



**NSW Council for Intellectual Disability**  
**Summary of NSW CID's position paper on**  
**accommodation supports for people with**  
**intellectual disability**

**About CID**

- NSW CID is a peak organisation in NSW representing the rights and interests of people with intellectual disability.
- We believe that people can live full and meaningful lives in their communities and have the same rights as all citizens.
- We see people with intellectual disability as leaders and experts.
- We seek to engage constructively with government and political parties.

**Background**

There is significant unmet need for accommodation for people with intellectual disability in NSW. This is the case in spite of the July 2006 *Stronger Together* plan and the recent Commonwealth announcement to fund additional accommodation, both of which were welcomed by NSW CID. The new funding will provide additional accommodation, respite and therapy services. However large residential centres (LRCs) are still operating and there are plans to redevelop some rather than close them. Families remain under pressure and at risk of crisis. NSW CID questions whether any redevelopment of current LRCs into other congregate models are consistent with the DSA and the NSW Disability Service Standards

**Vision**

NSW CID believes that all people with intellectual disability should live in community accommodation and not in congregate settings. With correct planning a range of models of supported living with the necessary safeguards and appropriate supports can be developed. There is ample evidence to demonstrate that cluster style accommodation is not suitable to people with intellectual disability.

**What is needed now**

While there has been an injection of additional funding it is clear that more is required to address unmet demand. Importantly Governments must only develop supported living models that will ensure true community inclusion for people with intellectual disability. Key ingredients that underpin successful community living include geographic proximity and good linkages to mainstream and other disability services and supports and a true 'person-centred' approach to service provision. See page 4 for more details.

**Scenarios**

The last section of the position paper describes two scenarios, one of a person living in a large residential centre and the second of a person living in the community. Both individuals have similar support needs. Simon lives with friends in a group home and is well connected into his community. Peter lives in a LRC and while there have been improvements in some areas of his life recently, particularly in relation to nutrition, his daily life is limited to the routine of the institution therefore he has limited personal choice and he has few personal connections with other people. See page 5 or more details.



**NSW Council for Intellectual Disability**  
**Accommodation support for people with**  
**intellectual disability**  
*Position Paper*

**About CID**

The NSW Council for Intellectual Disability (NSWCID) is a peak body representing the rights and interests of people with intellectual disability in NSW. Our roles include providing policy advice, systemic advocacy, community education and information provision and dissemination. We undertake all of our work with the active participation of people with intellectual disability and work to enhance the meaningful participation of people with intellectual disability in their communities.

**Background**

For many years NSW CID has advocated for more money for accommodation services for people with intellectual disability in NSW. In May 2006 the NSW Government announced a plan for disability services, *Stronger Together* that promises to deliver significant additional accommodation, respite and therapy places for people with disability. NSW CID welcomes this progress. However this will only go so far to address the significant unmet need that we know still exists. Specific details on unmet need are not yet available, as no data in relation to level of need or waiting lists have been kept. However a recent report from the Australian Institute of Health and Welfare<sup>1</sup> estimates that there were 23,800 people with unmet need for accommodation and respite services in 2005. Based on population figures approximately 7-10,000 of these will be people living in NSW.

Whether we have precise figures or not we do know, through our community meetings and callers to our Information Service, of the enormous pressure on families who have their adult children with intellectual disability still living with them at home. Families and carers are ageing and are concerned about their son or daughter's future. Many are in crisis relating to their own health and lack of access to supports for their family member with intellectual disability.

For more than twenty years legislation has recognised that people with intellectual disability should not be institutionalised, yet currently in NSW approximately 2400 people with disability live in institutions or large residential centres (LRCs). We understand that the NSW Government is undertaking a process to develop service plans to close or redevelop both the Department of Ageing Disability and Home Care (DADHC) run and non-government run LRCs. We are told that that it will be consistent with the *Disability Services Act (DSA) 1993* and the DADHC Standards in Action. However NSW CID questions whether any redevelopment of current LRCs into other congregate models can be consistent with the DSA and the Disability Standards.

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<sup>1</sup> AIHW Report *Current and Future Demand for Specialist Disability Services June 2007*

## **NSW CID's Vision**

Our vision for people with intellectual disability is still based on the concept of a 'decent life' in community-based accommodation. Community-based accommodation means support to live in a manner that is in keeping with community norms; i.e. people who are adult living alone, with partners or sharing houses or flats where they have their own room and where they choose who they live with, children living with families. (See on page 3 for some key ingredients that underpin successful supported living models). NSW CID believes that this can be achieved for all people, including those people with complex medical needs, people who require behaviour support and people who are ageing.

There is ample research to indicate that any style of congregate accommodation including cluster housing is not suitable for people with intellectual disability. To quote from a presentation delivered by Professor Eric Emerson in 2002: *"Small community-based supports offer better outcomes than....."*

- *State operated institutions*
- *Larger community-based supports*
- *Cluster and campus style developments*<sup>2</sup>

NSW CID believes that redeveloping institutions into village style accommodation or cluster housing is not the answer. We believe that with the correct planning a range of other models of supported living with the necessary safeguards and appropriate supports can be developed. Because people feel so desperate and fearful about the future a few families have recently been promoting cluster models. NSW CID is convinced that in 5 or 10 years time the disability service sector, families and generally the community will be looking at such models and realising that they do not meet the needs of the individual but have perpetuated the institutionalisation which the DSA and the Disability Standards are seeking to avoid. We are concerned that once the 'bricks and mortar' is in place it will be difficult to move away from these models.

A paper produced by Family Advocacy<sup>3</sup> in February 2006 (in which Professor Eric Emerson comments on the Accommodation and Support paper produced by the NSW Government) indicates there is no wide-spread evidence for village or cluster style housing: *"....there is **no evidence at all** to suggest that either a substantial or increasing proportion of people with intellectual disabilities would wish to live in medium and high-density housing, villages and intentional communities"*. The Family Advocacy paper presents a range of arguments that demonstrate the benefits of supported living models for people with intellectual disability.

NSW CID believes that we must learn from the both the mistakes of the past and the evidence of success in community inclusion and accept only accommodation options that ensure people with intellectual disability have

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<sup>2</sup> Eric Emerson, Institute for Health Research, Lancaster University UK

<sup>3</sup> *Presenting the Evidence: Accommodation and Support for People with Disability 2006*  
[www.family-advocacy.com/systems\\_advocacy.php](http://www.family-advocacy.com/systems_advocacy.php)

necessary supports and safeguards to live meaningful lives with access to their communities in ways that the rest of society takes for granted.

***What is needed now.....***

There is a range of issues that must be addressed to ensure secure ongoing funding for accommodation services. Significantly the Commonwealth Government's contribution to State disability services has been decreasing over the years and this must be immediately reversed. The current stalled CSTDA negotiations must be resolved. NSW CID and our National Council on Intellectual Disability (NCID) is lobbying for the Commonwealth Government to match the funding that NSW has contributed to disability services through the *Stronger Together*<sup>4</sup> ten year disability plan.

NSW CID commends the recent work within DADHC to address the accommodation issue in a more planned and comprehensive manner. However we believe the Government must only pursue the development of appropriate supported living models that will ensure true community inclusion. Furthermore, we are convinced that any clustering or village style accommodation will become the institutions of the future and none of us want that for people with intellectual disability.

In NSW, service plans for all large residential centres must only lead to supported accommodation for residents that are community based and that ensure the residents are provided appropriate support to transition to the community.

There are some key ingredients that underpin successful community living models. These include:

- Geographic proximity to community and mainstream generic supports and services.
- Good linkages into disability and mainstream generic supports and services.
- Incentives for the community to be more inclusive.
- Proactive facilitation of social life, friendship and informal supports – this requires skilled support workers.
- Well-trained staff with good interpersonal skills.
- High staff to resident ratios.
- Recognition of the importance of considering compatibility between residents – the vacancy management process does not allow for this to be a priority.
- True 'person-centred' approach to service provision, which would lead to improved independence and self-reliance, better transitions through life stages, more timely supports and avoidance of crises.
- Being able to have control over the way supports are provided.
- Opportunities for options to choose individualised self-directed funds management – this occurs in some jurisdictions and is considered to provide good value for money and excellent individual outcomes.
- Planned safeguards, appropriate supports and protection.

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<sup>4</sup> NSW Government disability plan – contact NSW CID for more information

- Age appropriate supports for people with intellectual disability reflecting societal norms.

### ***So what is life like living in community-based accommodation and within a large residential setting?***

After discussions with people with intellectual disability and their families living in a range of settings we can build up a picture of how a person's life fares within the different arrangements. Below is a description of the daily life of someone living in the community and someone living in a large residential centre. For this exercise we have assumed that both services are of a high standard and that both Simon and Peter have a similar support needs.

#### ***Simon's life in the community***

Simon lives in a group home in a regular suburban street. The house looks similar to the other houses in the street. It is an easy walk to local shops, where Simon works part time, a Leagues Club and the train station. Simon shares with two other people with disability and has his own room.

Simon likes to be woken by his favourite breakfast show announcer. Sometimes his support worker brings him a cup of tea and they spend a few minutes talking about what are his plans for the day, the weather and what clean clothes he has in his cupboard. After choosing his outfit he gets dressed with the assistance of the support worker. He usually has breakfast in the kitchen with his two friends and housemates, Leah and Paul. Breakfast is a fun time of the day. They all eat a lot of cereal because they follow the competitions that are found on the cereal breakfast boxes and there is quite a bit of healthy competition amongst them all as to who will be the first to travel to one of the exotic locations offered as first prize. Simon then brushes his teeth, which he can do now – thanks to a new electric toothbrush that has been bought for him and his dedicated support worker who helped him gain the necessary skills to use it effectively.

Two days a week Simon has a job at the local newsagent and three days a week Simon does volunteer work at a disability rights organisation. Fortunately both workplaces are close by and he is now able to walk there by himself – for the first few weeks a staff member used to accompany him.

Most evenings the housemates eat together – they plan their menus and go shopping together with a support worker. This evening Simon is having dinner in the local club with a friend from his bowling group and the advocate who helped him get his job – he wants to buy her a drink to thank her.

When Simon gets home he has his bath. Simon experiences insomnia and he likes having a long bath at night as it helps him to sleep better. Simon has some mobility problems but his support worker is always on hand to help in and out of the bath.

After his bath Simon watches TV for a while and then is helped into bed. He is able to flick through some magazines for a while – the support workers

have set it up so that his books are on tray over his bed at just the right level for him to be able to read and he has a remote control switch for his light so that he can turn it out when he is ready to sleep and if he wants to read during the night.

### ***Peter's life living within a large residential centre***

Peter lives in a large congregate setting, which is similar to a hospital. There are large grounds with lots of lovely trees but it is a long way from the rest of the community – there are no shops nearby. In fact the main entrance is so far from the unit in which Peter lives that you have to go there by car. Peter has his own room but some people share rooms. There are routines for everything including; showering at a particular time, meal times and outside activities.

Peter is woken early. First showers start at 6am and most of the 12 showers need to be completed by 9am. So even before he is properly awake two staff (one he doesn't know and they are not introduced) help him out of bed and send him through to the communal bathroom. He is helped to have a quick – and not hot enough – shower, with a curtain surrounding him that is not closed properly. He can see other people shuffling by so no doubt they can see him. Peter would prefer to get his shower over and done with early so that he is ready for his day program or any other appointments he may have. Too many times he has missed out on an activity because he wasn't ready when the rest of the group was going.

After being dressed quickly - if there was more time Peter could help to dress himself – he goes to the dining room. He waits here alone with the radio on a station that he finds annoying – he can hear the kitchen staff talking; sometimes one of them, Anna, comes to talk to him but she isn't there today. As he sits there Peter notices he is wearing clothes that he doesn't recognise. After his usual breakfast of porridge, which Peter is so sick of but he doesn't like mushy Weetbix, he usually goes to the bathroom where his support worker brushes his teeth. Often there are other residents in the bathroom at the same time and sometimes he sees other people lash out at the support workers.

Then Peter is then sent to the hall where he waits for the others and the staff to go across the garden to the activity centre. He sometimes waits here for half an hour. He can hear Sunrise on TV in the day room and wish he could hang out there while he is waiting but the door is locked.

Then he is off to the activity centre – where Peter spends his morning doing very little. He has become very tired of doing the same craft activities year in and out and he is never asked what individual activities/projects he would like to be involved with. About twice a month Peter gets the opportunity to go out for the day into the community. Sometimes he goes out for a meal, goes shopping or participates in a recreational activity, he looks forward to these activities.

Then it's back to the unit for lunch, which is delivered in shifts so there is never a lot of time to spend in the dining room talking to others or enjoying your meal. The temperature of the food has greatly improved in recent years when the kitchen was upgraded. Food can now be safely maintained at a fixed temperature for a number of hours and there is more ability to provide meals of each resident's choice. Individual menus are now planned a month in advance.

Most afternoons Peter spends in the day room, which is noisy and chaotic – he would like to be able to go to his room but the door is locked. Then around 4:30pm he and the other residents return to the dining room for a very early supper and some times Peter has to get into his pyjamas and then return to the day room to watch TV until bed time around 8:30pm, which is very early for a 39 year old man.

During the day Peter has had one brief chat with another resident, his friend Greg at the day program and the staff member who helped him with his lunch. Greg and Peter lived together for many years and became close friends. Last year Greg was moved to another unit and now they don't get to spend much time together.

In summer if there are enough staff rostered on he sometimes gets to go for a walk after supper around the grounds. Peter loves this time when the sun is setting and he can hear the birds in the huge trees that surround his unit.

### ***Living Stories***

In May 2006 NSW CID produced a booklet<sup>5</sup> outlining some personal stories of how people with intellectual disability live. Some of the stories are told by people with intellectual disability and some are through the eyes of a family member when their loved one was unable to speak for themselves. If you would like to order a copy of *Living Stories* please contact NSW CID.

**For more information contact NSW CID. Phone (02) 9211 1611 or 1800 424 065 or email [info@nswcid.org.au](mailto:info@nswcid.org.au)**

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<sup>5</sup> *Living Stories* NSW Council for Intellectual Disability 2006