

Consultation with people with disabilities and their families from Spanish-speaking communities

Summary Report

Who are we?

The Disability Council of NSW is the official advisor to the NSW government on issues affecting people with disabilities and their families. The Disability Council monitors the implementation of all Government policy in relation to people with disability, advises Government on priorities for services, and consults with people with disability, their families and carers.

The NSW Ombudsman is an independent and impartial watchdog body. The Ombudsman's office has an interest in issues that affect people with disabilities who use, or are eligible to use, community services. Functions of the Ombudsman include dealing with complaints about community service providers, and monitoring standards for the delivery of community services.¹

What are we doing?

During 2002 and 2003 the Disability Council of NSW and the NSW Ombudsman² jointly consulted with people who have a disability, their families and carers from various culturally and linguistically diverse ('CALD') communities. The joint consultations are designed to inform the Disability Council and the Ombudsman about:

- service needs of people with disability and their carers
- barriers to accessing services, and
- how people solve problems with service providers.

Information from the consultations is being used by the Disability Council and the Ombudsman's office to ensure these two agencies are accessible and responsive to all NSW communities.

People with disability of Spanish-speaking background in NSW

The Spanish-speaking population is diverse, with more than 20 countries where Spanish is the official language and from where migration to Australia occurred at different times. The following information is drawn from 2001 Census data about people who speak Spanish at home, collated by the Community Relations Commission.³

Spanish-speaking people in NSW

Spanish-speaking people make up the seventh largest language group in NSW with 49,382 people (0.8% of the NSW population). About 7,786 (16%) of Spanish-speaking people report

¹ The Ombudsman's office is not an advocate for individuals, but promotes improvements in the delivery of community services and the rights and best interests of consumers through its recommendations.

² Formerly the Community Services Commission. On 1 December 2002 the Community Services Commission amalgamated with the NSW Ombudsman.

³ www.crc.nsw.gov.au - *The People of New South Wales*.

they do not speak English well or at all. The Spanish-speaking population of NSW is also diverse in age. The largest numbers are aged between 20 and 60 years, with high concentrations in the 20 – 35 years and 45 – 60 years age groups.

People of Spanish-speaking background are scattered across the Sydney area, with concentrations in the south-west Sydney region (particularly the Botany Bay local government area) and western Sydney region (particularly Campbelltown, Camden, Fairfield and Liverpool local government areas). Outside Sydney, the Illawarra region has the highest concentration of Spanish speaking people.

Spanish-speaking people with disability

There are no conclusive statistics available about the number of people with disability within non-English speaking communities in NSW, or specifically of Spanish-speaking background. However, 1998 statistics show that 15% of the population in NSW has a disability.⁴ The Multicultural Disability Advocacy Association (MDAA) estimates, using 2001 census data, that approximately 5% of the NSW population are people with a disability who have a non-English speaking background.⁵

How we consulted

Consultation with people with disability and their families from Spanish-speaking communities was conducted via consultation sessions held by the Ombudsman's office and the Disability Council. Consultations held at Eastlakes on 5 November, Dee Why on 10 November and Fairfield/Cabramatta on 24 November were open to all people with disability and their families from Spanish-speaking communities. The days were advertised through Spanish community organisations, particularly those for people with disability, Spanish newspapers (Extra Informativo, El Espanol and the Spanish Herald) and radio (Radio Austral and SBS Radio). Spanish speaking community workers were also approached to distribute information to their clients. A consultation held on 19 November with a group in Gladesville was not publicly advertised.

At each of the consultations, participants formed small focus groups to discuss a series of questions developed by the Disability Council and Ombudsman's office. These focus groups were facilitated by bilingual community workers and were conducted in both English and Spanish. Bilingual notetakers recorded participants' comments. Focus group facilitators and note takers were recruited from community agencies. Focus groups ranged in size from six to 10 participants.

Who attended the consultations?

42 people attended the consultation sessions, with five people reporting that they have a disability, 26 reporting they are family members or unpaid carers of a person with a disability, and 11 reporting they are friends of participants or 'interested in the issues'.

Most participants (16) reported physical disability as their (or their family member's) primary disability, ten participants reported intellectual disability, six reported sensory disability, five

⁴ ABS (1998) Disability, Ageing and Carers: Summary of findings

⁵ www.mdaa.org.au/faqs/figures.html accessed February 2004.

reported psychiatric disability as the primary disability and five did not state their (or their family's member's) primary disability.

The majority of participants (31) reported Spanish as their preferred language, eight indicated no preference between Spanish and English and three reported English as their preferred language.

Experiences of support and assistance

We asked participants about what they like and do not like about the support and assistance ('help') they use in relation to their, or their family member's, disability, and they provided the following information:

- **Specific NESB services** were identified by participants as providing a necessary and important service, particularly the carers' groups. Participants identified that services such as the Multicultural Disability Advocacy Association and the Spanish-speaking carers groups provide a link for them into mainstream service providers, including writing letters on their behalf, or informing them of assistance they may be able to access.
- **Limited service availability** –Common responses were that services offering home and community care have long waiting lists, tend not to offer help when needed at times of crisis due to limited resources, and often provide time limited assistance (varying from six weeks to six months).
- **Quality of services** being provided was identified as a concern by participants. Some of the concerns were linked back to the limited resources available for services, such as the impact of time limitations on the quality of cleaning assistance being provided. Concerns were also raised about the poor quality of care provided by workers in some accommodation and respite services for people with disabilities.
- **Service flexibility** was identified as important to participants, and many people expressed frustration with the lack of flexibility demonstrated by a number of services. Examples included the inability to change respite bookings to accommodate crises such as death in the family, and services refusing access to people due to their level of disability being too severe, not severe enough, or their support needs including challenging behaviour.

What stops people from using services?

We asked participants what they thought made it difficult for them to get the support and assistance they need or want, and they provided the following information:

- **Eligibility criteria** - participants commented that they perceived the eligibility criteria of services to often be restrictive and inflexible. Examples provided by participants included people being declared ineligible due to having challenging behaviour or for having support needs that were either too high or not high enough. Others commented that they often have to endure a lengthy and bureaucratic process before they are informed that they or their relative is ineligible for support or assistance.
- **Access to respite services** was reported by many participants to be difficult, particularly at times of family crisis. Participants indicated that they were required to book respite months in advance, and had reduced access to respite due to it being

available at times that did not meet the needs of the family. It was also noted in one of the focus groups that there is a lack of respite options for older people (eg: elderly parents being cared for by their adult children).

- **Access to information** - many participants reported that it is difficult for them to access information on what services are available and what support they or their relatives may receive. Some participants tied this lack of information to language barriers, reporting that the information may be available, but it is difficult for the Spanish community to access when it is in English. Participants commented on the importance of carers groups in disseminating information, indicating that it was often the only way they received that information, and citing the example of the carers allowance. Participants advised that when the carers allowance first became available it took three months for that information to filter down to the community, and even then that information was received 'by accident'.
- **Financial issues** were raised as particular barriers to accessing services. One example included the difficulty of paying for transportation in taxi's even with a mobility allowance or subsidised taxi travel. Participants reported that they still have to pay for half of the fare under the taxi subsidy scheme, and this is often unaffordable. Other participants reported difficulties affording respite when it involves both the taxi fare and spending money.
- **Language barriers** - many participants stated that language was a significant barrier in accessing services. Completing forms was a key issue raised by complainants, with services asking intrusive questions, and the forms being difficult to understand for people from a non-English speaking background. Participants considered it to be an unnecessary barrier in some instances, particularly in relation to applying for the disability support pension where they are asked to complete the same forms more than once and all the information is already contained on a computer database.

Participants expressed frustration over the lack of interpreters available to provide assistance when needed, for example in medical appointments. It was noted that while some hospitals provide an interpreter, some medical staff were better than the official translator, and it often takes too long for the interpreter to arrive. Other participants advised that there is a lack of Spanish-speaking workers to assist members of the Spanish community who have no or minimal understanding of English.

Many participants commented that their limited English is a barrier to accessing services as they try to speak English, people do not understand them, they feel embarrassed, and then lack the confidence to try accessing those services again.

- **Requesting assistance** - Some participants commented that in the Spanish culture it can be very difficult to ask for things, and this leads to people of Spanish background missing out on services. Others advised that Spanish people tend to use a high degree of emotion in their language, and service providers can misunderstand what is being said as a result. Some participants noted that service providers label them as being difficult, or take their words to be criticisms, due to language and expression misunderstandings.

What could be done about this?

We asked participants what would improve their access to the support and assistance they want. Two themes emerged from the focus groups:

- **Accessible language formats** - Some participants said that services would be more accessible to the Spanish community if information were provided in Spanish, as well as English.
- **Accessible information** - Participants said information about available services, entitlements, and eligibility criteria needs to be more widely distributed throughout the Spanish community. Many participants commented on the importance of the existing Spanish carers groups, and the Spanish-speaking workers who coordinate the groups, and suggested that this could be a good way to pass on information to the community.

What do you do if you are not happy with a service?

We asked participants what they do if they are not happy with the support and assistance they are getting, or have problems with a service provider, and they provided the following information:

- **Reluctance to complain** - Participants indicated a reluctance to complain due to past experience in this area. Some participants noted that they have complained to services about something that is not right, but have been told that the service cannot do anything about the situation, as that is how the system works. Other commented that while they will raise concerns with other carers, that is as far as they will go, due to past instances of being labelled 'difficult' by service providers.
- **Advocacy assistance** - Some participants advised that they have received support from the Multicultural Disability Advocacy Association, and have found their assistance to be valuable in raising complaint issues with services on behalf of individuals.

Others indicated that they have approached other disability-focused advocacy services but had not been able to obtain their assistance. One participant commented that when she had attempted to obtain support from mainstream advocacy services, she had either received no response or had been told by the service that there was limited action they could take.

Summary

From our consultations, the following key points emerged:

1. There is a need for accessible, culturally appropriate information about disability support services for people with disabilities of Spanish-speaking background and their families.

2. There is a need for additional and accessible information about people's rights and consumer protection mechanisms, including options for pursuing complaints about disability and community services.
3. Carers' groups and multicultural support agencies are highly important in providing a support base for Spanish-speaking carers and people with disabilities, in providing information on available services, and in providing support in linking service users and carers into complaint bodies. The importance of such groups may provide the link for service providers and complaint bodies to reach people with disabilities of Spanish-speaking background and their carers.
4. The major concerns about services for people with disabilities and their carers of Spanish-speaking background largely mirror those expressed by the wider community, and are consistent with those raised in other forums.

What will be done with this information?

The information that has been provided by the Spanish-speaking community through these consultations will be combined with that of the other communities we are consulting (Arabic, Greek, Vietnamese, Chinese and Italian) in order to produce a final report. This report will be considered by the Disability Council in its advice to government, and will be used to inform the work of the NSW Ombudsman.

If you wish to comment on any of the issues raised in this summary report, please provide them in writing, by phone, by mail or by email, to either of the following addresses:

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All comments will be considered for incorporation in the final project report.