Disorder and their families. The latest international prevalence figures suggest that as many as 40,000 people in NSW may be on the Autism Spectrum. Across the whole of Australia that number climbs to 130,000.

Mother abandons son in bid to access respite care.

07/04/2005. ABC News Online

[This is the print version of story http://www.abc.net.au/news/newsitems/200504/s1340500.htm]

A Sydney woman says she abandoned her intellectually-disabled son because she believed it was the only way he would become eligible for care in a state-run group home.

Sue Filacouridis says for the past four years she has been trying to find her 18-year-old son a group home because she is unable to cope with his often violent behaviour.

Ms Filacouridis says last month she did "the unthinkable" - she told police and the Department of Ageing and Disabilities that she was walking away from him.

She says she hoped the move would get him the care he needs.

"I went home and I thought, 'My God what have I done'," she said.

"I just knew I had no other choice.

"I heard years ago that this is what parents did and I was horrified but here I was doing it myself."

Ms Filacouridis says she felt terribly guilty.

"I thought I don't know where he would be put," she said.

New South Wales Opposition Leader John Brodgen has taken up the plight of the family with Premier Bob Carr in Parliament.

Mr Carr says the teenager is currently being looked after in respite care until a more permanent solution is found.

"I'm advised that Andrew's currently in respite care in a group home in Arncliffe," he said.

"The Department of Ageing and Disability and home care is trying to find a more permanent arrangement."

Mr Carr did not respond to accusations that the Government had forced Ms Filacouridis to abandon her child.

National News

Fundraising for ASD research

Congratulations to Peter Hill and the Dapto Rotary Club for their Special Autism Project to fund ASD research.

You can help … in several ways. You can contribute or do some fund-raising.

Please look at the new webpage www.a4.org.au/research for more information.

Inclusive Society

Warning: the following contains information that may depress or annoy some readers.

The story at the following link shows just where we are at in relation to achieving a so-called "inclusive" society.

http://theage.com.au/articles/2005/04/22/1114152321960.html

Luckily, the magistrate in this story had some understanding.

If one believes the story, systems in Victoria that are supposed to support and protect people with a disability failed utterly up to that point. It seems the so-called police "ethics" section condones (and by this account encourages) abuse of people with a disability. The Ombudsman failed in its role.

I see no reason to believe things are significantly different anywhere else in Australia.

The idealism of an inclusive society is as remote as ever. The ideological dogma of inclusion is at least as naive as communism. I remain deeply concerned that such idealism underpins many plans for people with a disability.

Regards
Bob Buckley

Emails to A4 & Editor

Hi Bob,

After quickly reading your comments on the topic of "parent programs" for parent of children with an ASD I would like to discuss this further.

I am involved in running regular 10 week programs. The feedback from all (and I mean all!!) participants has been positive…it's more than just a parent program…I do agree that the focus should be on developing programs for the kids, but why cant you also have programs to support and educate the parents…as a parent of a child with an ASD., I wish I had had access to such a program in the early days after diagnosis…I would like to discuss this further as I think that autism affects the whole family unit and not simply the individual.

Cheers,
Frossa Mrakas
Parent and Project and Development Manager for the ABIA

Hi Frossa

It sounds like your program is precisely what I do advocate. I think it makes sense for parents with the right skills and sufficient experience to help other parents.

My concern is with professionals who abrogate their professional responsibility to supervise a minimum of 20 hours of intervention per week … and seek to transfer their responsibility onto parents. Especially when the program potentially or actually makes parents feel responsible if they do not succeed.

Parents need to be responsible for their children and for doing what they reasonably can do to meet the needs of their children. But some of these new programs get it quite wrong.

For example, I have a letter from the head of Therapy ACT that says their priority is to provide social work because families may breakdown following an ASD diagnosis ... and the breakdown process might prevent or inhibit families from getting their children to therapy services (that don't exist because the chronically limited resources are being used to provide the new program). Frankly, I just can't make sense of their argument. I'm pretty sure it is because the head of the service is a social worker. Where you only have a hammer every problem looks like a nail. If the only staff you can employ and keep is social workers, then you provide a service you can deliver with social workers.

I think we are in agreement on this issue. I don't object to parent training when it is appropriate. I object to parent training when it replaces treatment for children; especial where its purpose is to make parents responsible for providing clinical intervention for their child. Parents of children with cancer are not made responsible for their child's treatment. I know of no other diagnosis where the state places this burden on families. And I don't think parents should be responsible for treating their child, no matter what condition the child has.

I think parents who want to understand and even augment their child's treatment should be helped and even encouraged to do so if the additional resources needed to do this are available. I understand the evidence shows this produces better outcomes for the child.

I'm sorry if I was not clear in what I wrote. And I hope this helps you understand my intention.

Regards
Bob Buckley

Hi Bob

Thought you and A4 community might be interested - 2 US senators are going to announce the following bill to combat Autism (primarily it seems increasing funding of existing programs, including diagnosis and treatment - does Australia have *any* national programs like this to start with?). How is it that the US Government acknowledges and acts on specifically Autism, yet our Governments can't even seem to make the leap of even recognising Autism as a condition separate from generic health classifications, let alone launching a response?

I assume another press release may follow in the next few days.

Cheers
Peter

U.S. Senators Santorum and Dodd to Announce Introduction of the Combating Autism Act of 2005: Combating Autism Through Research, Screening, Intervention and Education

Autism Community Unites to Enact the Legislation During Autism Awareness Month
4/18/2005 12:29:50 PM

WASHINGTON, April 18, 2005 /PRNewswire via COMTEX/

WHAT: U.S. Senators Rick Santorum (R-PA) and Christopher Dodd (D-CT)

- introduce the Combating Autism Act of 2005, which would provide
- for significant increases in and expansion of the federal
- government's funding for Autism:
    - Doubles the number of National Institutes of Health (NIH)
    - Centres of Excellence Programs for research on Autism
    - Expands collaborative National Institute of Child Health
    - programs of Excellence in Autism
    - Funds the Centre for Disease Control epidemiological
    - surveillance programs

  - Significantly increases the resources to provide information,
  - education, early screening, diagnosis and treatment of Autism
  - Establishes environmental health research programs
- National Autism advocacy organizations including Autism Speaks,
- Cure Autism Now, the National Alliance for Autism Research and the
- Autism Society of America will comment on the legislation, offer
- personal perspectives on the importance of the Act and explain why
- it needs to be passed this year.

WHO: *Senators Rick Santorum (R-PA) and Christopher Dodd (D-CT)

- *Bob Wright, Vice-Chairman of GE and Chairman and CEO of NBC
- Universal, and co-founder of Autism Speaks
- *Jonathan Shestack, Founder, Cure Autism Now Foundation
- *Prisca Chen Marvin, Board Chair, National Alliance for Autism
- Research

WHEN: TUESDAY, APRIL 19, 10:45 a.m.
WHERE: DIRKSEN SENATE OFFICE BUILDING, Room 406
SOURCE Cure Autism Now

Linda McGrath, +1-212-541-4814, (on-site) +1-917-536-7184, or Craig Brownstein, +1-202-326-1799, both for Cure Autism Now

Hi Peter,

Damb good issue. Can you get a federal opposition Senator from your state to ask a "question on notice" to the government?

Regards
Bob Buckley

Hi Bob,

Today's Mental Health Forum was very worthwhile. Prof Susan Sawyer of Royal Children's Hospital Adolescent Health is especially worth talking to about early intervention to prevent ASD related mental health problems in adolescence. Bruce Tonge also impressed me and talked about ASD, intellectual disability and parent's depression being easily identifiable risk factors for serious mental health problems in teenagers.

Throughout the day much of the discussion about models of service provision focussed on Schizophrenia. It was interesting that the models discussed all recognise treating the condition according to its severity and recognises the need for health, education and social services not just one service area trying to do everything. There was no ideological to-ing and fro-ing about where schizophrenia "belongs".

That is not to say that we should envy the current standard of care for those with schizophrenia - there are plenty of ghastly parallels with ASD and heartbreaking stories. I do think however, that the ASD community and govt should study the models put forward for schizophrenia.

AMA representatives did not provide any great insights although there was agreement that GP's need better training and need to play a more active role in helping patients with brain related behavioural disorders. We definitely need to raise their awareness and understanding of ASD.

It was also noted that psychiatric patients must not be kept waiting for long periods in hospital emergency waiting rooms as the noise, lights and busy atmosphere exacerbates their crisis. This is a big problem for people with ASD too. It was suggested that psychiatric patients must have a place to wait that affords them more dignity - people with ASD need this too. I hate hospital waiting rooms.

Cheers,
Wendy

PS. I should also have mentioned the unanimous support for professionals to treat carers as a valuable resource rather than keeping them out of treatment/management planning. It was also supported that it is very hurtful and disrespectful to view carers as part of the problem. Networks of self help and support groups were also seen as vital steps to "recovery" for both mental health consumers and carers.

Hi Bob,

Wanted to let you know that I recently wrote to my local newspaper to ask them to do a story on Autism during Autism Awareness Week to try and help promote understanding.

They are going to come out and interview me on Monday and take photos of my son Zac so they can put a story in during the week.

I guess it just goes to show that if everyone wrote a letter to their local newspaper we can only imagine what kind of awareness we might get.

Debra Henry

Bob,

My son's story was published in the Saturday Manly Daily. If you would like to view the story it is also on their website http://www.manlydaily.com.au/

I just wanted to say that I was overwhelmed to see that they considered our story front page news. He got the whole cover as well as a number of additional pieces more specifically related to autism. This paper goes out to around 92,000 people every day and I know from living in the area that most residents read their Saturday paper and everyone looks at the cover story.

I have already seen a difference in people’s response to him just over the weekend while we were shopping and I hope it continues for some time to come. I would encourage everyone to contact their local paper; you just can't buy that kind of exposure.

I hope you like the story,

Debra Henry

Submissions

The Select Committee on Mental Health published many of the submissions it received at:

http://www.aph.gov.au/Senate/committee/mentalhealth_ctte/submissions/sublist.htm

The A4 submission, number 92, is the only one that mentions autism/ASD or Aspergers syndrome. Based on file size, A4's is the second biggest submission (though this may not be a good thing).

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