

# **‘Everybody needs a home’**

**People from a non-English speaking background with disability and their families living in communities**

**- a research project about their concerns and hopes and their implications for public policy**



Multicultural Disability Advocacy Association of NSW

October 2005

Robert Gruhn researched and wrote this report for:

Multicultural Disability Advocacy Association of NSW (MDAA)

PO Box 9381

Harris Park, NSW 2150

Australia

Ph. +61 (0)2 9891 6400

Fax: +61 (0)2 9635 5355

e-mail: [mdaa@mdaa.org.au](mailto:mdaa@mdaa.org.au)

website: [www.mdaa.org.au](http://www.mdaa.org.au)

© Multicultural Disability Advocacy Association of NSW

MDAA is a non-profit peak body for people from a non-English speaking background with disability and their families and carers in NSW.

First published October 2005

ISBN 1-920821-20-1

This report is copyright. Non-profit community groups have permission to reproduce any part of the report, so long as the original meaning is maintained and proper credit is given to the author and the Multicultural Disability Advocacy Association of NSW. All other persons and organizations wanting to reproduce material from this report should obtain permission from the Multicultural Disability Advocacy Association of NSW.

# Contents

Acknowledgments.....	1
Summary .....	1
Introduction .....	2
Key issues facing people from a NESB with disability and their families.....	2
Outline of this report .....	5
Part 1     Background.....	6
People from a NESB with disability .....	6
Families and Carers from a NESB.....	6
Supported accommodation available to people with disability .....	7
Part 2     The Research .....	9
Methodology.....	9
Statistics .....	9
People with disability.....	9
Family members/carers .....	11
Part 3     What people said they were worried about .....	13
Worries about the future .....	13
Cultural barriers and the lack of information and knowledge .....	13
Being alone .....	15
Who can we trust? .....	15
Money and Resources .....	16
Family member /carer burn out.....	17
Concerns about de- institutionalisation.....	18
The physical environment.....	18
Part 4     What people said they want.....	20
Home is where my heart is .....	20
This is me.....	21
Getting the right support .....	22
Getting the support right .....	23
Part 5     Policy and Practice Implications .....	24
Public policy challenges and opportunities.....	24
Developing policy frameworks that work .....	25
Policy and program implications .....	25

Conclusion .....	29
Appendix 1 – People with a disability - Interviewee Profiles .....	31
Appendix 2 – Family members/ Carers - Interviewee Profiles .....	32
Appendix 3 - Accommodation survey for people with disability .....	34
Appendix 4 - Accommodation survey for family members .....	35

# Acknowledgments

MDAA would like to thank all those who made this research possible, especially our members, consumers and their families. This report is based on the comments, ideas and experiences of fifty three people who participated in this project – thank you for generously sharing your stories and giving your time.

MDAA also gratefully acknowledges the support of the NSW Department of Ageing, Disability and Home Care and the Commonwealth Department of Family and Community Services.

## Summary

This project aimed to ascertain and document the hopes and concerns of people from a non-English speaking background (NESB) with disability and their families about their accommodation and more broadly the circumstances in which they live. We undertook this project because there is a lack of information about the experiences of living in the community of people from a NESB with disability. We have not found any research or any systematic attempt to identify what people from a NESB with disability and their families want or need by way of support and we wanted to have a firm foundation for our contribution to the current debate about supported accommodation for people with disability in NSW.

We asked people from a NESB with disability and families/ carers associated with MDAA about their current and past accommodation experiences, what types of place they would prefer to live in and what kinds of support they wanted or needed. We interviewed 53 people; 27 people with disability and 26 family members/ carers. Most people with disability who we interviewed lived with their families or close by in group homes with other people with disability.

What participants reported about their current accommodation confirmed the need to change the way support for living in the community is currently provided. As we explore later, the challenge for providers and funders of support programs such as supported accommodation is to create systems that strengthen meaningful relationships and networks which form the foundations for community support within local communities.

At present, supported accommodation and other government provided and funded services in NSW are planned, provided and used by Anglo-Australians. Thus, services are delivered on the basis of ethnicity/ culture rather than need. Throughout this report and the research on which it is based, MDAA's focus is on the needs of people from a NESB with disability, particularly those who want to live with their families, and the barriers people experience in trying to meet those needs.

We see this report as our contribution to the debate on making systems work for people and to how Government can respond more effectively to a growing demand for new support systems within NESB communities. This report seeks to identify how the disability sector overall and supported accommodation systems in particular can best support people from a NESB with disability, the majority of whom wish to live and participate actively in communities.

# Introduction

In January 2005, the Department of Ageing, Disability and Home Care (DADHC) started a consultation and discussion process about supported accommodation options for people with disability.

There are various reasons why the NSW Government would engage in such a process at this time, including:

- **delays in closing large institutions:** in 1998 the NSW Government promised to close all large residential state run institutions by 2010, but by 26 May 2005 only 271 people<sup>1</sup> had been relocated from those institutions. Further, in a recent submission to the NSW Government, the Council of Social Service of NSW (NCOSS) states that 'less than 25% of people living in institutions have been relocated by the end of 2004'<sup>2</sup>.
- **high levels of unmet need:** in 2001 there were 12,500 people with disability under 65 years of age in Australia with unmet needs for accommodation and respite services. In NSW alone there were over 7,000 people with disability who needed supported accommodation services.<sup>3</sup>
- **ageing population**, including carers who are ageing and increasingly unable to provide support to their family member with disability: it is estimated that in NSW approximately 4,000 ageing family members/ carers of people with disability need support to provide sufficient support and assistance.<sup>4</sup>
- **the need to find better ways to provide support:** overall there appears to be an acknowledgment that the way things have been done in the past have not met the needs of many people with disability and have not furthered one of the primary objectives of the *NSW Disability Services Act 1993*, to 'ensure the provision of services necessary to enable people with a disability to achieve their maximum potential as members of the community'.

---

<sup>1</sup> NSW Legislative Council Hansard (26 May 2005): 'Residential Institution Closure', p. 16218, see: <http://www.parliament.nsw.gov.au/prod/parlment/hansart.nsf/V3Key/LC20050526014>

<sup>2</sup> By the end of 2004, about 1,800 people remained in large residential facilities in NSW. Council of Social Service of New South Wales (December 2004): 'Submission to the New South Wales Government', p. 30, see: <http://www.ncoss.org.au/bookshelf/pbs/submissions/2005-06pbs.pdf>

<sup>3</sup> Wadiwel, Dinesh (December 2003): 'Accommodation and support crisis for people with disability?' see: [http://www.ncoss.org.au/bookshelf/disability/articles/0312\\_accomodationcrisi.html](http://www.ncoss.org.au/bookshelf/disability/articles/0312_accomodationcrisi.html)

<sup>4</sup> Ibid.

# Key issues facing people from a NESB with disability and their families

In relation to people from a NESB with disability there are several critical issues for government and the service systems to consider and respond to.

While people from a NESB make up about 25% of the total disability population, in NSW only 0.2% of accommodation support service consumers are from a NESB. This is the lowest figure among all the Australian States and Territories.

This figure is shocking and totally unacceptable. It speaks not only of the racist nature of the supported accommodation system (whether deliberate or not) but also of the system's inability to provide services which are culturally competent and appropriate. This inability results in some people from a NESB not knowing about the services available, while others who do know about them make a considered decision not to use them, because the services operate in ways that do not support people to continue their cultural or religious practices or they do not communicate in ways people can understand.

MDAA has provided advocacy assistance to people from a NESB with disability and their families since 1997. For the past five years accommodation has headed the list of the top five issues for which people need MDAA's advocacy assistance. This led to our report *Hitting the Roof* in 2003, which described the experiences of people from a NESB with disability with public housing. Two years later, when we searched for references, that report was still the only publication we found which specifically addresses accommodation issues for people from a NESB with disability living in NSW.

A 2004 DADHC initiated discussion paper on supported accommodation models states that a successful service evaluation needs to involve all stakeholders, including people with disability.<sup>5</sup> Taking up that challenge, in the research described here in this report we attempted to bring to light the voices of people from a NESB who have previously been excluded.<sup>6</sup> MDAA considered that people from a NESB with disability and family members needed to be able to express their needs and wishes from their own individual point of view. We therefore consulted the community by interviewing a diverse range of people from a NESB with disability and families and carers of people from a NESB with disability.

The research described here shows what people from a NESB with disability want from systems. What is needed from the NSW Government now, if equity is to mean something more than meaningless rhetoric, is the will to address the following key issues.

## Inequitable access

The accommodation service utilisation rate for people from a NESB with disability remains at a disturbingly low level. As with other services, the quality and availability of services is crucial, as many people from a NESB with disability and their carers only access accommodation services when they are already facing a crisis.<sup>7</sup>

---

<sup>5</sup> Centre for Developmental Disability Studies (CDDS) (December 2004): 'Innovative Models of Community Support for People with High and Complex Support Needs' [Prepared for the NSW Department of Ageing, Disability & Home Care (DADHC)], p. 19.

<sup>6</sup> An MDAA commissioned research and literature review revealed that so far there is very little information on access to services and utilisation rates in the disability sector by people from a NESB. See: Procter, N.G. (2004) 'Moving forward together: An international comparison of successful strategies to improve access and equity for people from ethnic minorities', University of South Australia, Adelaide.

<sup>7</sup> MDAA (2005): Response to DADHC Supported Accommodation Models Discussion Paper, p. 5.

## **Cultural incompetence**

The research reported here and much of our earlier work<sup>8</sup> highlights that the NSW disability support system, including the supported accommodation system, lacks the competence to respond appropriately to differences such as culture, ethnicity and religion.

## **Lack of culturally and linguistically accessible information**

Lack of access to information remains one of the key barriers. Despite policies and directives from the former Premier, DADHC services are actively encouraged not to use interpreter and translation services.<sup>9</sup> In addition, information about services available is often too complex and difficult to understand, particularly if it is not provided in community languages.

For many people from a NESB with disability, better access to and knowledge about services, for example community programs, is crucial for achieving equal participation.

If services such as the Translation and Interpreting Service (TIS) and the Community Relations Commission for a multicultural NSW (CRC) continue to use the 'user pays' principle for language services, the NSW government has to ensure that individuals and not-for-profit service providers are financially adequately equipped to access, for instance, free or subsidised on-site and telephone interpreting sessions. Until it does so, this policy creates unnecessary barriers for 25% of the NSW population to getting the information they need. With 25% of the NSW population either first or second generation from a NESB, this policy creates unnecessary barriers for many people to getting the information they need.

## **Unexpressed demand**

Due to cultural and linguistic barriers many people from ethnic communities do not know that there are services available which they could ask for, and would ask for if only they knew about them. Ethnic communities therefore do not demand services at the same levels as their Anglo-Australian counterparts and thus miss out on expressing and registering their needs.

## **No accommodation growth for 'new' people**

Unexpressed demand then leads to people from a NESB with disability missing out on any new resources allocated to address unmet need. MDAA believes that the growth in resources in Disability Services over the past five years has increased the gap between the service utilisation rates of people from a NESB compared with their Anglo-Australian counterparts. Thus, additional resources have led to an increase in the relative marginalisation of people from a NESB with disability, not a decrease.

## **Ageing carers**

As with their Anglo-Australian counterparts, carers from a NESB are ageing. The numbers of people from a NESB with disability who will need services due to the age of their carers will increase rapidly over the next 10 years. There are many adult children of post-World War II migrants, who are now in their 40s and 50s. Many of these adults with disability have never used any service and many have lower skill levels than their Anglo-Australian counterparts.<sup>10</sup>

---

<sup>8</sup> For example: Kingshott, Maureen: "Hitting the Roof. Public housing experiences of people from a non-English speaking background with disability" [published by MDAA], 2003, p. 22.

<sup>9</sup> MDAA (2005): Response to DADHC Supported Accommodation Models Discussion Paper, p. 6.

<sup>10</sup> Given that people from a NESB with disability are in the 'highest risk group' to miss out on services, the current lack of knowledge about NESB residents of large institutions and their families' cultural background is

Thus, the main challenge facing governments and bureaucracies concerning people from a NESB is to provide services in culturally competent ways that will meet the diverse and changing needs of people, and enhance and further the potential of people from a NESB with disability living in communities in NSW. MDAA believes there is a real danger that supported accommodation service systems will remain culturally incompetent and provide inappropriate and ineffective services. People from a NESB with disability and their families will not use (or will not be comfortable using) a service that is not culturally appropriate. No-one would expect Anglo-Australians to use a service that ignored or did not respect their cultural needs. Yet this is what many services expect people from a NESB to do: take it or leave it and if you don't like it, that's your problem. If services continue to ignore the cultural diversity of the NSW population, the result will be a continuation of the present institutional and structural racism, unintended perhaps but real none the less. Ignoring cultural diversity will *not* make it go away, but it *will* perpetuate avoidable hardship and resentment for up to 25% of the people the system is supposed to serve.

## Outline

The first part of this report provides some background information about the various types of supported accommodation in NSW and explains why we undertook this research project. It will become clear that people from a NESB with disability face specific challenges within the current de-institutionalisation process and the supported accommodation system.

Part two introduces the research, which comprises interviews with individuals from a NESB with disability and family members/ carers of people from a NESB with disability.

Based on the experiences of these participants, part three and four describe the particular needs expressed and provides some general comments about the hopes, dreams and concerns. Recognising that most of the participants favoured either in-home or family support options, these parts explore the importance of establishing an 'integrated' disability service system.

Part four examines the scope for implementing alternative policies, particularly community focussed service options and culturally competent management practices. In this part we propose that community responses are promising and will achieve outcomes for people with disability, their families, community and the NSW Government.

# Part 1 Background

## People from a NESB with disability

### Definitions of NESB and disability

MDAA defines a person from a NESB as a person who is:

- born overseas and whose language or culture is not English or Anglo-Australian;
- born in Australia and who has at least one parent whose first language or culture is not English or Anglo-Australian; or
- born in Australia with linguistic or cultural background other than English or Anglo-Australian who wishes to be identified as such.

Further, MDAA believes that any narrow definition of 'disability' leads to the use of labels and classifications. While this may be necessary for bureaucratic, statistical or budgetary purposes, it needs to be acknowledged that these classifications do not hold true across cultures, as definitions of disability are predetermined by a person's cultural background and hence do not reflect the variety of culturally determined beliefs and attitudes.

### Statistics

People from a NESB with disability make up about 25% of all people with disability (334,350 people) [Australian Bureau of Statistics 2004].

Available research on the numbers of people from a NESB with disability living in supported accommodation (Mullane at a CDDS Health Promotion Forum, April 2002) shows that no more than 2.23% of people with disability living in supported accommodation are from a NESB. The *Steering Committee for the Review of Government Service Provision* identified that about 25% (1 in 4) of the eligible population receives only 0.2% (1 in 50) of the places made available by accommodation support services (*Steering Committee for the Review of Government Service Provision: 'Steering Committee Report: Report on Government Services 2004'*).

## Families and Carers from a NESB

Carers are family members or friends who give support and assistance to a person with disability. According to 2005 statistics, 2.6 million Australian carers provided informal care adding to a total of 1.2 billion hours of care.<sup>11</sup> In Australia, the value of resources necessary to replace the support and assistance provided by informal carers would be \$30.5 billion – an equivalent of more than 60% of the total sum spent on other formal health care.<sup>12</sup>

In NSW, one in eight people are carers. This represents about thirteen per cent of the population or almost 800,000 people (ABS, 1998). MDAA estimates that at least 24 per cent of those 800,000 or 192,000 people are from a NESB.<sup>13</sup>

---

<sup>11</sup> Access Economics Pty Limited (August 2005): 'The Economic Value of Informal Care', p. i, See: <http://www.carersaustralia.com.au/images/stories/Access%20Economics%20study%20full.pdf>

<sup>12</sup> Access Economics Pty Limited (August 2005): p. i.

<sup>13</sup> 42% of the population (6,038,696) were either born overseas (English speaking + non-English speaking countries) or have one or both parents born overseas (English speaking + non-English speaking countries) [ABS, 1996 Census]. 57% of those born overseas or who have one or both parents born overseas come from a non-English speaking background [ABS, 1996 Census]. Thus, 24% of the population is from a non-English speaking background.

There is a myth that all people from a NESB have access to extended family support. This myth continues to be upheld by many service providers and funding bodies. In reality, however, many migrant families with a member with disability tend to socialise less and have fewer contacts with other people, usually only people who accept the disability. Often beneath this isolation lies a migration process which may have been traumatic.

Carers from a NESB often only seek help when they reach a crisis point. Excessive responsibilities are carried by families and carers from a NESB and they may experience multiple layers of disadvantage – disability, poverty and disruption to the family as a result of migration, diminished support networks and lack of sufficient and appropriate services. In general, carers from a NESB have a ‘grin and bear it’ attitude, even more than their Anglo-Australian counterparts. Asking for support is seen as failing, not only in one’s caring role, but also failing the family, the community and, most importantly, the person they are caring for.

In addition, the impact of ageing will become critical, especially in some of the communities who arrived in large numbers shortly after World War II. A recent MDAA project on people with a disability who are ageing and their carers revealed the increasing difficulties experienced by ageing carers in providing the support needed by family members with disability.<sup>14</sup>

## **Supported accommodation available to people with disability**

While this research project did not focus on particular types of support but on the wishes, dreams and needs of people with disability, nevertheless it is useful at the outset to clarify the current types of programs provided to people with disability in NSW.

Recent developments in NSW, including an ageing population and the ongoing deinstitutionalisation process, have led to increasing expectations and an increasing demand from people with disability and their families for supported accommodation programs. Supported accommodation programs range from more traditional options, such as group homes and institutions to various community living support programs.

### **Institutions**

Institutions, also called ‘large residential facilities’ are most commonly described as hospital type accommodation with large ‘wards’ and grounds separate from the community. Large numbers of people continue to live in Government owned institutions.

### **Group homes**

Group homes are mostly small houses, owned or rented by a disability service provider, which accommodate between 3 to 6 people who live together mostly because their disability related needs are deemed to be similar. Group homes have become the most popular option, and often the only option, for many people with disability. It is generally accepted that some group homes function quite well and deliver services based on individual needs, while others are run as mini-institutions.

### **Independent living and in-home support**

Independent Living programs are a handful of different programs available largely through the non-government disability services sector to people with intellectual disability to support them to live in their community. In-home supports provided through the Home and

---

<sup>14</sup> Gichia, Christine for MDAA (September 2004): ‘I like to go to Queensland... I have no other future plans. Growing older: Hopes and fears of people from NESB with disability and their families and carers.’, see: <http://www.mdaa.org.au/service/systemic/04/carers.html>

Community Care (HACC) program can offer a range of more individual needs based, practical assistance and personal care programs supporting people to live in their own home. The Attendant Care program and the High Needs pool can also offer flexible services for a defined group of people with disability. These programs are popular and seen by many people with disability as being more flexible and responsive in meeting their needs. Most of these programs have very long waiting lists.

### **Family support**

Currently, a considerable part of the informal social infrastructure provided to people with disability, including most of the social, emotional and financial support needed to participate as members of the general community, is provided through family support. '*The Economic Value of Informal Care*'<sup>15</sup>, a recent report commissioned by Carers Australia, identified that carers (and families) contribute \$30.5 billion (value of potential replacement) to the Australian economy. The Federal Government supports carers through the payment of a Carer Payment of \$488.00 (maximum per fortnight) and a Carer Allowance of \$92.40<sup>16</sup> (per fortnight). As mentioned above, as the family carer grows older, support for their adult children with disability becomes increasingly difficult.

---

<sup>15</sup> Access Economics Pty Limited (August 2005): 'The Economic Value of Informal Care', see: <http://www.carersaustralia.com.au/images/stories/Access%20Economics%20study%20full.pdf>

<sup>16</sup> The Carer Payment is subject to assets and income tests; the Carer Allowance is not.

## Part 2 The Research

### Methodology

We wanted to collect information directly from people from a NESB with disability and families and carers of people from a NESB with disability. To do this we identified possible interviewees in consultation with MDAA's Individual Advocates (IA). We designed a questionnaire (see Appendix 1) to gather information about people's accommodation experiences, their hopes and concerns now and for the future. To introduce the project and invite people to participate, IAs contacted MDAA members and consumers, and family members/ carers of people from a NESB with disability, e.g. where a person with disability was unable to participate themselves; we contacted a member of their family. MDAA staff then contacted each of the people who agreed to participate, by telephone or face to face, and recorded their responses to the questionnaire.

Participants included people with a range of disabilities, from a variety of cultural backgrounds, with a broad range of support needs, and family members/ carers of people from a NESB with a range of disabilities, cultural backgrounds and support needs. People with disability who live in large residential institutions, people with high support needs and people without any family support were under-represented in this research. While this is a serious shortfall, it does not detract from the *wishes* and *aspirations* of the people we interviewed or the validity of the policy responses needed to address those wishes and needs.

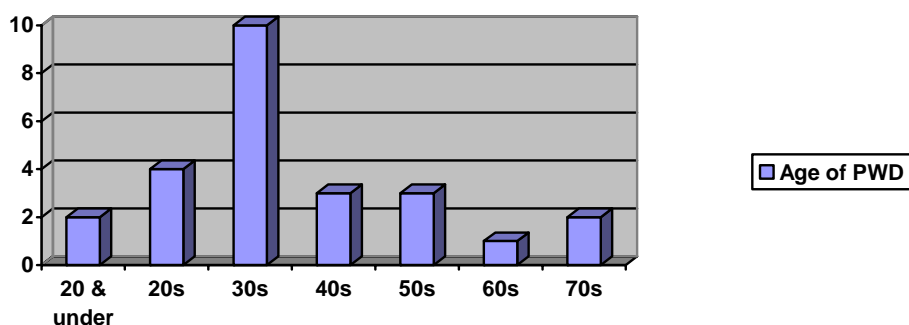
### Statistics

We interviewed 53 people of whom 27 were people from a NESB with disability and 26 were family members or carers of a person from a NESB with disability.

#### People with disability

##### A) Age

Most of the participants with disability were in their 20s and 30s. People in their 40s and 50s were the second largest group. Considerably fewer participants were 60 years or older.



## B) Gender

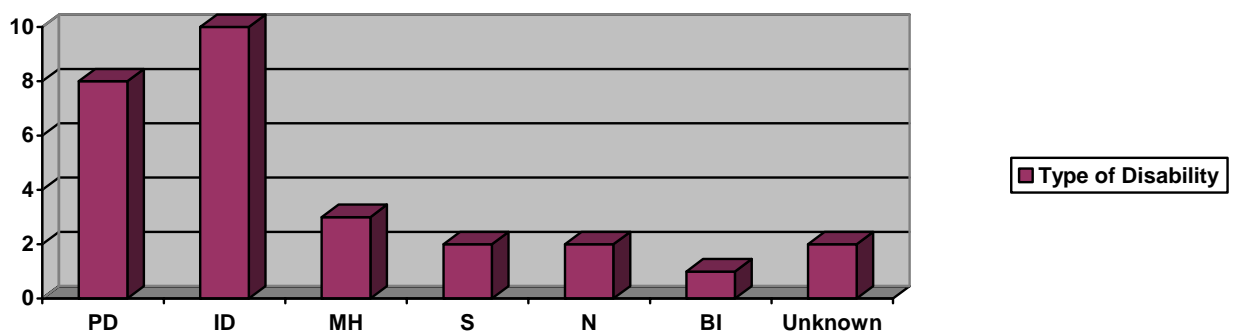
There were almost equal numbers of male and female participants with disability.

## C) Ethnicity

The ethnic background of the participants with disability reflects the diverse community in New South Wales. The participants were from different ethnic backgrounds, including from Chinese (7), Indian (4), Italian (3) and Lebanese (2) background. The rest of the participants were one each from Chilean, Turkish, Ukrainian, Croatian, Bulgarian, Philippine, Fijian, Samoan Islander, Cook Islander, Tongan and Malaysian background.

## D) Type of disability

More than 50% of participants with disability had either a physical (PD) and/or intellectual disability (ID). Other disabilities included mental health (MH), sensory (S), neurological (N) and brain injury (BI).



## E) Where do people live

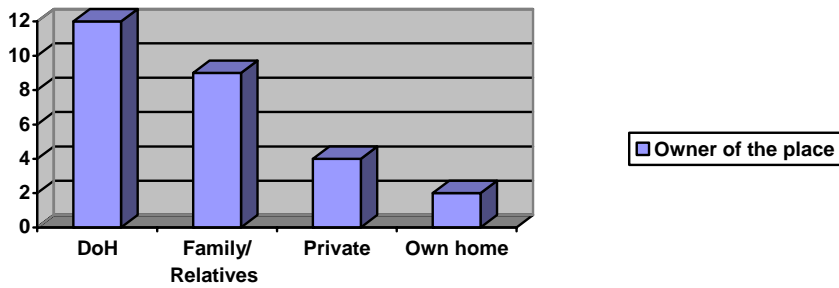
The largest group of participants with disability (21) live in Sydney. 6 live in the regional cities of Wollongong and Griffith or in rural areas close to those regional cities.

## F) What sorts of places do people live in

Almost a half of the participants with disability live in their family house or unit. The second largest groups of people live either in a group home or a public housing unit provided by the Department of Housing (DoH). The remainder reside in private rental units, DoH subsidised private housing or refuges.

## G) Owner of the place

The DoH owned more places than anyone else, followed by the family or relatives of the person with disability, then private landlords, with the smallest group of home owners being people with disability themselves.



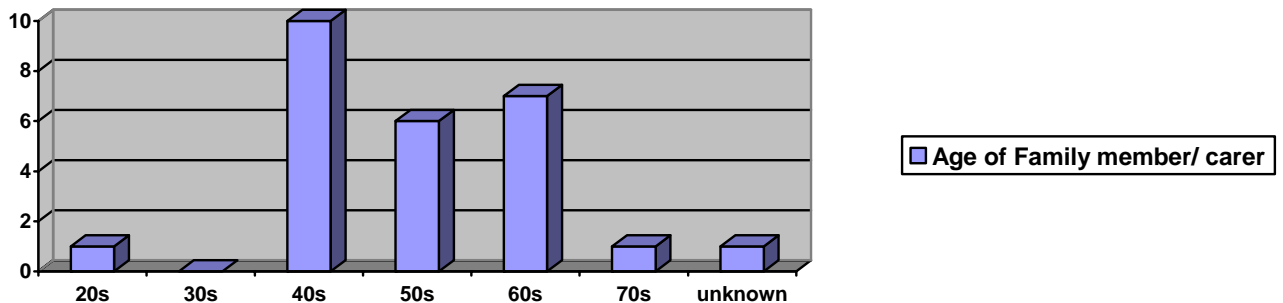
## H) Who chose the place?

Most of the participants with disability said that either their parents or the DoH made the choice about their place of residence. Due to the lack of alternatives and choices there is considerable pressure on people with disability and their families and carers to accept inappropriate housing offered by DoH.

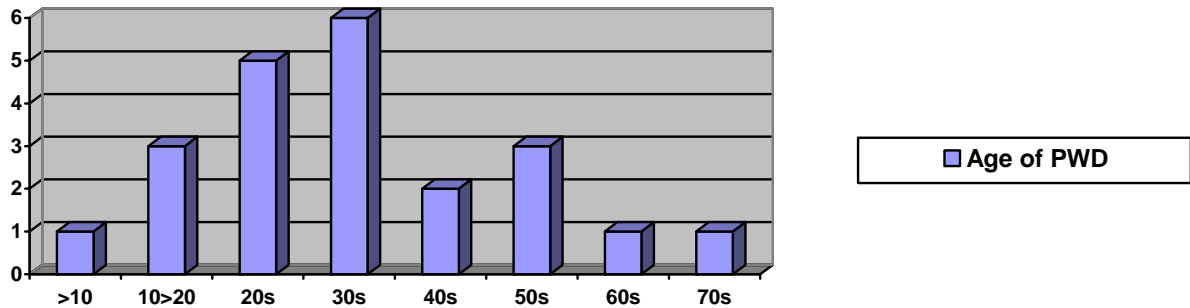
## Family members/ carers

### A) Age of family member/ carer

Most of the family members/ carers of people with disability were in their 40s; the second highest group were in their 60s; the third highest group were in their 50s; and a small proportion was in their 70s. The largest group of people with disability being supported by family members/ carers were under 20 (most were between 10 and 20); the second largest group were in their 30s; followed closely by people with disability in their 20s; then almost equal numbers of people with disability in their 40s and 50s.



## B) Age of the family member with disability



## C) Gender of family member/ carer

A disproportionately high proportion (75%) of family members/ carers was *female*.

## D) Ethnicity of family member/ carer

The family members/ carers were from a range of different ethnic backgrounds, including Lebanese, Indian, Samoan Islands, Sri Lankan, Argentinean, Greek, Chinese, Macedonian, Serbian, Italian and Filipino.

## E) Type of disability of family member with disability

The two biggest groups of family members/ carers supported members of the family with an intellectual and/or a physical disability. Other family members with disability had mental illness or neurological issues.

## F) Place of residence of family member with disability

The vast majority of family members with disability resided with their family, either in family homes or units. Four individuals lived in a group home; two lived independently in private rental housing and one in a DoH unit. One other person with disability lived in a mental health hospital and another one in a different institutional setting.

## **Part 3      What people said they were worried about**

### **Worries about the future**

Many of the people with disability and families/ carers we interviewed worried about the future. The main concerns were about the ability of the person with disability to live independently and safely within the local community. Repeatedly, people were worried about the lack of access to much needed services. Many said that there was a lack of assistance and support in case of emergency, but equally people talked about the need for accessible educational and employment resources and long waiting lists for accommodation services, respite, transport and other community programs.

Further, given that many of the parents we interviewed are ageing, there is a lot of concern about what will happen to adult children with disability in the future. Many parents and carers are concerned about better service provision for future care and support for their family members with disability. This worry is often focused on the size, accessibility and location of a place, the adequacy of the supports provided to the person with the disability and the need for culturally competent support staff.

### **Cultural barriers and the lack of information and knowledge**

*'Because we are from different cultures, we do not know what they like to do or their favourite activities. I don't want to talk to them because they might be surprised because I am a stranger, they might think I will do something to them.'*

As was expected, many participants talked about various barriers they face, including cultural barriers and barriers arising from their lack of knowledge.

Through the interviews it became very clear that people do not know 'where to start' and 'who to ask'. People talked about simply not knowing the service system, in some cases not knowing that there are services, not knowing what services there could be, not having any words to ask for a service because there is no word in the person's language for that service type, e.g. 'respite'. This combined with not being able to access interpreters easily adds many layers of complexity to an already very complex system. Many people reported simply giving up.

*'It is almost impossible for us to develop as human beings as we have to care for our son on an everyday basis. I tried enrolling at various courses at TAFE and tried looking for work; however I always find it difficult to get into anything. There is no-one to care for my son while I am away. ...I do not actually know anything about the variety of supported accommodation options available. Anyhow I would not allow my son to live anywhere else except with us. Our culture does not allow sending a person with disability into a group home or a nursing home.'*

Other difficulties included limited English language being seen as a barrier to gaining access to disability programs. Unfortunately, many people from a NESB with disability and carers said that they are unable to attend programs because services were unwilling or unable to supply interpreters or bilingual workers.

'Rurik does not have any friends and his social contacts are limited to us. Rurik wants to learn how to care for himself, for example, to get into a Living Skills Training so that he can further develop his skills and abilities. Being a person from a NESB poses a real difficulty for him because he has limited English proficiency and Post Traumatic Stress Disorder. Due to his limited abilities Rurik has serious difficulties in adjusting to Australia. We think that the emotional distress Rurik experienced as a result of what happened during the war has worsened since his arrival in Australia.'

'Our Rurik was put into an institution for 8 years in his country. Many times he also had to go to hospitals by himself. These were long separations from us. He also had to live in a refugee camp. These were very disturbing experiences for Rurik. We will never consider sending Rurik to live in an institution again.'

Many participants said that not knowing about services they are entitled to prevents them from accessing supported accommodation, community care and health services. In addition, information about services available is often too complex and difficult to understand, particularly if it is not provided in community languages. For many respondents, better access to and knowledge about services, like recreational activities or community programs, is regarded as crucial for achieving equal participation in community life.

'Although Rurik receives support from us as well as from a range of services, he is unable to attend a Living Skills program because his English is limited and no service is willing or able to supply interpreters or bilingual workers to assist. Without attending this program Rurik will not be able to get any independence. I am really worried about this.'

Many family members who support a person with disability believe there is nothing available to support them and that if they didn't support the person with disability the person would end up in either a group home or a nursing home. A few participants also knew about institutions which were usually considered to be like hospitals. In relation to the supported accommodation program, many families believed group homes and nursing homes were the only options available. Many families rejected both options. Group homes were largely regarded to be culturally inappropriate, while a few older parents said that nursing homes were better because sometimes people from the same culture lived there.

'We belong to the Kurdish community. We have the same difficulties as many other people from NESB have. Our biggest concern is that we are unable to communicate in English (unable to discuss our concerns for Akasma in our native language - sometimes interpreters are unavailable). Also, we do not feel comfortable to disclose our family situation to people outside our family and we are reluctant to seek assistance from people outside our immediate family.'

Participants, both people with disability and family members, regarded living at home with or close to family as the most appropriate option. For many families from a NESB, putting a family member with disability in the hands of others can be very difficult. Often, even if a family member may not be able to live independently and/or requires considerable personal care, the current options are not seen as desirable, and families do whatever they can to stay together. Almost all participants stressed continually the importance of family, of being part of the community and the importance of everyone participating in cultural events.

There seemed to be little understanding that while families wanted to support the family member with disability themselves, they wanted and needed culturally appropriate support. The lack of that support appears to have fuelled the myth that people from a NESB look after their own.

A further concern raised by participants is that insufficient regard is given to people from a NESB with disability who have experienced trauma in their country of origin.<sup>17</sup> Participants were very clear that anything that vaguely resembles institutional care is not a culturally appropriate support option. Participants who have had traumatic experiences said that the family home was the only suitable option to provide a quality life for the family member with disability.

## Being alone

As identified above, the vast majority of participants had close or at least regular contact with their families and many said that this contact was of critical importance to them. Those few who did not have family expressed a strong sense of isolation.

'I am so alone, I have kids [but I] don't have time to play or I don't have someone I can share my things with. Because I am from another country and by myself...I always feel alone. I [have] been here for the past ten years and when I go to town I am the strange person because I have not many friends. People from the same community they behave to me like I am the very bad person, sometimes they talk; sometimes they turn their face to the other side. I feel like they talk about my clothes and that I have no good taste. But I am not happy because I don't [know] anyone so I can talk to them as family or friend or as a human. Because I am depressed - I got depression because I am alone.'

Many family members who had placed the person with disability in an institution or a group home worry a lot about the isolation and loneliness experienced by the person with disability. The father of a young woman living in a group home sums up the concerns raised by many in similar situations.

'Natasha has no friends. She does not socialise very much. She has been often subjected to abuse from other people housed with her and often comes home with bruises to various parts of her body. She gets easily into conflict with other people. Natasha spends much of her time being locked up in the group homes and usually watches TV. She is rarely taken outside the group home. There are no recreational activities provided to people with disability in that place.'

One of the myths that people from a NESB with disability and their families have to contend with is the myth of the extended family, where everyone will pull together and rally around each other in a time of crisis. As with all communities, disability is regarded with suspicion in NESB communities, and as in the Anglo-Australian community, many people with disability and their families live isolated and marginalised lives.

## Who can we trust?

Many people with disability and their families expressed substantial concerns relating to their stability and privacy. Like everyone else, people from a NESB with disability and their families enjoy their privacy and value living in a place with secure tenure.<sup>18</sup> A friendly,

---

<sup>17</sup> The separation from parents and torture, trauma and war or life in refugee camps makes it even more necessary to provide a stable environment and secure accommodation.

<sup>18</sup> The issues of providing safe and secure community-based accommodation, treatment programs and health/rehabilitation services become even more crucial for families and individuals from a NESB who have torture and trauma related disabilities, e.g. Post Traumatic Stress Disorder (PTSD).

peaceful and quiet neighbourhood and familiar surroundings were highly valued by participants.

'The Department of Housing interviewed me about where to live and what I wanted. The first Department of Housing place was not appropriate. They chose it. I was not asked. The environment was not good. The neighbour was an alcoholic and there were drug addicts in the building. I lost my independence and self esteem. I did not feel safe and confident.'

Many families and carers who have a family member with disability living in a group home and who are unable to support them at home wished for places to live and support systems that are permanent and secure. The lack of security and stability was considered by many to be detrimental to the health and well-being of the person with disability.

'I was told that once the Department finds another accommodation owned by the Department as a replacement then I have to leave this accommodation. This makes me worried as I feel comfortable here and I don't want to lose it.'

Participants valued their personal safety, and several reported that they felt unsafe in their neighbourhoods, some of which have high rates of crime. Others said that they had neighbours or co-tenants who were rude, selfish, noisy, interfering or threatening.

Several participants regarded the family home as safer and more suitable because of the potential exploitation or abuse of people with disability.<sup>19</sup>

'Hermes moved into this group home after a dispute with the service provider. Hermes had been harassed in the group home he lived in for over 10 years. It all fell down because a new resident moved in, nobody asked us and Hermes what we wanted and then that resident started to harass our son. We had extensive advocacy but the best that could be done was to move our son. It's not fair, why should he move? He had lived there for a long time.'

## Money and Resources

Many participants who currently accessed some services were acutely aware of the lack of resources in the system and how everything they received had been achieved as a result of persistent struggle and determination. One family member answered the question about what they could do to access the supported accommodation service required by saying:

'This question is a joke as we have done everything possible through our case manager over the past 2 years, but we have been told that there are no places available and there is no funding for new places. If there is anything left to be suggested please let me know as soon as possible.'

Particular areas of concern identified were:

- long waiting lists
- lack of affordable respite
- lack of and narrow eligibility criteria for specialist services, such as hearing services, visual aids and speech pathology

---

<sup>19</sup> One family reported that the family member with disability was sexually assaulted by one of the group home workers. Since then the family had decided to withdraw their daughter from the group home and look after her at their family home.

For many people with disability, getting the support to acquire and develop living skills as soon as possible, e.g. through early intervention programs is crucial. Because of the barriers identified above, people from a NESB with disability often do not receive those services and if they do receive them it is too late. Participants emphasised the need for speech pathology, hearing and visual aids and behaviour management programs. Participants with mental illness and families of people who have a mental illness particularly raised the issue of being completely unsupported for any kind of independent living at home.

'I do not know what is available for my granddaughter. I and my wife are both elderly people who have been diagnosed with various medical conditions. We find it increasingly difficult to care for Zorana. Four years ago we spoke to a social worker from DADHC and asked her about the variety of supported accommodation available to our granddaughter. The social worker told us that there is nothing available for Zorana. We were very disappointed to hear this and we constantly worry about what will happen to her when we are gone. One thing we know is that we do not want to see Zorana being placed in an institution.'

'We requested residential respite services - have been approved but not yet commenced. My sister was also referred for a home gardening assistance program, to teach her gardening at home but this never occurred. She was also to be taught how to prepare simple meals, to care for herself but she has not received anything so far.'

'I am not sure what we are supposed to do to get a supported accommodation place. Is there are something like that available for our Zorana Right now the only thing we want is to get appropriate accommodation for all of us through the Department of Housing. We would like to see the government giving Zorana an opportunity to move into long term housing in the community and be supported through various services. However, at present Zorana lacks the skills to live independently. I am concerned that she may not be able to move either one of her hands.'

An issue raised by families who have a member of the family living in a group home or institution is the increasing costs they are expected to pay for recreational and other activities as well as for essential clothing, toiletries, etc. Several participants reported that they had been asked to contribute to the costs of employing staff.

### **Family member/ carer burn out**

Some family members/ carers are very close to burn-out, especially those who have a disability themselves. This has led to an inability to support the family member with disability under current circumstances and if no intervention takes place, will inevitably lead to a family breakdown.

'We try our best to give Giulia all her needs at home but because of our commitment towards her brothers and sisters and due to the high support needs for Giulia and the continuous care required for her survival we find ourselves exhausted and unable to care for her sometimes. We have a few hours from different service providers for Home Care and Respite.'

## Concerns about de- institutionalisation

Families whose members are from a NESB with disability and who live in institutions face different concerns. Respondents indicated that there is little understanding among family members about what is happening to their children in these institutions. This concern confirms MDAA's work in 2002 with Arabic speaking families who have family members with disability living in institutions.

## The physical environment

While the physical environment is an issue not only for people from a NESB, many participants raised the physical environment of the places where people lived as important. As many participants lived in places provided by DoH, their concerns have implications for the provision of public housing in NSW.<sup>20</sup>

Participants raised three main issues:

- the need for places to be near the person's community, work and services
- overcrowded, inaccessible and unmodified public housing accommodation
- the effects of housing environments on the mental health a person who has experienced torture or trauma

First, respondents expressed a common desire to live near amenities: work, shops, medical, transport and religious facilities. People believed they could achieve high-quality family and community relationships by being accommodated close to family members and to places of worship. For people with disability who are less mobile, it is particularly important to live closer to, e.g., their work, bus and trains, doctors, places of worship and shops.

Prior to the accident Burian lived with his aunt in a two bedroom unit provided by the Department of Housing. After the accident Burian stayed in hospital for three months. Then the hospital needed the bed, but appropriate accommodation needed to be found. A family member said the hospital staff pressured the family to send Burian to a nursing home.

For the past few months Burian and his family have lived in a privately rented property in the community. The family like living in this area as they have some family support as well as some friends they met from the community who can provide some assistance and support. In turn their son has more opportunities to socialise with other people from his community and be involved in more activities.

---

<sup>20</sup> Concerns to exclude service users, e.g. from the Supported Accommodation Assistance Program, are supported by a 2004 report by the NSW Ombudsman stating that potential service users from this group were discriminated against on the grounds that 'Clients with limited mobility cannot be accommodated due to the physical nature of the building and lack of facilities' See: NSW Ombudsman (April 2004): Summary Report: *Assisting homeless people – the need to improve their access to accommodation and support services*, p. 10.

Secondly, many respondents who live in public housing referred to the lack of access to appropriate, accessible and spacious places. A considerable number of the respondents live in overcrowded, inaccessible and unmodified accommodation. Examples of need include: ground floor or wheelchair modified accommodation; larger floor spaces and room sizes; more accessible amenities like the bathroom and enough storage for specialist equipment. Many respondents with disability explained the need to overcome architectural barriers and for specialist disability accommodation with wheelchair accessible rooms and facilities to suit various disability-related needs. Many of the concerns relate to a lack of purpose-built facilities and repairs in older homes and run-down flats. Several families also pointed out that the current public housing stock does not accommodate larger families.

Finally, some families who experienced torture and trauma before migrating to Australia reported that there was little understanding about the effects that living environments can have on their mental health.

Burian and his family are refugees. They experienced severe torture and trauma during the war in their country of origin. They had to flee their home leaving all their possessions behind. They moved somewhere else in the country where their father was killed in front of his family. The family then had to live in refugee camps under difficult conditions and were regularly mistreated and abused. The lack of appropriate secure accommodation is a key factor in heightening the fear and terror they experienced. The family were offered accommodation by the Department of Housing on two occasions but rejected both offers because:

- The first was opposite the cemetery. This could trigger the most common physical and psychological disorders of the experience of torture and trauma such as intrusive memories, panic attacks, nervousness, as well as feelings of powerlessness, worthlessness, alienation, depression and guilt.
- The second was outside the area the family are familiar with, far away from transport and from the school Burian's sister attends. The property was also too small for the family's requirements.

## Part 4 What people said they want

In our interviews we wanted to focus not only on people's concerns and the things that do *not* work for them, but also on what people wanted, what they dreamed about and what their hopes for the future were. People with disability and families/ carers were overwhelmingly clear about what they wanted. Everyone wanted people with disability to live in the community, with or close to family and friends, supported by services to achieve the highest quality of life possible.

It was very clear that people understood 'home' to mean something very different from simply a place to live or a supported accommodation program. Participants in this research spoke of wanting a home, a safe place where there was a sense of belonging and comfort, where people experienced a connection with others around them and where people believed they could make a real contribution to their community.

Unlike the notion of independence we believe the best term to describe what people dream about, is encapsulated in the notion of interdependence. This means that, to be part of society, people with disability are equal members of their social network (e.g. families, friends and carers) providing and receiving practical and emotional assistance. Interdependence, unlike independence, acknowledges that all human beings are social beings who rely on two-way relationships with each other, created by family, friends, neighbours, associations and communities.

The way respondents talked about the importance of belonging and creating a sense of interdependence with communities can best be summed up in people with disability and their families:

- having many significant and diverse relationships with a broad range of community members;
- being included and supported in a safe community/ environment;
- having opportunities for personal growth and development; and
- having something to look forward to.

For people with disability and their families to achieve interdependence and feel a sense of belonging, several things need to be right for people.

### Home is where my heart is

*'A place is just a place, but people around you make it a lot better. I want to live with my kids and my parents as well. People [have] got the sister, brother, cousins, mum's cousins, dad's brother, sister all they got a big group of family so they meet someone one time here or there. So they don't have a place for sadness.'*

One of the most important things highlighted by our research is that everyone we interviewed expressed a need to have a home and to belong. Meeting this need was perceived to come primarily from living within local communities and by having significant relationships with family members, friends and neighbours.

Many respondents believe there are many benefits from living as a family. Many stressed the importance of living with or close to people from a similar cultural and language background or in a small-scale housing arrangement close to the family home. Respondents said that their own home is more likely to provide varied social interaction and consequently to meet the emotional needs of people, particularly people with disability. Families from a

NESB considered that living at home gives people with disability more opportunities to grow and develop cultural and social skills.

Opportunities to create and maintain strong ties to the neighbourhood and the local community were seen as other crucial aspects in developing a sense of identity, home and belonging. Indeed, to be part of the community and to live with or be surrounded by family or friends was one of the most important things people from a NESB with disability talked about.

Of course there were differences in response and while the vast majority of those interviewed wanted to live with, close by or near their family and friends, some female respondents wanted to live away from their spouse because of abuse.

A large number of respondents wish for a range of close contacts in the local community, to form good relationships with friendly neighbours and to build a strong, close network of friends. In order to 'escape' the 'client role', people with disability said they want to strengthen existing links and support networks. Respondents living in group homes want to be included, rather than being seen as 'special' and isolated from others in the community.

## **This is me**

'I have a lot of friends in the place I live now. It was very difficult when we first moved into our new house as I had to leave everything behind. It took me a while to get used to the new environment. However, I really feel content now. I do not have to travel far to get to the beach. Sometimes I go to disco, bowling, and football matches with friends.'

Having a sense of self and associated with that a sense of self-determination was one of the main issues talked about by people with disability. This was raised particularly by people with disability living in group homes. Simple things like having a room to oneself or 'giving personal touch to things' were issues talked about. The majority of respondents with disability value independence highly and expressed the wish to have more choice and control over their accommodation and everyday life generally. People want to be involved in decision-making and have the freedom to have friends over at their place.

Many respondents emphasised the need to support the development of friendships in the community. There is considerable concern that the person with disability does not have many social contacts. Many people raised the issue that within the community at large and their community in particular there is stigma and misinformation about people with disability. Respondents recognised that being physically present in a community, for example at schools, workplaces and neighbourhoods, does not automatically mean being 'actively involved' or having strong relationships with community members, thus being integrated into the community.<sup>21</sup>

There was a clearly expressed urgent need to address the stigma and prejudice towards people with disability in the general community. Respondents also talked about the need to support people with disability to feel empowered to develop the skills and abilities which enable people to live interdependently in different communities.

---

<sup>21</sup> People from a NESB with disability living in group homes have particular difficulty finding friends and building social networks.

## Getting the right support

Respondents talked about getting the types of support which are right for them as individuals and which will enable them to achieve interdependence and live fulfilled lives in their communities. Many respondents made suggestions about the services they needed to improve the quality of their lives.

A considerable number of respondents expressed their interest in sharing accommodation to be in contact with and live among the local community. There were several suggestions about sharing which involved people without disability. Wishing to integrate into an 'everyday' work life and to be socially integrated in the community, the vast majority of respondents preferred types of support to enable the person with disability to live near or in the family home.

Reflecting the importance of family, many respondents strongly expressed the wish for everyone in the family to be involved with any external support service and saw it as a partnership, working together to achieve the same outcomes for people with disability. This included opportunities to use funding to pay for the support and personal care provided by family members and friends.

'Services don't have the capacity to provide adequate support - they need a more flexible approach. Jai would benefit by living at home and having a carer for supervision and companionship. I believe he will continue to improve and develop all his life to become almost independent but he needs a carer now to foster this.' What needs to happen for this to become a reality? 'I understand that in Victoria there are more options for a person with disability staying in a home of their own, with assistance with financial matters, budgeting, shopping, banking, etc. Jai would need a trust fund for this. He would also need support for shopping, cooking and personal care at the moment although I believe he will increase his skills in these areas over the next 10 years.'

Family members of people with disability with higher support needs suggested that their family member with disability should and could be encouraged to live interdependently, preferably by developing programs which focus on skills development. Family members repeatedly referred to the importance of teaching living and language skills, speech therapy and the opportunity to participate in early intervention programs.

'The extra support I need is learning how to stand up for myself and communicate better with the landlord and the neighbours and to get a job. The job agencies don't know how to work with people with depression.'

Many respondents addressed the issue of access to meaningful and age-appropriate activities to do during the day. Many respondents with disability focused on developing their skills and want to be involved in programs which further their skills and education. Areas listed as requiring further training included 'Learning how to cook', 'How to do shopping', 'Help with money management' and support with jobs and employment matters.

Many family members of people with high support needs asked if they could be trained to provide more of the 'medical' support and if that care could be provided in their homes. In spite of the high carer burn-out rate, many carers said they want to continue their caring role, but to do so they need easy access to respite and other support services, particularly in times of crisis.

## Getting the support right

'The decisions/choices should be made in consultation with the person with disability and their family. People with disability need to live in the community and not be segregated away from the community, e.g., in a block of flats inhabited only by people with disability. We need better planning for where the accommodation is located - close to public transport, shops, and doctors. Apollo would also need someone he trusts whom he could call on for support and assistance with financial matters, like budgeting, shopping and banking.'

Many respondents were very clear about what they need and how the support they are currently getting could be improved, so that they actually work for them, not against them.

'I get all my emotional and social needs from my family and friends who live close to me here in Bondi, I have a friend who comes and sleeps at my place once every week, I get support from Community Options for shopping and some domestic work. Otherwise I know how to cook and look after my hygiene.'

Further, many families having a person with disability living in group homes suggested that managers be appointed and more skilled staff be employed. Other requirements to improve life for the family member were having separate bedrooms; and renting a place close to the family, public transport, schools and universities, shops, medical services and hospitals.

'I would like to see my sister reside with people of similar cultural and language background as she does not speak English. I do not like to see her being locked up and not going out. I really hope that she will be allowed to come home occasionally. Hua needs to be taught how to behave in front of other people. I think a supervised and fully supported place might be an option for her quality of life. Otherwise, to house her close to us could be another option for her to be cared for and supported.'

Respondents spoke generally about a lack of options and a lack of flexibility to meet their individual needs. Several respondents suggested that empowering service users and their families to make decisions about the extent and quality of service provision would considerably assist in getting services right.

Finally, respondents made a range of suggestions to deal with language barriers, from the use of interpreters to the employment of bi-lingual workers.

'I think it's the right support there for him being from a NESB because they are a mixed group of people living here and staff are multicultural.'

## Part 5 Policy and Practice Implications

The final section of this report considers the policy and practice implications arising from participants' responses.

In response to the NSW Government's commitment to stakeholders, that it is 'not only listening but also acting to address their concerns'<sup>22</sup>, we put forward suggestions arising from what people from a NESB with disability, families and carers told us and what we believe are good ways to start resolving the issues raised.

### Public policy challenges and opportunities

Various policy challenges arise from our research.

Firstly, how can public policy generate what respondents in this research call 'home'? What can Governments and public policy do to contribute to that feeling?

Secondly, the current disability services system and the supported accommodation system are racially biased, with little capacity to respond to the diversity of the people they are meant to serve. How can the system respond to racial inequity issues as well as all the other challenges it faces? How can the resources be divided more equitably, and how can additional resources be used to increase service utilisation rates of people from a NESB? In this context it is also clear from our research that organisational and staff attitudes within the disability sector must be addressed. It is also critical to consider how to develop a system that is much better at responding to the individual needs of people (be they cultural or other needs).

Thirdly, ageing of carers will generate increasing pressures, particularly from some of the communities who came in large numbers to Australia after WW II. This will become more critical in the face of high levels of unmet need and, particularly within ethnic communities, very high levels of unexpressed demand.

Fourthly, like the wider human service sector, the disability services sector is facing increasingly serious shortages of workers. How can a skilled workforce be developed that is competent and embraces notions of flexibility and continual change?

Finally and most immediately, what can be done now to ensure that institutions are closed in accordance with the promised timeline and how can we ensure that the cultural needs of people from a NESB with disability living in those institutions are not overlooked?

Our research has also identified a range of public policy opportunities which we strongly recommend and which public policy makers must act upon to turn present opportunities into positive outcomes. First, there is an almost unlimited capacity and goodwill of people with disability, families and communities to use their potential, capacity and willingness to create opportunities for people with disability to live ordinary lives and to do ordinary things in their community. Secondly, we know from extensive research that a little money invested early will save more money that would have to be spent later<sup>23</sup>. Thirdly, we know that if applied in

---

<sup>22</sup> Della Bosca, John, Minister for Ageing and Minister for Disability Services (September 2005): Minister's Foreword, AssistAbility Newsletter, See: <http://svc148.bne099u.server-web.com/AssistAbility/Issue105/AssistAbility1.htm>

<sup>23</sup> Results from Cost-/Benefit Analysis in Crime Prevention (conducted by the Australian Institute of Criminology), for example, showed that *early intervention programs* can financially and socially contribute to reduce government spending's in the long-term. The Perry Preschool Program, a two year pre-school enrichment program for disadvantaged children, was found to be particularly cost-beneficial. With every dollar spent on this early childhood program, about seven dollars would be saved in the long run. See: Chisholm,

its broadest sense, the notion of cultural competence has the potential to deal with ongoing change and flexibility and could thereby create systems and services that people actually want – and, by tapping into ethnic communities, could contribute to workforce development and assist in preventing or overcoming workforce shortages.

## Developing policy frameworks that work

Good public policy frameworks are developed by responding to and developing systems and programs that people actually want, rather than persisting with the development of systems and programs that people do not want and then spend their time and energy resisting at all levels. *To succeed, public policies must respond to the needs of the people.* From our research it is clear that what is required is not simply a supported accommodation policy, but a much broader consideration of what policy can do to develop programs and services that create a sense of home for people. This will require critical reconsideration of what is currently provided, because many of the people who currently access programs and services experience them as alienating and working against the development of any feeling of home and belonging.

As people have very diverse needs and wishes, public policy frameworks need to be underpinned by some key principles. This research has identified some of the *key principles* for delivering public policies and systems which can meet the needs of people from a NESB with disability and their families:

- **The policy/ system is fair:** People from a NESB with disability and their families have a right to a fair share of the resources being spend. They are also entitled to those resources being spend in ways that are accessible to them.
- **Nothing about us without us:** Policies and programs that are built on rigid, finite models are bound to fail. People from a NESB with disability and their families are the experts on their lives and need to be at the centre of all consideration and policy making. Knowing what people want means having to engage, consult and listen in a way, so that people know they are being listened to. Critical here are the principles and application of principles articulated in the Disability Services Act.
- **Building on what is already there:** Currently the capacities, resources and potential of people with disability, families and ethnic communities are ignored. Instead they could be used to enhance the disability service system to achieve what people want.
- **It's about more than bricks and mortar:** Everything the respondents to our questionnaire said indicates that public policy has to contribute to a sense of home. People want much more than simply bricks and mortar, but not necessarily something more expensive than bricks and mortar.
- **Public policies are culturally competent:** If used properly, promoting and implementing cultural competence will result in the flexibility required to meet changing diverse individual needs, which change over time.

## Policy and program implications

Understanding that the policies, programs and services aimed to address the issues raised need to be much broader than they are now (broader than supported accommodation

programs and in-home support programs) means that we will start to address some of the needs and wishes of people from a NESB with disability and their families and communities.

### **Developing a consultation strategy for NESB communities**

Critical to the success or failure of any policies, programs and services is the involvement of the people they are designed to assist. DADHC must develop, as a priority, a NESB Communication Strategy, which can be used to develop and trial programs and services for people from a NESB with disability and their families. People from a NESB with disability and their families must be consulted at all levels: during the policy development, and more concretely, when their individual service delivery is being developed, to generate a sense of ownership and partnership between people with disability, their families, communities, non-government and government service providers.

### **Developing an information dissemination and knowledge creation strategy**

People from a NESB with disability, their families and communities not only have little access to information, but more importantly they miss out on knowing anything about options, systems and programs. For programs to succeed, people from a NESB with disability, their families and communities must participate, contribute and make informed choices and give informed consent and advice about the issues concerning them. To enable this, DADHC must develop new knowledge creation and information strategies.

### **Creating communities that welcome people with disability**

It is clear from our interviews that people from a NESB with disability and their families want to live and participate in all activities in the community, including their community of origin. As the lead agency on disability, DADHC has a responsibility (together with many others) to generate initiatives and programs which reduce stigma in communities and assist in making communities places where people with disability can feel at home.

### **Strengthening capacity**

People from a NESB, their families and their communities want to contribute and be part of creating opportunities for people with disability in the community. Many services want to work with people to advance the quality of life of the people they serve. Policies and programs need to be designed with this in mind and build on and strengthen existing capacities and goodwill.

- Strengthening the capacity of people with disability: Many people we interviewed talked about not being able to access programs that would enhance their skills and abilities to participate in and contribute to the community. In our interviews, people talked about very practical programs such as living skills programs, learning to speak up and educational programs. People need to have a sense that they are at the centre of their lives.
- Strengthening families and communities: Notwithstanding their individual capacity, all families wanted to be part of the lives of their family member with disability. To be an active partner and to be involved, diverse and responsive community participation programs must be developed, particularly programs which support families. To achieve stronger communities with stronger ties to people with disability, ethnic community agencies and support services must be supported and strengthened so that they (in turn) can support and strengthen individuals and families in their communities. This is especially necessary in communities which are currently under pressure, for instance, in communities where many people have experienced torture and trauma and communities with a large percentage of ageing carers.

## **Being a leader in the disability services sector**

MDAA believes DADHC has an ongoing responsibility and the capacity to take the lead in improving the disability sector (including its own services) to address the racial inequities for people from a NESB with disability and their families. Ways to demonstrate such leadership and to foster diversity and equity in the disability workforce must include requiring all provided and funded services to:

- specify in tender documents and funding agreements what strategies they will use to address the needs of people from a NESB with disability;
- monitor service utilisation rates by people from a NESB with disability and their families; and
- provide support and mentoring to the disability services system, embracing and practising cultural competence as good practice etc.

## **Learning from what's working in other areas, running trials and evaluating them**

We know that the current disability support system is under-utilised by people from a NESB with disability. We know that for many people many of the current models of services do not work, yet we know little about what does work.

We know from our research with people with disability who live with or close to their families that they and their families want support and assistance to continue so that people with disability can live in the community. We know from our research that people want programs designed to enhance and strengthen their sense of home and belonging. Currently a lot of programs tend to do the opposite as they enhance the individual's sense of being different and isolated from others.

We also know that people want individualised programs tailored to their own and their families' specific needs. From other program areas, such as Community Care, we know that the Community Aged Care Package (CACP)<sup>24</sup> is one of the few forms of support that has been embraced at equitable rates by people from a NESB. MDAA supports the design and use of these kinds of packages in the disability sector because of their flexibility and ability to meet the cultural, linguistic and religious needs of service users. In addition, ethnic community service agencies are currently delivering many of those packages and those services could also deliver services to people with disability.

In addition, new flexible options must be developed which contribute to long-term support within family and community residences and provide ongoing support for cost effective, flexible and individually tailored accommodation options. All of these initiatives must be developed and tried in consultation with and involve ongoing input from people with disability, their families and communities. Further, all programs must be evaluated, by considering not only what impact the program has had on the life of a person with disability, but also what impact it has had on their family and community.

Some of the more flexible models that could be tried in NESB communities are:

- Use of ethnic community services as brokers to buy in the services and support that the person with disability and their family need;

---

<sup>24</sup> Community care initiatives: Community Aged Care Packages (CACP): maximum of \$90,000 for individualised packages (support by service providers/NGOs) funded by the Commonwealth government.

- Trialing models such as the Attendant Care High Needs Pool Programs and allow people with disability to fund family members and friends to provide the support needed;
- Trialing flexible support options which have access to hump funding;
- Funding of individuals and groups of individuals and their families to manage their own funding;
- Investing in community brokers to assist people from a NESB with disability and their families to negotiate the service systems;
- Investing more money into more flexible services for people with higher needs, either for challenging behaviours or higher medical support needs;
- Developing new programs that facilitate the creation of new, more 'natural' support systems, for example, people with and people without disability living together (using public funds to pay a flat mate to provide some of the support required).

One of the public policy challenges is to create flexible, responsive services, while at the same time supporting the development of a skilled workforce. The current funding system keeps people with disability at the same level of disability support irrespective of their actual needs. People who may need less funding for a period of time and then, during other periods may need more cannot be easily accommodated in the current system.

### **Building a stable and culturally diverse workforce**

Creating secure, stable services is imperative if we want to invest in and develop the skills and competence of the workforce. Systems must be put in place which enable service providers to have some certainty of funding to deliver flexible and individual needs based services.

At the same time, more resources must be invested to attract new workers to the human services sector. Like all human services, disability services are facing increasing difficulties in recruiting staff. Ethnic communities have traditionally not been targeted to provide workers for the disability services sector. A targeted recruitment campaign in ethnic communities is likely to produce positive results. This would also contribute to diversifying the workforce, which in disability services particularly continues to be largely Anglo-Australian.

### **Building cultural competence principles into all policies, programs and services**

One of the key principles of cultural competence is to recognise, understand and work effectively with the impact and influences culture has on individuals.<sup>25</sup> If cultural competence principles and practices were incorporated on all levels of policy, programs and service delivery the following outcomes could be expected:

- Increased knowledge and skills in working with people from a broad range of backgrounds; and
- Provision of the best possible service quality and most effective support for all people with disability and their families/ carers.

---

<sup>25</sup> Harris, Patrick (June 2005): 'Cultural Competence Works! A manual to put it into Practice.' [commissioned by the Multicultural Disability Advocacy Association], p. 12.

## Conclusion

In summary, our research reveals the need to build community resource networks and response systems that support community and family living. This is consistent with consumer demands for experiences and opportunities for positive growth and development: principles which are also enshrined in international conventions on the rights of people with disability and in the NSW *Disability Services Act*.

The results of our research emphasise that people from a NESB with disability and their families believe that existing supported accommodation mechanisms do not deliver appropriate services to people who wish to live and participate in their community. To meet these needs more effectively, we argue that a greater range of accommodation options should be made available which enhance the individual's sense of home and belonging.

Further, we argue that to improve accommodation, especially in an integrated community, new strategies and frameworks have to be developed that are more likely to achieve best outcomes for each individual. To improve services for people from NESB, it is also important that reliable, long-term plans and ongoing commitments must be made to provide a decent quality of in-home and community based options.

The key results of our research highlight that accommodation service utilisation by people from a NESB with disability can be improved by involving people and their families in the early stages of the planning and proposal process.

The main challenge for the supported accommodation system is to meet the strongly expressed wish for putting people with disability and their families at the centre of the policy and decision making process.

# References

Access Economics Pty Limited (August 2005): 'The Economic Value of Informal Care' See: <http://www.carersaustralia.com.au/images/stories/Access%20Economics%20study%20full.pdf>

Centre for Developmental Disability Studies (CDDS) (December 2004): 'Innovative Models of Community Support for People with High and Complex Support Needs' [Prepared for the NSW Department of Ageing, Disability & Home Care (DADHC)].

Chisholm, John (February 2000): 'Benefit Cost Analysis and Crime Prevention in Trends and Issues in Crime and Criminal Justice', published by the Australian Institute of Criminology, No. 147.

Council of Social Service of New South Wales (December 2004): 'Submission to the New South Wales Government'. See: <http://www.ncoss.org.au/bookshelf/pbs/submissions/2005-06pbs.pdf>

Della Bosca, John, Minister for Ageing and Minister for Disability Services (September 2005): Minister's Foreword, AssistAbility Newsletter. See: <http://svc148.bne099u.server-web.com/AssistAbility/Issue105/AssistAbility1.htm>

Gichia, Christine (September 2004): 'I like to go to Queensland... I have no other future plans. Growing older: Hopes and fears of people from NESB with disability and their families and carers.' [Initiated and published by MDAA] See: <http://www.mdaa.org.au/service/systemic/04/carers.html>

Harris, Patrick (June 2005): 'Cultural Competence Works! A manual to put it into Practice' [commissioned by the Multicultural Disability Advocacy Association]

Kingshott, Maureen (2003): 'Hitting the Roof. Public housing experiences of people from a non-English speaking background with disability' [published by MDAA]

Multicultural Disability Advocacy Association (MDAA) (2005): 'Response to DADHC Supported Accommodation Models Discussion Paper'.

NSW Legislative Council Hansard (26 May 2005): 'Residential Institution Closure', p. 16218. See: <http://www.parliament.nsw.gov.au/prod/parlment/hansart.nsf/V3Key/LC20050526014>

NSW Ombudsman (April 2004): 'Summary Report: Assisting homeless people – the need to improve their access to accommodation and support services'.

Procter, N.G. (2004): 'Moving forward together: An international comparison of successful strategies to improve access and equity for people from ethnic minorities', University of South Australia, Adelaide.

Wadiwel, Dinesh (December 2003): 'Accommodation and support crisis for people with disability? See: [http://www.ncoss.org.au/bookshelf/disability/articles/0312\\_accomodationcrisi.html](http://www.ncoss.org.au/bookshelf/disability/articles/0312_accomodationcrisi.html)

## Appendix 1 – People with a disability - Interviewee Profiles<sup>26</sup>

Gender	Ethnicity	Age	Disability	Accommodation type	Location
Female	Phillipino	64	Physical	DOH unit	City
Female	Chinese	31	Intellectual	DOH unit	City
Unknown	Turkish	36	Physical	Private rental flat	City
Male	Cook Islander	38	<i>Unknown</i>	Own house	Rural
Male	Tongan	35	Physical	Housing Commission	Rural
Female	Indian	30-35	Mental health	Own house	Rural
Male	India	70	<i>Unknown</i>	Own house	Rural
Male	Italian	<i>Unknown</i>	Mental health	Private rental unit	Rural
Female	Chinese	30	Physical	Own home	City
Female	Lebanese	22	Sensory	Family home	City
Male	Lebanese	29	Neurological	Family home	City
Male	Lebanese	52	Intellectual	Subsidized private housing	City
Male	Ukrainian	40s	Physical	Own house	City
Male	Italian	33	Physical	Private housing	City
Female	Bulgarian	54	Sensory	Private housing	City
Female	Chilean	33	Intellectual	Family home	City
Male	<i>Unknown</i>	71	Neurological	Own home	City
Female	Italian	38	Cerebral Palsy	Group home	City

<sup>26</sup> The names of all interviewees have been changed for privacy reasons.

Gender	Ethnicity	Age	Disability	Accommodation type	Location
Male	Italian	48	Mental health	Supported Acc.	Regional
Male	Chinese	30s	Intellectual	Group home	City
Male	Chinese	25	Intellectual	Group home	City
Female	Chinese	19	Intellectual	Group home	City
Male	Chinese	45	Intellectual	Group home	City
Female	Filipino	30	Brain Injury	Townhouse	City
Male	Fijian Indian	55	Physical	House	City
Female	Malaysian Indian	20	Intellectual	Refuge	City
Male	Chinese	24	Intellectual	Bed-sitter	City

## Appendix 2 – Family members/ Carers - Interviewee Profiles<sup>27</sup>

Gender	Ethnicity	Age	Disability of PWD	Accommodation type for PWD	Location
Female	Greek	47	Intellectual	Family home	City
Female	Indian	64	Physical	Private rental	Rural
Female	Samoan	45	Mental health	Farm house	Rural
<i>Unknown</i>	Indian	57	Physical	Private rental	Rural
Female	Samoan	41	Neurological	Family home	City
Male	Lebanese	67	Behavioural	Group home	City
Female	Lebanese	?	Intellectual	Family home	City
Female	Sri Lankan	56	Intellectual	Mental health	City

<sup>27</sup> The names of all interviewees have been changed for privacy reasons.

Gender	Ethnicity	Age	Disability of PWD	Accommodation type for PWD	Location
				hospital	
Female	Indian	54	Behavioural	Family home	City
Female	Croatian	40	Physical	Family home	<i>Unknown</i>
Female	Arabic speaking	40s	Intellectual	Family home	City
Female	<i>Unknown</i>	29	Intellectual	DOH provided unit	City
Female	Kurdish	40	Developmental	Family home	City
Male	Lebanese	60s	Intellectual/ Mental Health	Family house	City
Female	Argentinean	45	Physical/ Developmental	Family house	City
Female	Greek	60s	Intellectual	Group home	City
Female	Chinese	45	Intellectual	Family unit	City
Female	Macedonian	69	Intellectual	Family home	City
Female	Serbian	55	Intellectual/ Physical	Group home	City
Male	Serbian	76	Physical/ Developmental	With Family member	City
Female	Arabic speaking	60s	Intellectual	Family home	City
Female	Italian	50s	Down Syndrome	With family member	City
Female	Serbian	63	Dementia	Family home	City
Female	Filipino	48	Autism	Institution	City
Female	Filipino	55	Physical	Family home	City
Female	Filipino	42	Neurological	Family home	City

## Appendix 3 - Accommodation survey for people with disability

What is your name?

How old are you?

Can you tell me what disability you have?

What sort of place do you live in?

Who owns the place you are living in?

How long have you been living there?

Where have you lived before?

Did you choose to live where you are now?

What do you like about where you live?

What don't you like about where you live?

Does it feel like your place?

Why does it feel like your place? Why doesn't it feel like your place?

Do you feel safe at your place?

Is there anything about where you live that you want to change?

What support/ help *do you get/ do you need* with living where you are?

Do you get enough support/ help for you?

Do you have a say in how you get the support/ help?

Do you feel you are part of the neighbourhood or part of a community? Or do you feel you belong where you live? Why/ why not?

If you can have anything you want, where you'd live? With whom would you live? How would you be supported?

## Appendix 4 - Accommodation survey for family members

What is your name?

How old are you?

What is the name of your family member with disability?

How old are they?

What is their disability?

Where is your family member currently living?

Is where they are living right for them in terms of their *age*, their *level of skill*, their *support needs*?

Is where they are living right for them in terms for their emotional and social needs?

Is where they are living right for them being from a NESB?

Do you feel that your family member is supported to live the life of their own choice?

What did you and your family member do to get the place where they are living now?

What do think you and your family member will have to do to get a supported accommodation place?

What is your understanding of the variety of supported accommodation options available to people with a disability?

If you could have anything you want what would the ideal supported accommodation look like?

If you could have anything you want what would the ideal supported accommodation look like? Why?

What needs to happen for this to become a reality?