

**INQUIRY INTO SERVICES PROVIDED OR FUNDED BY
THE DEPARTMENT OF AGEING, DISABILITY AND
HOME CARE**

Organisation: Disability Advocacy NSW
Name: Mr Mark Grierson
Date received: 2/08/2010



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2 August 2010

The Director
 Standing Committee on Social Issues
 Parliament House
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 Sydney NSW 2000
 Fax: (02) 9230 2981

Dear Sir/Madam,

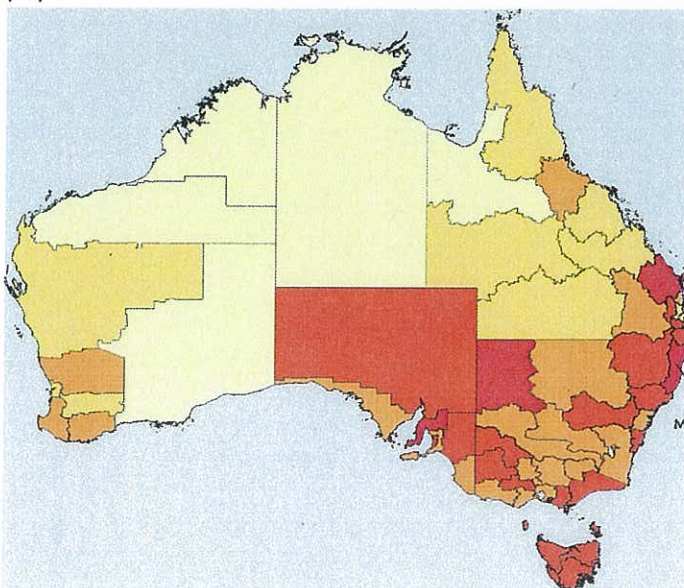
Submission to: Services provided or funded by the Department of Ageing, Disability and Home Care (Inquiry)

Submission Focus: Inadequate Disability Advocacy Service Provision in NSW Far West

While Disability Advocacy NSW Inc. is funded by ADHC to provide advocacy support for people with a disability in the Hunter, Mid North Coast and New England regions of NSW our service has become acutely aware of the anomaly that the western areas of the state (e.g. Dubbo, Broken Hill and Bourke) have no direct access to advocacy support. ADHC is a key funding agency of advocacy service in NSW; therefore this issue is particularly relevant to section 1(b) ii of this inquiry.

Advocacy provides a crucial independent safeguard mechanism to ensure that people with a disability are not subjected to unfair treatment. Good local advocates can identify instances of unfair treatment, bring it to the attention of key decision makers and service providers then negotiate better outcomes for people with a disability.

The western areas of NSW (e.g. Dubbo, Broken Hill and Bourke) clearly have a smaller population than the coastal areas of the state but the ABS statistical map (figure 1) shows



there are an above average number of people with a disability in Western NSW. Western NSW also has a significant indigenous population.

Per cent

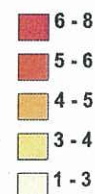


Figure 1 - ABS 2006 "Disability Map" (Percentage of Population Requiring Assistance)

Equitable access to advocacy across the state is clearly important: but it is not being delivered. Our service believes that this can only happen if more emphasis is placed on providing equitable access to advocacy for people in a disability in regional, remote and rural areas of the NSW.

Servicing these areas from Sydney in reality is not feasible or beneficial for people with a disability in these areas. Western NSW and other regional and remote areas need local advocates who are mobile and have local connections to ensure they pick up cases of unfair treatment then negotiate better outcomes. A pertinent example of this is the case of Kate Bugmy a 26 year old indigenous women from Broken Hill who died recently (see attached Sydney Morning Herald article also located online at <http://www.smh.com.au/nsw/tragic-kates-death-reveals-care-flaws-20100711-105ps.html>). Perhaps if there had been an advocate closer to Ms Bugmy, there would have been a person who would have independently checked and negotiated appropriate support for her.

Providing strategically placed local advocates in remote areas is not an overwhelming task as our service and other regionally based services have shown. It is possible to place skilled advocates into remote settings at a reasonable cost and back them up with professional support to do their job. Currently our service provides support and supervision for locally based advocates in areas over 400km from our main office. This approach will always provide better advocacy outcomes than an occasional visit from services in Sydney that also have the pressures of servicing large metropolitan populations.

While there will always be flaws in the system at least locally based advocates will give people with a disability in remote, regional and rural areas a fighting chance of getting a fair go.

Yours sincerely

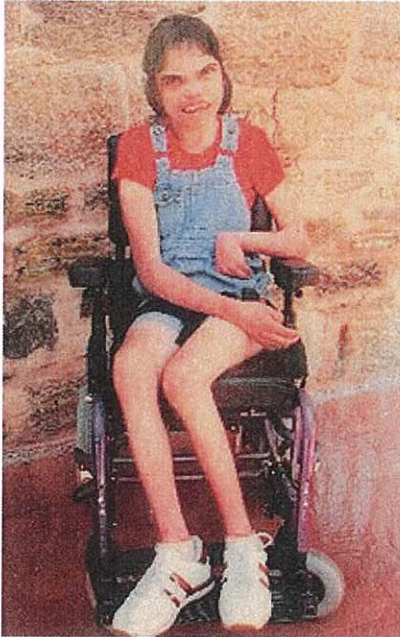
A handwritten signature in black ink, appearing to read 'Mark Grierson', with a long horizontal line extending to the right.

Mark Grierson
Chief Executive Officer/Advocate
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Tragic Kate's death reveals care flaws

SAFFRON HOWDEN

Sydney Morning Herald July 12, 2010



Kate Bugmy ... dead at 26. *Photo: Peter Rae*

BY THE time Kate Bugmy was examined in hospital, she was unconscious and carried on her tiny frame little more than one kilogram for each of the years she had lived: 26.

She never had statistics on her side. Ms Bugmy was indigenous, lived in far western NSW and was born with cerebral palsy and suffered from epilepsy.

But an inquest has heard her death may have been preventable and that she fell through the cracks of poorly co-ordinated and stretched health and community services in her home town of Broken Hill.

The year before she died at Broken Hill Base Hospital in 2007, her father passed away.

At their home on the dusty outskirts of town, her grief-stricken mother, Daphne Hall - battling her own heart condition - and her pregnant sister, Jenna, were left to administer alone the constant care she required.

An inquest is examining how she came to hospital on June 19 three years ago malnourished, acutely dehydrated, with bed sores, infected eyes, and ulcers on her back, buttocks and mouth - leading, nine days later, to her death from pneumonia or sepsis.

According to court documents, Ms Bugmy had spent two weeks in respite care in the months before her hospitalisation.

Despite her deteriorating health during the stay, no official visited her after she was released on May 4 that year - just six weeks before she presented at the emergency ward.

One expert witness believed Ms Bugmy's chances of survival when she arrived were less than 20 per cent.

Some, such as the veteran hospital physician in charge of her treatment in the final week of her life, David Pugsley, blamed the young woman's family for her condition, "the most parlous he had ever seen".

In a statement to police, Dr Puglsey said: "Kate probably weighed no more than 25 kilograms ... It seemed very likely to me that this woman's health had been neglected in the days and probably weeks prior to her admission."

But other potentially fatal flaws in the state care system for the disabled emerged throughout the inquest hearings before State Coroner Mary Jerram.

The NSW ageing and disability department had just one community services case worker servicing the vast plains of far western NSW, including Wilcannia, Menindee, Dareton, Wentworth, Gol Gol, Euston and Balranald.

A second case worker position at Dareton remained unfilled for three years between 2004 and 2007.

The department had regular contact with Ms Bugmy until 2002 but, although her needs were complex and her health poor, the department closed her file when she turned 21.

According to an expert witness, she needed a dedicated team of specialists to monitor and assist her: an occupational therapist; a nutritionist; a GP who visited regularly; equipment such as a pressure-relieving mattress and a hoist. She had none of that.

The coroner heard her family had requested a hoist before she died, but funding was not available.

"There was little, if any, co-ordination between any of the service providers involved in Kate's care," counsel assisting the coroner, Peter Hamill SC, and Kirsten Edwards told the inquest.

"Kate fell through the cracks. She needed a dedicated case worker with the time to organise regular periodic reviews," Mr Hamill said.

"The evidence suggests Kate's death may have been preventable."

Ms Bugmy died in hospital on June 28, 2007, weighing 36 kilograms.

The coroner is yet to hand down her findings.

<http://www.smh.com.au/nsw/tragic-kates-death-reveals-care-flaws-20100711-105ps.html>

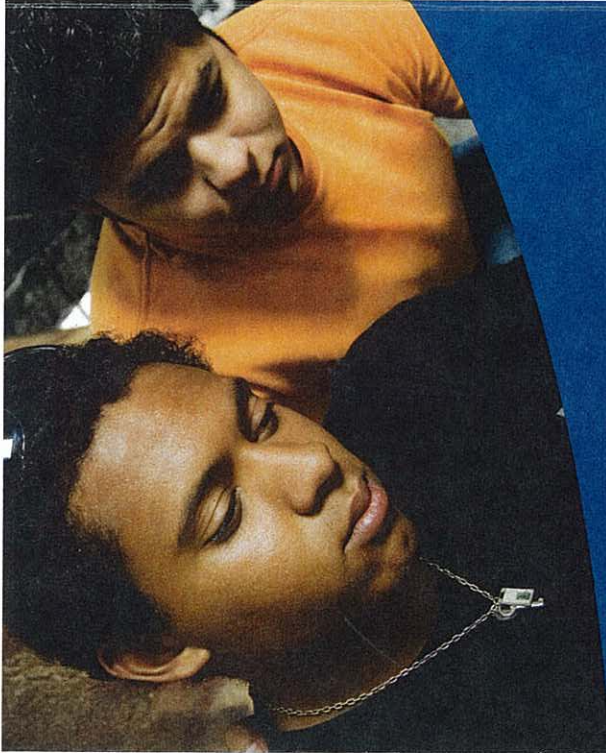
Advocacy support for individuals

Directly advocating on behalf of a person or providing advice and support so that a person can advocate for themselves –

- dealing with a landlord
- support when going to court
- support in dealing with a legal issue
- negotiating a better deal from a government department
- dealing with guardianship and financial management orders
- dealing with problems at work, school, TAFE or uni etc.

Linking a person with other relevant services –

- helping a person get legal advice from a solicitor or help from a financial counsellor



Education

Providing education programs for: people with a disability, non-disabled people, workers in the field, family members and carers –

- rights training for people with an intellectual disability
- advocacy workshops for accommodation support workers or carers



Supporting an individual to deal with disability discrimination or making a complaint against a service provider –

- discrimination complaint to the Anti-Discrimination Board
- complaining about poor treatment by a service

DA has a specialist advocate who can assist people from a non-English speaking background.

Systemic Advocacy

Advocate for changes to policies and practices that are unfair to people with a disability.

What is advocacy?

Standing by someone, or speaking out for someone's rights, or going into bat for another person – being on their side, especially when the chips are down.

Who is this service for?

For people with any type of disability –

- brain injury
- mental illness
- intellectual disability
- neurological disability
- physical disability
- sensory disability



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Funded by the Commonwealth & NSW Governments

Disability Advocacy NSW
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*advocacy for people
with a disability*

**Hunter, New England and
Mid North Coast regions
of NSW Australia**

