



National NoticeBoard

Newsletter of the Australian Association for Families of Children with Disability

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Auspiced by the Association for Children with a Disability

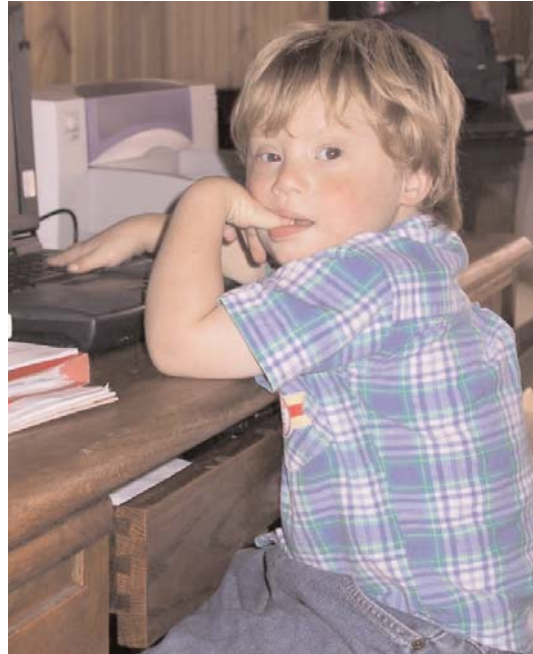
Edition 6
March 2003

Child Care Freeze - National Disgrace!

Our 3-year-old son, Jonathan, has Down syndrome and Acute Lymphoblastic Leukaemia. After an initial phase of intensive chemotherapy treatment, Jonathan endured numerous severe and life-threatening complications. However, Jonathan's medical prognosis is good. With appropriate support during his early development, he stands to undertake a mainstream education and ultimately live independently.

Throughout February, March and April of 2002 we made numerous attempts to return him to the child care centre he had attended since he was six months old. This was unsuccessful due to severe separation anxiety, behavioural problems and ongoing illness secondary to the chemotherapy. In May an application was made via Inclusion SA for child care assistance through the Special Needs Subsidy Scheme. This fund was capped a few weeks before on April 15th 2002. Jonathan's predicament was deemed to be urgent and emergency funding was sought and found via Carer Support and Respite Services. Further temporary funding was obtained from the Leukaemia Foundation. These one-off payments were meant to bridge the gap until SNSS funding was made available. This emergency funding ran out in December 2002. After which, we were unable to continue sending Jonathan to the child care centre. Clearly this threatened his rehabilitation.

Continued attendance at the child care centre is central to Jonathan's rehabilitation and he is already making excellent progress



Jonathan Spencer

in that environment towards overcoming his anxiety disorder.

Our family's sole income depends on the availability of child care for Jonathan. Gillian's work as a specialist anaesthetist requires firm commitments to be made well in advance. It is not possible to work as a medical specialist on an ad hoc basis for long, while still paying for indemnity insurance and other expenses, regardless of availability for work. Aside from this, Gillian's colleagues, patients and of course Jonathan all need certainty regarding her employment. Of note, is that the Commonwealth stands to lose tax revenue well in excess of the cost of Jonathan's child care should Gillian be unable to work.

(Continued page 2...)

'Surely if their rhetoric on families and children means anything at all, the Federal Government will fix the SNSS/child care crisis in the next Federal Budget. While lack of access to child care has a huge negative impact for the children and families affected, it is a very easy and cheap problem for the government to solve - a \$5 million increase in the SNSS budget to \$25 million is all that's required.'
See page 3.

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Quicknote:

Do you know your local Federal MP?

Does she/he know the major issues for you and your family? They should!

Make them aware. A good local MP will help individual families and positively influence policy debate in Canberra.

The Australian Association for Families of Children with Disability (AAFCD) is auspiced by the Association for Children with a Disability. For updates and more information see www.acd.org.au

“Our family's sole income is depends on the availability of child care for Jonathan. ”

“Making children with disabilities wait [for child care] longer than their contemporaries is cruel, counterproductive and, in our opinion discriminatory.”

We have approached numerous departments including FACS in Adelaide, Inclusion SA, and Minister Anthony's Office. Our federal representative, has also petitioned on our behalf. We have been advised that Jonathan is third in the 'queue' and has been there since May 2002. Despite this, we have had no indication of when Jonathan will begin receiving SNSS assistance.

We imagine that cases such as Jonathan's were not foreseen at the time that SNSS funding was capped. That consideration of Jonathan's plight has subsequently been constrained by this decision is presumably an unintended consequence. It is also appears at odds with the inclusive nature of the federal government's Child Care policy. We believe that unimaginative interpretation of this decision has contributed to our now desperate situation and sense of despair.

Financial assistance ran out in December 2002. Since that time we have been paying the full cost of the extra child care worker who looks after Jonathan, on top of the normal child care fees (\$80 - \$100 per half day that he attends). This is financially crippling and not sustainable in the long term. We have chosen this path in the hope that the SNSS funding will appear soon and so that Jonathan does not lose his place in the centre. We were very keen for Jonathan to continue there, as he had made such progress in his rehabilitation. We hope that his needs for additional assistance at child care diminish after he completes his second year of chemotherapy in September 2003.

The child care centre has been very supportive during this difficult time and we have nothing but admiration for the help the team has given us. We understand that they could not continue to provide the extra support without facing financial difficulties themselves.

As we write, Jonathan is still third on the waiting list although a number of children in South Australia have recently ceased using the services for various reasons. We were led to believe that funds would be made available to those waiting as children ceased to use the funds. This is clearly not the case.

If our child were 'normal', Gillian would be working part-time while I complete full time studies and while Jonathan attends child care part time. It seems unfair to us that because Jonathan has Down syndrome and is recovering from chemotherapy treatment, we have to go through so many 'burning hoops', deal with government departments and face significant financial difficulties. This probably sounds all too familiar to families of children and adults with a disability.

Early intervention is part of the investment we make in our children's future to help them achieve their full potential. Placing children in 'normal' environments such as child care while parents (out of necessity) work and study, is part of this process along with early entry to kindergartens and access to before and after school care. Making children with disabilities wait longer than their contemporaries is cruel, counterproductive and, in our opinion discriminatory.

Paul Spencer and Gillian Hood
Glen Osmond, South Australia

If your family is waiting for SNSS/child care (or if you're a worker in the field with knowledge of the impact of the child care wait) make sure your local Federal MP is made aware of the situation. Request their help in finding a solution.

SNSS Child Care Waiting List Data			
State	October 2002*	January 2003*	April 2003* (Estimate)
NSW	215	319	423
VIC	158	181	204
QLD	118	154	190
SA	60	102	144
WA	51	75	99
TAS	15	27	39
NT	12	14	16
ACT	0	2	4
TOTAL	629	874	1,119

Source: Official Hansard Records of Senate Estimates Committee meetings available via www.aph.gov.au.
April estimate assumes increase January to April matches that of October to January.

SNSS/Child Care Policy Solutions

"Are we as a nation valuing our most precious resource - our children?"

The Hon Larry Anthony MP, Minister for Children and Youth Affairs in the Foreword to the consultation paper, *'Towards the Development of a National Agenda for Early Childhood: Commonwealth Task Force on Child Development, Health and Wellbeing'*, February 20, 2003.

The Consultation paper begins with, 'The Howard/Anderson Government has identified early childhood as a priority area for action in its third term of government'.

In a separate initiative, the House of Representatives Standing Committee on Family and Community Affairs is running an inquiry into improving children's health and well-being. Its terms of reference include 'What are the gaps in existing services for children and parents? What additional effort is required to meet the needs of children with disabilities?'

It is hard to reconcile the Government's stated commitments to our children with their approach to child care for children with a disability and the Special Needs Subsidy Scheme (SNSS).

SNSS was introduced by the Howard Government in 1997 with bi-partisan political support (it had begun as a pilot project funded by the previous Labor government).

SNSS provides a subsidy for child care services to employ additional staff to include children with a disability who have 'on-going high support needs'.

This time last year, the government announced what amounts to a 'freeze' of SNSS funding, 'From April 15, 2002 new procedures for the administration of SNSS are being introduced to ensure that the available funds are managed closely and fairly...all new applications, including requests to extend hours, will be assessed and where SNSS is considered appropriate they will be placed on a waiting list.'

Government documentation at that time noted that yearly expenditure on SNSS was expected to exceed \$20 million per year with more than 4,600 children receiving assistance (an average of approximately \$4,350 per child). The government wanted to try and 'cap' SNSS at \$20 million per year, 'funds are limited and expenditure on SNSS cannot continue unchecked'.

\$20 million sounds like a lot, but in the overall budget context, it's a very small amount.

Jonathan's story (see pages 1 and 2) is only one of the 1,000+ stories of hardship created by the government's SNSS freeze. Jonathan is lucky to live in a family where his parents have been in a position to consider 'self-funding' aspects of his additional child care needs. The vast majority of families do not have this option.

In some political and bureaucratic circles there is a myth that SNSS is/was 'over-generous' and child care centres were being swamped by applications from families of children with a disability.

The facts suggest otherwise - around 720,000 children are currently using formal child care services in Australia. The latest data (Dec 2002) indicates there are 3,645 children receiving SNSS (0.5% of children in child care). If the current SNSS waiting list of 1,119 were all funded tomorrow, this percentage would rise to 0.7%, that's less than one in every 100 children, well below accepted statistical benchmarks for the percentage of children with severe or profound disabilities. Children with a disability are under-represented in child care and the SNSS freeze means they are falling even further behind.

Surely if their rhetoric on families and children means anything at all, the Federal Government will fix the SNSS/child care crisis in the next Federal Budget. While lack of access to child care has a huge negative impact for the children and families affected, it is a very easy and cheap problem for the government to solve - a \$5 million increase in the SNSS budget to \$25 million is all that's required. Otherwise, there might just be 1,000+ new disability discrimination applications on the way to the Human Rights and Equal Opportunity Commission.

Barbara Alexander AO
Convenor AAFCD



Barbara Alexander AO

Standing Committee on Family and
Community Affairs

For more information contact the
Committee Secretary on
02 6277 4566 or
e-mail: fca.reps@aph.gov.au

Also see [www.aph.gov.au/house/
committee/fca](http://www.aph.gov.au/house/committee/fca)

'Towards the Development of a
National Agenda for Early
Childhood'

The Consultation paper and more
information can be found at
www.facs.gov.au/early_childhood

Productivity Commission Inquiry into the Disability Discrimination Act

Make sure families are on the
agenda! Contact the Disability
Discrimination Act Inquiry Team
on 1800 020 083 or
dda@pc.gov.au or see
www.pc.gov.au/inquiry/dda



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Cheryl's daughter, Erin

My name is Cheryl Shuttleworth and I am the parent of three adult children. My second child and only daughter has severe autism and also suffers from psychosis.

In my professional life I am an advocate for the Speak Out Association of Tasmania, which supports individuals with disabilities to have a say and take control of their lives. This is a very new position for me and I am still doing some work for Playgroup Tasmania, an organisation for whom I have worked for many years as a consultant and Inclusion Officer.

I am also the state President of the Association for Children with Disability (Tas.) Inc. which has around 150 members - largely comprising parents, carers, families and parent support organisations. ACD (Tas.) is a statewide organisation providing advocacy, information and referral to families of children with disabilities. ACD (Tas.) caters for all types of disability and has been operating since December 1997. Our contact details are: phone 1800 244 742 or e-mail acdtas@bigpond.com.

On a personal note, I enjoy quilting, doll making, many different art forms and most of all spending time with family and friends.

Cheryl Shuttleworth



Australian Association for Families of Children with Disability National NoticeBoard Membership/Subscription Form

If you're not already on our mailing list, to ensure that National NoticeBoard is mailed to you directly, you need to register as a member/subscriber by sending in this completed form. It's free for families and service providers.

I would like to be put on the (free) membership/subscription list for information from the Australian Association for Families of Children with Disability, including National NoticeBoard.

I am a: Parent/Carer A young person with a disability
 Service Provider Family friend/Concerned person Other

Name:

Organisation & Title:

Postal Address:

Town/Suburb: Postcode:

Phone: () Mobile:

E-mail:

(Optional) If parent/young person, child's name/your name, DOB and disability:

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Send this completed form to:

Australian Association for Families of Children with Disability
8 Grubissa Court, Benalla, Victoria, 3672 or Fax to (03) 5762 7000

AAFCD

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To be put in contact with your State/Territory representatives, phone Barbara on freecall 1800 222 660.