



Submission to the Productivity Commission in Support of the NDIS

The Respite Alliance Whittlesea (RAW)

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The Respite Alliance Whittlesea (RAW) was formed on the 9 February 2010 and members include people with disabilities, carers, service providers, community groups and concerned individuals.

Support for the NDIS

RAW is delighted to have the opportunity to make a submission to the Productivity Commission in response to the draft report: *Disability Care and Support*.

RAW welcomes the main recommendations in the draft report, especially the establishment of a National Disability Insurance Scheme to begin from 2014.

RAW believes that the NDIS is one-off opportunity for Australian governments at all levels to shift to a rights based model of disability services.

Inadequate provision for facility-based respite

It is noted that the NDIS will fund a broad range of individually tailored supports.

Key supports will include aids and appliances, personal care, domestic assistance, respite, home and vehicle modifications and community access.

However RAW believes that the current NDIS proposal overlooks the provision for capital works funding associated with the construction and fitting out of age appropriate facility-based respite

This is currently a state government responsibility.

The following slides present the case for such funding to be made available as part of the NDIS, but separate from the individualised support packages.

Benefits of age appropriate facility–based respite

For the person receiving care:

- To promote independence, especially for children who may at some time in the future have to live without their parents
- To provide an opportunity to have contact with others in different surroundings
- To encourage participation in activities that might not normally be available.
- To lead to increases in quality of life for dependent persons and their family caregivers.

Benefits of age appropriate facility–based respite

For the carer:

- To allow time for rest and relaxation
- To give ‘time out’ to have a holiday or visit family and friends
- To help to restore physical health and well-being
- To promote the preservation and strengthening of marriages or relationships in families caring for a dependent family member or needing crisis respite care for a family member.
- To contribute to a reduction in the likelihood of child abuse and neglect, and in the likelihood of removal of children from their homes; and contribute directly to the safety of children receiving care.
- To contribute to reductions in stress and related mental/physical health problems

Different types of respite

Facility-based respite e.g. overnight, extended or emergency support for those with complex needs

Centre-based respite e.g. day cares programs

In-home respite e.g. in-home day programs, overnight stays, carer vouchers

Community based flexible respite e.g. day/evening outings, host family stays, carer support groups, short breaks, weekend or holiday stays

Facility-based respite

The availability of, and funding for age appropriate facility based respite has fallen way behind the other forms of respite in Victoria.

Victorian Statistics

- There are more than 700,000 family carers across Victoria – people caring for ageing parents, children with disabilities, and spouses with mental illness or chronic health issues. (Carers Victoria)
- They deliver over 93 per cent of all accommodation and personal care needs of people with a disability. (National Carers Coalition)
- The estimated value of the contribution by carers to the Victorian economy is \$8 billion annually. (DHS Website, Carers' Card)
- More than 50 per cent of primary carers have a lower than average income (Deakin University, October 2007)
- Over one million Victorians have some form of disability, and this is likely to increase as the population grows and ages. (Fairer Victoria 2009)

A Case Study: The City of Whittlesea

The City of Whittlesea is located in Melbourne's north about 20 kilometres from the CBD and covers an area of around 487 square kilometres

Geographically it is one of the largest municipalities in metropolitan Melbourne and has over **160,000** residents.

City of Whittlesea Statistics

There are 17 suburbs, and no age appropriate facility-based respite centres.

- The City of Whittlesea is the 6th most disadvantaged Local Government area out of 31 metropolitan municipalities.
- Approximately 4.5 per cent (6000) of residents in the City of Whittlesea receive a disability support pension from Centrelink.
- This is 32% higher than the Victorian average.

- 45% of the disabled population of the City of Whittlesea has a profound or severe disability, which means they require help or assistance with core daily living tasks.
- There are approximately 10,000 local residents providing unpaid carer support to a person with a disability.
- Five families in the City of Whittlesea relinquished a loved one with a disability in 2010 to the Department of Human Services because they could no longer cope without facility-based respite.

DHS North and West Region Statistics

- There are 14 local government areas in the North & West Region of the Department of Human Services (DHS)
- DHS' own figures indicate that over 1.5 million people live in this region. It includes 4 of the 5 growth areas of metropolitan Melbourne of which the City of Whittlesea is the fastest growing with 160,000 residents and still counting.

Facility-based respite support is available to unpaid carers of people who:

- have an acquired brain injury
- have an intellectual or physical disability
- have an degenerative neurological condition
- are aged between 6 and 64 years.

However, facility based respite is only available on a 3 monthly cycle

Carers have to wait until a respite booking form is sent out, unless there is an emergency situation

Even then, there is no guarantee from DHS that respite will be available when it is requested.

Some of our RAW members have not been able to get facility-based respite for two years.

There are 15 respite facilities with only 87 beds in the North and West region of DHS.

On any single night, 15 of these respite beds are reserved for emergency respite

As at June 2009, there were 28 facility-based respite beds in the NW Region occupied by people with a disability who required long-term accommodation and

had been in care for more than four weeks. (Hansard 11 Aug 2009)

This means only 34 beds for the entire NW region would be available for non-emergency bookings on any given night.

Lack of Transparency

- DHS is not transparent in the provision of facility-based respite.
- There are no published criteria to indicate how requests are prioritised
- There are no published waiting lists
- There are no published occupancy rates for the 15 respite centres
- There are no up to date public records of the number of respite beds that are occupied by permanent residents waiting for relocation
- There are no statistics showing the number of applicants for these respite beds, what municipalities they live in or how often they get their preferences.
- Even though facility-based respite centres cater for different types of disabilities and different age ranges, there is no data publicly available that compares demand with supply
- Anecdotal evidence from RAW users of respite centres in other municipalities indicates excessive waiting periods with some centres having no beds available for new applicants for 3-4 years
- There is no way to compare the equitable allocation of these respite beds across Local Government areas
- There is no way to compare the availability of facility based respite services across the other metropolitan DHS regions.
- In short, when a resident from the City of Whittlesea completes their Respite Request form and submits it to the Intake and Response Team, there is no way of knowing whether their request is being treated fairly and equitably or not.
- Even if respite is successfully booked, it cannot be guaranteed by DHS.

Problems for residents of the City of Whittlesea in accessing facility based respite

- Currently, residents have to travel outside the municipality to get facility-based respite because there is none located within the city.
- The travel distances are restrictive for residents
- This combined with a shortage of beds makes it inequitable for residents
- The lack of timely public transport only makes access to current respite beds even worse.
- The inconvenient and unrealistic travel times make it inequitable to get to services in other municipalities.
- For example, a carer living in South Morang who obtained respite at the Special Kids facility would take 2 hours and 10 minutes using 5 different individual trips on public transport for a Friday night drop off just to access the service.
- Then there is the return trip afterwards.
- Then it happens all over again on Monday morning.

Questions to consider?

- Carers of people on ISP's in Victoria continue to relinquish their loved ones to the state because of a shortage of age appropriate facility-based respite beds.
- How will the NDIS prevent this from continuing?

The Victorian Government's Plan For Carers (Nov 2010)

- "Respite is fundamental to improving the quality of life of a carer and the people they care for.
- The current system for respite care is fragmented." (Page 3)
- "Respite waiting lists are long and carers often reach crisis point before they can access any relief.
- Across the state carers often wait more than a year to access even a weekend of respite." (Page 3)

- “The Auditor General found that respite care is used to meet the accommodation needs of persons awaiting Shared Supported Accommodation.
- This has resulted in a significant reduction in respite for families and people with a disability.
- The crisis has denied many desperate families access to urgently needed short-term respite.” (Page 4)

A Liberal Nationals Coalition Government will:

- “Reform respite services to deliver efficient, simple and timely provision of vital relief.
- Establish a pool of \$20 million over four years to support the development of innovative models of respite care to meet the range of carer and care recipient needs.” (Page 10)
- ***“Give a priority to the development of further facility based respite options.***
- This will deliver people needing respite access to up to a half a million extra hours of available respite care.” (Page 10)

The Fact

In the May Victorian State Budget not one cent was allocated to the construction of age-appropriate facility-based respite anywhere in the state.

The Current Reality

There are not enough age appropriate facility-based respite beds available in Victoria.

Productivity Commission Draft Report Disability Care and Support Overview and Recommendations

- Tier 3: Access to publicly-funded, individualised supports
- “A person getting funded support from the NDIS would have a permanent disability” Page 13

Many carers of people in the City of Whittlesea who would qualify for funding under Tier 3 require access to facility-based respite.

However, facility-based respite is provided by the state government and there are just simply not enough beds

- Individualised support packages will be funded by the NDIS for people assessed under Tier 3

But even if they get a funding package, there will still not be enough facility-based respite beds.

There seems little point giving people with a disability much more power over what and how support services are delivered if services such as facility-based respite beds are not available

Individual Support Packages

- Victoria already provides Individual Support Packages (ISP) for eligible people under the Disability Act 2006, albeit with a waiting list of over 1200
- Many of our RAW members are in receipt of an ISP but still cannot use the money provided to access age appropriate facility based respite because there are not enough beds.

Recommendations

- The NDIS should make provision for an increase in the number of age appropriate facility-based respite beds for people who require them separate from Tier 3 funded packages
- The NDIS should make provision to fund the staffing of these facilities

Questions to consider?

- ISP's in Victoria have not led to an increase in the number of age appropriate facility-based respite beds to meet demand. How will the NDIS be any different?
- What incentives will there be in the NDIS to encourage the private sector and state governments to build and staff age appropriate facility-based respite beds?
- Carers of people on ISP's in Victoria continue to relinquish their loved ones to the state because of a shortage of age appropriate facility-based respite beds.
- How will the NDIS prevent this from continuing under an individualised support model of funding?