



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

Holding on, just hoping for help

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By Christine Jackman

JENNY McAllister had little time yesterday to think about a 517-page federal government report on the state of the welfare services.

While Family and Community Services Minister Kay Patterson was launching the report, titled Australia's Welfare 2003, in a plush theatre at Parliament House, Ms McAllister was in Melbourne living the reality behind the statistics. The storms that battered Melbourne earlier this week flooded the building where her 19-year-old son David attends a day-care program, temporarily shutting the service.

So David, who is blind and confined to a wheelchair with cerebral palsy, spent the day at home in North Balwyn with his mother and grandmother Judith Setford. Ms McAllister said emergencies such as this demonstrated the constant juggling act that faced the primary carers of people with a disability.

"It's hard for people who look after a child like David to find care at the drop of a hat," she said.

"Relatives will often pick up the pieces with a normal child, but they're not as forthcoming with a child with high needs or behavioural problems."

Even when they could access day-care programs like David's, Ms McAllister said many primary carers did not have the flexibility or the support system to return to the paid workforce.

She said her day began when David woke at



Jenny and her mother at home in Melbourne with David.
Picture: Brett Hartwig

7.30am and had to be bathed, dressed and fed before being picked up by the day-care bus. "The bus is terrific — I just didn't realise the strain of constant major lifting to get him in and out of my car," Ms McAllister said.

"As your child gets older and heavier, you're getting older as well — so it's funny that the respite care services are mainly available for children up to 18."

With services to support David now limited, Ms McAllister worries what will happen when she becomes too frail to care for him in the future.

"It's actually a really raw nerve for me because I've had a back problem this year which I know isn't going to get better," she said. "For now, I'm simply going day to day."

This article is reprinted with permission from 'The Australian', which ran the story on December 5, 2003 with an accompanying article detailing that parents/carers do the equivalent of \$28 billion per year of unpaid caring work. Jenny McAllister is an active member of our Victorian Association.

Carer Allowance

The rate of Carer Allowance is currently \$45.05 per week (that's \$90.10 per fortnight and \$2,342.60 per year).

To assist our efforts to convince politicians and their advisers about the merits of an increase in the rate of Carer Allowance (see page 2), write and tell us what you'd spend an extra \$20 per week (\$1,040 per year) on. Please be as blunt and passionate as you like about the costs of caring for your child and the value of Carer Allowance. Politicians need to hear it 'as it is'.

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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

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Telstra Foundation
www.telstrafoundation.com

Carer Allowance — time for a rise!

December 4, 2003, Press Comment Re: AIHW Report - 'Carers' doing \$28 billion in unpaid work. Convenor of the Australian Association for Families of Children with Disability — a national self-help support group for families of children and young adults with a disability — Ms Barbara Alexander AO said,



The Australian Institute of Health and Welfare (AIHW) report, 'Australia's Welfare 2003' is available online at www.aihw.gov.au, under publications, or in hard copy (\$45, GST included). It is a large report (over 500 pages) but Chapter 3, 'Informal care' and Chapter 8, 'Disability and disability services' are the key chapters of interest to families of children with a disability. If you don't have Internet access, we can post you a hard copy of Chapters 3 and 8 free of charge.

Contact Barb at our national office on 1800 222 660 or barbaraa1@inet.net.au

"The AIHW report should be a wake-up call to Federal and State/Territory Governments.

"It's not only the value of the caring work we do that needs to be taken into account, but also that for many parents, like Jenny McAllister, the demands of our caring role means that there's no way we can contemplate doing paid work.

"Whichever way you do the sums, parents of children with a disability deserve a better deal from government than they're getting at the moment.

"Our disability support system is bursting at the seams with families under stress because there are long waiting lists for basic

services such as respite and accommodation support.

"Right throughout the life cycle, from the point of diagnosis of disability through the teenage and adult years, our disability system just isn't funded at anywhere near the level that's needed to support parents and families.

"As a first priority, a rise in the basic rate of Centrelink's Carer Allowance is long overdue.

"I'm not sure how much a \$20 per week rise would cost, but I'm sure it would be a lot less than \$28 billion."

Carer Allowance customer numbers by State and Territory for adults and children

Data relates to Quarter 4, 2003 supplied by the Department of Family and Community Services, January 2004.

<i>State</i>	<i>Child</i>	<i>Adult</i>	<i>Adult & Child</i>	<i>Not Coded</i>	<i>Total</i>
NSW	29,963	62,923	834	160	93,880
VIC	24,410	48,649	686	101	73,846
QLD	17,595	38,309	549	62	56,465
SA	8,350	15,032	253	19	23,654
WA	9,346	14,014	208	34	23,572
TAS	2,469	5,586	65	6	8,126
NT	550	758	7	7	1,322
ACT	1,378	1,649	27	3	3,057
Unknown	2	14	0	105	121
Total	94,063	186,934	2,629	480	284,106*

* There are also another 17,658 Carer Allowance recipients who receive the 'Health Care Card only' version of the Allowance. This group does not receive the fortnightly payment of \$90.10 and have not been included in the below calculations of the cost of increasing the rate of Carer Allowance.

Carer Allowance — A rise of \$20 pw would cost the Government/Budget?

284,106 x \$20 x 52 weeks = \$295,470,240 — near enough to \$300 million.

'\$300 million!!!!' I can hear our politicians and their economic advisers coughing, spluttering, choking etc and saying something like, 'no way, that's just not affordable in the Budget context'. They might try and add to our sense of guilt by suggesting that asking for such an amount is 'pie in the sky'. Is it? \$300 million does sound like a lot of money. Is it really? How much would that amount to per taxpayer? How does it compare to other areas of government expenditure? What else does the government spend \$300 million on? Stay tuned for more budget mathematics in the next National NoticeBoard.

Family vindicated in struggle for son's schooling

BY: PAM CASELLAS

A PERENJORI family has extracted an apology from the WA Education Department after it claimed that six-year-old Liam Lakeman was not provided with the support he needed to attend Perenjori Primary School in 2001.

Liam has epilepsy and autism and his family took their grievances, which involved the amount of teacher aide time that was available to him and also his access to a school bus route from the family farm 25km from the town, to the Equal Opportunity Commission.

The claim, which the Lakemans made with the help of People With Disabilities (WA), was settled by mediation and also involved the department paying the family an undisclosed sum.

The department has apologised to Mr and Mrs Lakeman for any delays that the family encountered at the Perenjori PS during the 2001 school year.

Mr Lakeman said that Liam initially was refused permission to travel on the school bus and when an agreement was reached that he could do so if a special seatbelt was fitted, it took months for the belt to be provided. By the time it was installed, Liam had outgrown it.

The family had to travel about 700km a week to drive Liam to the school, even though his sister travelled by bus. We were in the ludicrous position of driving behind the bus each day,' Mr Lakeman said.

There also had been concerns about Liam's care while he was at school. Mr Lakeman believes other families whose children have disabilities have chosen to leave the town because they could not get enough support.

The department's complaints management unit manager, Peter Denton, said the department was pleased the family's concerns had been resolved satisfactorily.

A spokesman for People With Disabilities said that going to the commission was a long



Barry Lakeman with six-year-old Liam and Emma, 9.

and stressful process that few families would be prepared to undertake.

In mainstream WA government schools, there are almost 3,100 students with disabilities who are allocated teacher assistant time.

A review of educational services for students with disabilities in government schools has been completed and is with the director-general for approval.*

Reproduced courtesy The West Australian. The original article appeared in The West Australian on Oct 25, 2003.

* At the time of writing, the WA Government had still not officially released the education review, although some of its positive recommendations, eg. increased disability/inclusion related training of teachers in mainstream schools, have already begun to be implemented.

For more information you can call the review's Executive Officer, Elizabeth Fairclough on 08 9264 4926 or email (disabilitiesreview@det.wa.edu.au), or via the switchboard of the WA Department of Education and Training on 08 9264 4111. The Department's Internet site is www.eddept.wa.edu.au and the original background material for the review was at www.eddept.wa.edu.au/disrev/.

Your Story?

The parent/family stories are the most popular part of National NoticeBoard and we always need new stories.

Send your story and a photo to The Editor, National NoticeBoard, Association for Children with a Disability, 590 Orrong Road, Armadale, Vic, 3143 or email (fionag@acd.org.au).

Vehicle Modifications — Another Tilt Pending

Readers who have followed our Association and National NoticeBoard from the beginning will remember the parent story, 'Vehicle Gymnastics' from this time last year (Edition 5, January 2003)*.

In 2004, we're going to have another tilt at getting politicians (both Federal and State/Territory) and the vehicle industry interested in discussing solutions for families who need financial assistance to get access to an appropriate vehicle to transport their child. Anybody with a story to tell on this issue is encouraged to write to us and/or better still, write to the Prime Minister and your Premier/Chief Minister and send us a copy.

* Back copies of National NoticeBoard are available free of charge. Ring Sue in our Victorian office on 1800 654 013 or 03 9500 1232. National NoticeBoard is also online at www.acd.org.au/aafcd/nat_noticeboard.htm



AAFCO Convenor, Barbara Alexander AO, whose two sons, Drew and Simon (now deceased), had the rare degenerative condition, Cockayne syndrome.

Feel free to contact Barb on 1800 222 660 for more information about her role on the NFCV

Note: The NFCV survey return date is February 6, but late returns will be included.

National Family Carers Voice

Through Barb Alexander, our Association is represented on National Family Carers Voice (NFCV), a newly established Federal Government advisory body made up of 'family carers' from across Australia. NFCV is supported and resourced directly by the Federal Department of Family and Community Services (FACS).

NFCV's two year workplan indicates its activities will include:

- Gathering broader information than is currently available on who are family carers, where they are located, what their needs are, what services and information networks are available, service gaps and unmet needs.
- Evaluating and interpreting that information and making recommendations for policy directions to the Minister for Family and Community Services.

NFCV Committee members include: a carer with experience in Indigenous communities; a carer from a culturally and linguistically diverse background; carers from rural and remote areas; young carers; carers of young children, partners, adults, the aged, and carers of people with mental illness. For more information, including a needs survey, phone 1300 653 227 (extension 441849) (local call rate), email nfcv@facs.gov.au or see their web site at www.facs.gov.au/aboutfacs/programs/disability-nfcv.htm.

What is the AAFCD?

Our Association is a 'grass roots' organisation, run by parents/families for parents/families. Our Association includes all types of disability. Our formally defined purpose is:

'To provide information, support and advocacy to families of children aged 25 and under with disability in all States and Territories of Australia. The advocacy role includes provision of information to the Federal Government about family needs and issues and advocacy for changes required to Federal policies and programs to address these needs and issues.'

AAFCO Committee Members

Australian Capital Territory

Karen Connaughton
Cheryl Patrick

New South Wales

Sue Griffin
Kylie Ramstadius

Northern Territory

Bruce Young-Smith

Queensland

Christine Saunders
Leonie McKnight

South Australia

Mary-Ann Murphy
Cale Dalton

Tasmania

Cheryl Shuttleworth
Diane Fugslang

Victoria

Barbara Alexander AO
Jan De Witte
Lyn Kemperman

Western Australia

Clara Harris
Cherie Shaw

Contact Barbara Alexander AO on 1800 222 660 to be put in contact with your State/Territory rep.



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

If you're not already on our mailing list to receive National NoticeBoard, you need to register as a member/subscriber by sending in this completed form (or ring/email us with your details). 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