

AOC 16/7/08
Submission No. 806
(Inq into better support for carers)

02 July 2008

From Daryl & Rosina
Parents / Carers of a 6yo Autistic boy.

To The Secretary of the Committee
Inquiry into better support for carers
fchy.reps@aph.gov.au

Please accept and read our submission : Inquiry into better support for carers

We are South Australian parents of a 6yo non-verbal, severely autistic boy. We would like to advise the inquiry committee on challenges that we have had as well as our expectations with future challenges that we anticipate we will have.

Firstly, we wish to advise the Secretary of the Committee that we would like to participate in the public hearings in Adelaide: Tuesday 12 / Wednesday 13 August 2008 and await a favourable reply to this request.

Enclosures to this submission:-

Page 2 – Summary of Challenges we as parents of an Autistic child face in our daily lives.

Page 3 – Copy of an invoice for services – 45 Minute session of Occupational Therapy (OT)

Page 4 – Copy of an invoice for services – 45 Minute session of Speech Therapy (ST)

Pages 5 & 6 – Copy of a quotation for services – 50 Minute session with a qualified psychologist, familiar with Applied Behavioural Analysis (ABA therapy specifically for treating Autism).

Page 7 & 8 – Summary of the prevalence of autism and how lack of state government forward planning has impacted on carers lives. Some suggestions on how state and federal governments can expedite some of the shortfalls in services and assist carers to have normal and stress free lives without the huge financial burden.

Please be advised that our family like many others do not qualify for the recently announced government funding of \$12000 for autistic children aged six and under that have not begun school yet. This is highly discriminatory. This funding should not necessarily be a blanket amount for all families that have a child with a diagnosis of autism, but should be needs assessed on severity of symptoms and should be monitored to ensure that the money be spent on ABA, ST or OT. Bare in mind, some families have more than one child on the spectrum of varying ages. Many of the families who do not qualify (because of age) have been pleading for therapy and funding help for years. We would like some compensation for the amount of money that we have had to outlay getting our children ready to participate in a special ed. class in a mainstream school. Also, autism and intensive therapy does not stop at age 6. We need ongoing therapy support, if not, financial support to help compensate for caring for a child with a severe autism spectrum disorder.

The committee is welcome to visit our home to see what we do as carers and what it costs us amongst witness all of the day-to-day challenges that living with autism brings.

Thank you for your attention,
Daryl & Rosina
Parents of a 6yo early-onset ASD boy

Page 2 - Summary of some of the Challenges we as parents of an Autistic child face in our daily lives.

- **Stress Issues**
- **Separation issues**
- **Financial issues**
- **Future issues**

Stress

We are forever having feelings of hopelessness and being inadequate. This is due to being left alone with your own child's autism management plan. Besides forever having to nurse a child with a disability, there is the ever wanting the child to progress. We, like many other parent carers have had to resort to being our own case managers, our own practitioners and have had to be totally self-funded to try and make a difference with our children's early-intervention treatment programmes.

Lack of forward planning - local state authorities have left us with 12 month waiting lists, non existing services, inadequate and outdated practices. State run service providers have no or very poor outcomes. Traditional medical practitioners, paediatricians and state run Children's hospitals are not up-skilled with autism treatment trends and are not willing to research new treatment modalities leaving parents to investigate their own early-intervention treatments and use of overseas medical treatment centres and labs. See below for the costs involved with trying to improve a severely autistic child's future outcome.

Separation issues

Single income parent carers of autistic kids know that their children are so vulnerable to the elements. It is extremely distressing to have to go to work every day and have at the back of your mind.... Is your child safe at school?... Are they going to be able to make a difference with his cognition? The teacher has left the door open again!....Will he wonder off again.... Should I turn back and go and close the side door...Can we leave him with this respite worker?. Amongst many other issues like toileting and bullying, etc.

Financial issues

Up to now, the federal government has only funded (by virtue of the EPC), 5 visits to an allied health practitioner such as a Speech Pathologist and an Occupational therapist as well as 12 visits to a psychologist (MHCP) per child per calendar year. As of 01 July 08 there is an additional 20 visits to allied health professionals per child for their entire lifetime. This is still, way too inadequate as many severely autistic children such as our own son require **at least 20 hours a week** of a mix of Occupational Therapy, Speech Therapy & Applied Behavioural Therapy (ABA). The amount of funding support as offered by the Commonwealth through the Medicare Benefit Scheme (MBS) as stated above only **equates to one week of the minimum amount as advised in the Commonwealth Governments advice re. best practices of Autism (SEE LINK BELOW)**

For Example:-

OT Session for 45 Minutes = \$100.00

Speech Therapy per 45 Minutes = \$90

ABA Therapy By a Registered Psychologist per 50 Minutes = \$120

Total early Intervention Therapy = **\$ 1915.00 -**

(Equates to the min 20 Hours per week as stated in the following government brochure link)

[\[Link to government brochure\]](#)

Future issues

This is very daunting for us to contemplate. Who will look after our son and how will he cope when we are not around or unable to care for him? Because of the amount of expenditure on early intervention we are not able to make savings for his future care needs.

Tax Invoice

DATE	INVOICE NO
13/02/2007	13513

Bill To	Client

Date	Item	Description	GST	FEE
13/02/2007	Consult	Patient Consult Date of referral: 2/1/2007 Medicare item no: 10970	0.00	100.00

Insurance Co

Total Fees ex Tax	100.00
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Total GST	\$0.00
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Total Payable	\$100.00
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Balance Due	\$100.00
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Payment Received	\$0.00
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Payment is due on day of consult.
 Cheques payable
 Receipts issued on request only

TAX INVOICE

Date: 10/6/08

Service provided to: Vincent

Item	Amount
E210 Treatment	\$90.00
<i>TFd 10/6 Rec 371340248</i>	
Total:	\$ 90.00
Paid:	\$ 90.00
Balance:	\$ 0.00

Payment via direct deposit is required on the date of service.
Please make cheques payable to:

Pages 5 & 6 Copy of a quotation for services – 50 Minute session with a qualified psychologist, familiar with Applied Behavioural Analysis (ABA therapy specifically for treating Autism).

(Practitioners names blacked out – original available on request)

******* INTERVENTION SERVICES**

At ***** Intervention Services, we provide a private service to children, with a particular focus on social skills, anxiety, trauma, sleep, depression, anger management and other childhood and adolescent disturbances. Parent and sibling education, training and support can also be provided. We also focus on children with developmental disorders and conduct diagnostic assessments with children demonstrating difficulties consistent with these disorders.

******* Consultation Fees**

Effective January 1 – March 31, 2008.

Services	Fee
• Psycho-educational Assessment	
General IQ and Adaptive Functioning	\$400
Plus Achievement	\$600
Plus School Visit	\$750
• Diagnostic Assessment plus report (1-2 hours plus report)*	\$350
• Individual Consult;	
Registered Psychologist (20- 40 minutes)	\$100
Registered Psychologist (>50 minutes)	\$120
Clinical Psychologist (20-40 minutes)	\$100
Clinical Psychologist (>50 minutes)	\$160
Trainee-Psychologist **	\$80
• Therapy Session**	
(1 Hour)	\$50
(2 Hours)	\$90
• School / Home Visit	
Clinical Psychologist	\$250
Registered Psychologist	\$200
• Group Therapy*** with a group of 6 to 10 patients, per Client	\$50
• Social Skills Group Training (8 weeks)	\$800
• ABA Package 5 visits with a Psychologist	
• ABA Folder of Drills	\$100
• Evaluation of program / progress plus report	\$350
• Telephone Consult (by appointment)	\$60 per half hour
• Requested Report	\$100
• Cancellation Fee within 24 hours.	\$30

(This will be charged unless appointment filled as cancellations are costly)

Diagnostic session may involve 2-3 sessions and therefore **Rebates** will apply per session with appropriate referral. If you would like to have the diagnosis conducted over several sessions please inform us when making a booking.

**Medicare rebate as per Registered Psychologist (although limited sessions available)

***Therapy sessions are not provided by a Registered Psychologist and therefore do not attract a rebate. Should you wish these to be provided by a Psychologist full Psychology rates will apply.

Concessions available by negotiation.

Medicare Rebates may apply

All rates are set below the APS recommended rate of \$186 per one-hour consultation session.

Many people will be eligible for a Medicare rebate covering part of their consultation for up to 12 sessions. Please see your GP prior to your first consultation to obtain a referral and a Mental Health Care plan (Item 2710). Many doctors require a longer session to make a referral to a psychologist under Medicare, so please let your GPs receptionist know the reason for your visit when you phone to make an appointment. Referrals from paediatricians or psychiatrists will attract a rebate without a Mental Health Care Plan.

Rebates may be available from Health Insurers for people who don't qualify for a Medicare Rebate or after 12 sessions.

Payment is expected in full at the time of consultation. We accept cash, cheque, Visa, MasterCard and EFTPOS.

Rebates for MEDICARE are

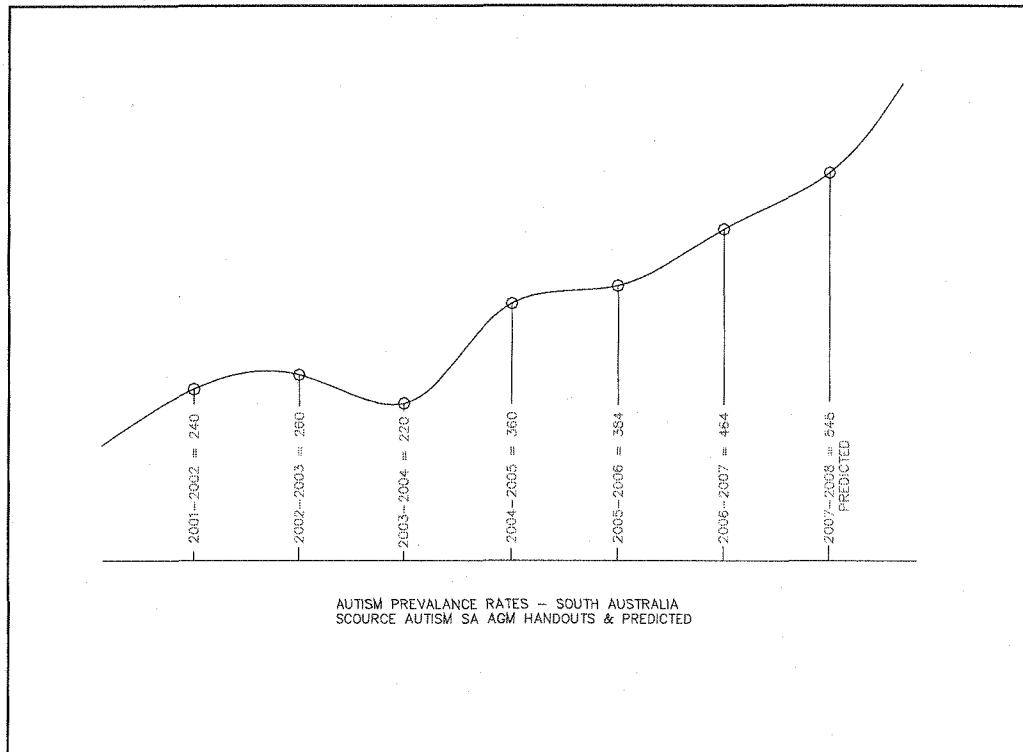
Registered Psychologist

	20-50 mins	Rebate	>50 mins	Rebate	Group (6-10 people) 60 mins plus	Rebate
***** Fee	\$80	\$54.30	\$120	\$76.65	\$50.00 per person	\$19.55 per person
Fee (attendance at a place other than consulting rooms*)	\$130	\$73.80	\$160	\$96.20		

Clinical Psychologist

***** Fee	\$100	\$76.65	\$160	\$112.45	\$50.00 per person	\$28.60 per person
Fee (attendance at place other than consulting rooms*)	\$160	\$95.75	\$200	\$131.55		

Page 7 & 8 – Summary of the prevalence of autism and how lack of state government forward planning has impacted on carers lives. Some suggestions on how state and federal governments can expedite some of the shortfalls in services and assist carers to have normal and stress free lives without the huge financial burden.



Autism Prevalence and school placements

The above graph depicts the trend in autism prevalence in South Australia. There are 12 month waiting lists for all services including an initial autism diagnosis. Parents/carers are being made to make rash schooling choices from authorities as there are not enough places to cater for all ASD children in their own districts. DEC's authorities have admitted that they have had to taxi children in to other schools from other districts because of burgeoning numbers in certain areas.

There are no intensive early intervention programmes for ASD kids in the DECS system. The Autism Association and the Briars school do not provide the necessary one-on one intensive early intervention programmes and therefore do not have effective outcomes. Speech and language programmes are only available for non-autistic children in public kindergartens. There are school issues like having to have numerous consultation meetings to try and get into a particular school model. There is an Early Intervention Research programme run by the Psychology Dept. at Flinders University. It now only has very minimal funding from the Government - This hole concept should have been taken over by the DECS or Disability SA several years ago. It still has a 12 month waiting list for entry due to lack of funding.

Continual self support

State government services are so far behind best practices for autism treatments. This is due to minimal funding now being consumed by autism diagnostic services which are still stretching way out to 12 months. Authorities are not listening to parents and providing the necessary forward planning to address adequate autism services. The impact of all of this is us Carers/Parents have to go it alone and foot the bill for all services related to autism treatments and therapies. We have written dozens of letters, met with local politicians and participated in numerous disability SA surveys and submissions and still nothing is forthcoming in the way of lessening the financial burden and lack of therapy support.

Families need to have Case managers assigned

My wife is physically exhausted from having to continually be a shadow to our son and hand-over-hand prompt him. I would like for her and other full-time carers to have much more free rest time and even some support for them... say regular home visits by a masseuse/physiotherapist while someone looks after our son. Case managers should be assigned to each family and should be able to recognize where parents or carers need time-out and make adequate steps for this. Also, most importantly, case managers would ensure parents/carers are informed and are doing what is necessary for their autistic child's therapy needs.

Current medicare funding

The current medicare funding and tax rebating for autism related services is confusing, inadequate and grossly unfair. This new funding announcement is not achievable on an average one income weekly wage. If this piece-meal medicare support is to continue, governments need to supply home gym equipment or approve gratuity funding for parents to purchase home gym equipment.... Such as gym balls, swings, gym mats, crash mats, walking beams, overhead vestibular equipment, hammocks wobble and wizzy boards and foam blocks amongst educational products and aids to improve speech and language.

Financial needs

Finally Parents or Carers who try and make a difference with their ASD children's future should be adequately compensated for their therapy expenditure. We are faced with a lifetime of carer responsibilities. Please understand it is necessary for families such as ourselves to have some financial savings for our child's future needs as well as for us as parents/carers. Providing for our own retirement needs is essential to our son's ongoing trust fund for when we are no longer around.

Thank you for your attention

Daryl & Rosina
Parents/carers for our 6yo ASD son