

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

Summary Report

1. Introduction

During 2002 and 2003 the Disability Council of NSW and the NSW Ombudsman¹ are jointly consulting with people with disabilities, their families and carers from various culturally and linguistically diverse ('CALD') communities. The joint consultations are designed to inform Disability Council and the Ombudsman about:

- service needs of people with disabilities and their carers
- barriers to accessing services, and
- how people solve problems with the services they are getting.

Information from consultations will be used by the Disability Council and the Ombudsman to improve their own services, and in their work in making recommendations to government and community service providers.

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

The NSW Ombudsman is an independent and impartial complaint handling body. The Ombudsman's office has a particular 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.

On 19th February 2003 a consultation day was held in Roselands, with the support of the ESTIA Foundation, with people with disabilities and their families from Greek-speaking communities. A further consultation day was also held in Randwick, with the support of Randwick City Council, on 11th September 2003. This summary report has been prepared by Disability Council and the Ombudsman as a record of what people told us on those days.

This report will be distributed to the people who took part in the consultations, to agencies and networks that helped facilitate the consultations and to other interested agencies. It is available in English and in Greek and will be available on both the websites of the NSW Ombudsman and Disability Council. This report will also be available in alternative format by request.

Disability Council and the Ombudsman plan to release a final report on the project by June of 2004, incorporating information from all consultations once complete.

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

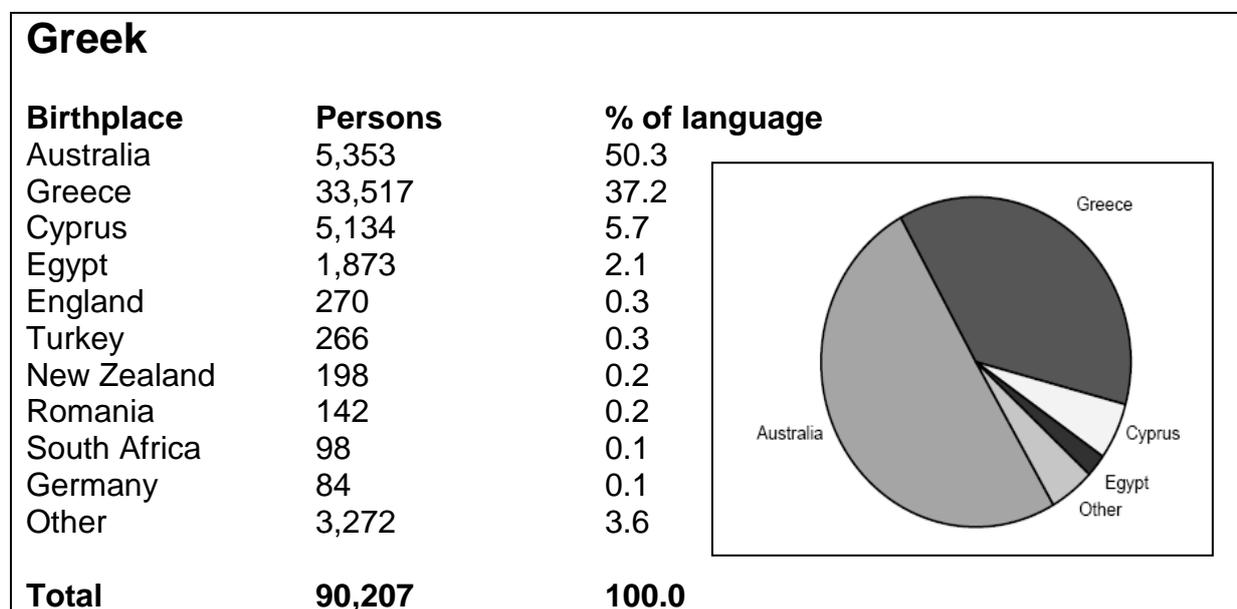
2. People with disability of Greek-speaking background in NSW

The Greek-speaking population of NSW is diverse, originating from many different countries, and observing different religions. The following information is drawn from 1996 Census data about people who speak Greek at home, collated by the former Ethnic Affairs Commission of NSW (now the Community Relations Commission)².

2.1 Greek Speaking People in NSW

Greek speaking people make up the 4th most common language spoken in NSW with 90,207 people (1.4% of NSW population). Out of this group 14,990 people (17%) reported that they did not speak English well. Approximately 37,000 or 0.6% of people living in NSW were born in Greece. Approximately 90,000 or 1.4% people living in NSW spoke Greek. 126,413 people or 2.0% of the NSW population are Greek Orthodox. (2001 Census)

The majority of Greek speakers in NSW (50.3%) were born in Australia, and 37.2% were born in Greece. The remainders are from Cyprus, Egypt, England, Turkey and others (see graph).



The distribution of age across the Greek speaking community is broad; however there are two main age clusters, with those aged 20 to 34 yrs making up approximately 26% of the Greek speaking population and those aged 55+ making up approximately 32% of the population and approximately 78% of those reported that they speak English not well/not at all.

The majority of Greek speaking people in NSW live in Sydney. The Greek-born community is clustered in the west and inner western suburbs of Sydney, with the majority in Canterbury (approximately 12.4%), Rockdale (7.9%), Bankstown (6.2%)

² www.crc.nsw.gov.au - *The People of New South Wales*.

and Randwick (6.1%). Small numbers of Greek speakers live in the Blue Mountains, Illawarra and Hunter Regions.

2.2 Greek-speaking people with disabilities

There are no conclusive statistics available about the number of people with disabilities within non-English speaking communities in NSW, or specifically of Greek-speaking background. However, 1998 statistics show that 19.3% of the population in NSW has a disability³. The Multicultural Disability Advocacy Association (MDAA) estimates, using 1996 census data that approximately 217,396 people in NSW with a disability (3.5%) are from a non-English speaking background.⁴

It is not possible to generalise about the experiences of people with disabilities from Greek-speaking backgrounds. Attitudes toward disability are shaped by religion and culture and personal experience. Each participant has her/his own explanation of disability, and often more than one explanation. There are examples in Christian cultures of disability being identified as a punishment for sins in some instances and as a gift in others. There are examples in cultures of people with disabilities being identified as inferior in some instances and important as a source of learning in others.⁵

Family and social culture also shape attitudes toward disability. While the cultural importance of family relationships and family loyalty provide a source of support to many Greek-speaking people with disabilities, stigmatisation of disability also exists among some groups and families, leading to its treatment as a shameful or 'taboo' issue.⁶

Some Cultural Aspects of Greek Life

There are two major representative religious and cultural groups in the Greek community in NSW - the Greek Orthodox Community of NSW and the Greek Orthodox Church (Archdiocese). The Greek Orthodox Church was established in Australia in the 19th century and became an Archdiocese in 1959. A split in the Greek community occurred in 1959, between the Greek Orthodox Archdiocese and the Greek Orthodox Community. Some argue that the conflict was over the desire by the Archdiocese for control over the secular activities of the community and because of political differences - especially in relation to the situation in Greece at the time.⁷

Throughout Australia, the Archdiocese has established many churches, schools and colleges. Today it operates hostels and nursing homes, and runs community organisations and social welfare services in many areas of Sydney.

The Greek Orthodox Community was founded in 1898, with the first church located in the inner-Sydney suburb of Surry Hills, and it was one of the first formal ethnic

³ ABS (1998) Disability, Disability, NSW: Summary of findings

⁴ MDAA (2000) *Less Talk, More Action*, p38

⁵ MDAA (2000) *Ethnicity and Disability Factbook*, pp ED7-15, RC3 and RI3

⁶ MDAA (2000) *Ethnicity and Disability Factbook*, pp ED7-15

⁷ MDAA (Web link) Ethnic Communities and Disability -> Information -> Greek (General Information) pp 4

organisations in NSW. It operates several language schools and child care centres, a hostel, a welfare service, and a radio program.

Within Greek society, many families including extended families are close, with people caring for their parents as well as their children. The teaching of Greek language and culture occurs at all levels of community life, including Greek bi-lingual state and community schools.

After World War II, Greek restaurants and coffee houses transformed the Australian culinary landscape. Greek cuisine is still a focus of the eating-out experience for Greeks and non-Greeks alike, with restaurants scattered throughout the country. Greek bakeries and delicatessens have proved to be extremely popular with many people living in Australia.

Attitudes towards People with disability

Like all communities, there are many differences within the Greek community, especially around perceptions or beliefs about disability and the causes of disability. Traditionally, Greek families frequently believed that the existence of a disability presupposes an 'illness' which is hereditary. This has led to tremendous guilt and shame at the birth of a child with a disability. Today explanations of disability have changed, but there can still be a stigma that attaches to the whole family as well as the person with a disability.⁸

Where families do feel shame, they may blame themselves, another person, a spiritual entity or perhaps medical personnel for the disability.

Many Greek families tend to be very focused on the well-being of their family, including people with disability. Care is often provided in a supportive home environment.

Social and cultural norms, coupled with a lack of knowledge of and unfamiliarity with services available, has often led to women caring for family members to the point of exhaustion.

Some Greek families may also hesitate to use services because of language difficulties, or because the services are perceived as not culturally appropriate and / or not meeting the expectations of the family.

In more recent years Greeks living in Australia are becoming increasingly aware of disability issues and services. Similarly, many service providers are becoming increasingly aware of cultural issues relevant to the Greek community.

3. How we consulted

Consultation with people with disabilities and their families from Greek-speaking communities was held through two public consultation days held in Roselands on 19th February 2003, and in Randwick on 11th September 2003. The day was open to all people with disabilities and their families from Greek-speaking communities. It was advertised through ESTIA Foundation, Randwick City Council and various local Councils, Greek Community Churches, Greek Welfare Centres, community

⁸ MDAA (Web link) Ethnic Communities and Disability -> Information -> Greek (General Information) pp 5

organisations, particularly those for people with disabilities, Greek newspapers, SBS Radio and Sydney Greek Radio Stations, and Greek community workers were also approached to distribute information to their service users.

At each of the consultation day, participants formed small focus groups to discuss a series of questions developed by Disability Council and office of the Ombudsman. These groups were facilitated by bilingual community workers and were conducted in both English and Greek. Bilingual note-takers recorded participants' comments in English on large sheets of paper in view of participants. Group facilitators and note takers were recruited from community agencies.

4. Participants

Roselands

Twenty nine people with disabilities, family members and carers attended the consultation day and took part in the focus groups. Nineteen participants (65%) provided demographic data (8 female, 11 male). None of the participant with disabilities filled out the form, 17 reported that they were family members of a person with disabilities and two reported that they were unpaid carers of a person with disabilities. All participants reported intellectual or developmental disability as the primary disability of their family members, two participants reported physical disability as the primary disability and one participant reported sensory disability (sight). The average reported age of participants was 53 years, ranging from 30 to 70 years. Eighteen participants indicated Greek as their preferred language, one indicated a preference for English but Greek is also OK.

Three focus groups of nine to ten people each were established and participants selected which group they would attend. Three bilingual workers facilitated the focus groups and a set of prepared questions were asked with three other bilingual workers taking notes.

Randwick

Forty one people with disabilities, family members and carers attended the consultation day and took part in the focus groups. 36 participants (88%) provided demographic data (21 female, 15 male). 13 of the participants with a disability filled out the form, 21 reported they were family members of a person with a disability and two reported that they were unpaid carers of a person with a disability. 18 participants reported intellectual or developmental disability as the primary disability of their family members, 10 participants reported physical disability as the primary disability, 4 participants reported sensory disability, 3 reported psychiatric disability and one did not report. The average reported age of participants was 62 years, ranging from 33 to 78 years. 22 participants indicated Greek as their preferred language, 9 indicated no preference between English and Greek and 5 indicated English as their preferred language.

Five focus groups of five to nine people each were established and participants selected which group they would attend. Five bilingual workers facilitated the focus

groups and a set of prepared questions were asked with five other bilingual workers taking notes.

5. What people told us

5.1 Experiences of support and assistance

We asked participants about what they liked and didn't like about the support and assistance ('help') they received or their family member with disabilities received.

In general, participants said they were very appreciative of the formal support services that they were using. These services included respite, which was viewed as particularly important to families because it provided time out for family members, accommodation services, Day Programs, in-home personal care services, Early Intervention therapy services, financial assistance for home modifications, taxi subsidy and community transport services. Interpreter services were also reported favourably.

Although appreciative of formal support services, participants also raised concerns about general service availability, quality and flexibility.

Assessment and forms

Participants expressed concern over the amount of time that it takes to complete forms, provide statistical information and having to be assessed and re-assessed on a regular basis when new workers/coordinators and/or programs start.

The paperwork required for the administration of case based funding is thought to be excessive and does not contribute to the quality of service delivery. Forms are not always provided in accessible and/or appropriate language.

Limited Service Availability

Participants reported frustration with limited service availability. Examples included a lack of local respite services (in particular emergency respite and centre-based respite options), waiting lists for personal care services and a general lack of early intervention and therapy services for children.

Participants also suggested that there is a lack of information (in appropriate language and format) about available services, rights and complaints process for people with disabilities, their families and carers.

A number of participants said that the family was their most important source of support for the person with disability, with several providing examples of support provided by family members in the absence of available services.

Quality of services

Participants said that the quality of services was important to them. For example, while caring staff was highly valued, issues such as worker unreliability (turning up late), untrained or poorly trained staff and a lack of relief staff at some agencies were reported as sources of frustration.

Language and Cultural issues

Other issues of service quality raised related to cultural attitudes and knowledge of service workers. For example;

- Choice of male or female workers to meet the cultural and religious needs of service users and the availability of bilingual workers were highly valued, although their availability was limited.
- Lack of flexibility and option of culturally appropriate food even when requested from respite and supported accommodation services, and Meals on Wheels.

Lack of worker sensitivity and lack of training for workers in cultural issues provided difficulties for a number of families. For example,

- Participants expressed particular concern over workers who were judgmental or made decisions based on their assumptions about the person and their culture.
- Inadequacy of understanding and appreciation of the "Greeks' way of life".

Services reluctant to engage Greek interpreter at meetings which made it difficult to have an open and frank discussion.

Service flexibility

Participants said that service flexibility was important to them. For example, while the flexibility of respite was generally reported favourably, a few participants stated that flexibility was determined by the service provider, limiting the usefulness of respite for the family.

Some participants expressed frustration with a lack of flexibility due to a compartmentalised care system with restricted guidelines for service delivery within individual agencies. Examples include frustration with in-home personal care guidelines that prevented the service providing assistance with tube feeding and Occupational Health and Safety guidelines which necessitated costly house renovations for one family. Respite users expressed frustration with guidelines that prevented the service from managing medication and filling prescriptions. Families were also prevented from having the flexibility to accumulate unused respite hours.

Many participants also expressed a genuine fear of retribution if they push these issues too far.

5.2 Barriers to using services

We asked participants what made it difficult for them to get the support and assistance that they need or want.

Many barriers participants identified were similar to the negative aspects of services they had experienced which lead them to stop using the service, or limited their use of it. These barriers related to issues of service availability, quality, and cultural and/or language barriers.

Lack of services and waiting lists

Participants strongly identified that there is a high demand for services, particularly short term respite, supported accommodation services and in-home personal care. They were also concerned that the waiting list is very long for services such as speech therapy, occupational therapy, physiotherapy, etc. When it is their child's turn to receive services, that child becomes too old to be eligible or could only access the service for a short time before the cut-off age. This resulted in lost opportunity for early intervention and delayed their children's developmental stages even further.

Poor service quality

Poor service quality prevented some participants from using existing services, and reduced the level of trust participants held which influenced the extent to which they used or relied on services. For example, a few participants were concerned about unreliable safety in respite due to the grouping of incompatible clients, which impacted on their level of use of the service.

Financial issues

Financial burdens were raised as particular barriers to accessing services. Examples included the costs of traveling to services that weren't available locally, such as medical and therapy services, and the high costs of equipment, such as wheelchairs. It was stated that many families had significant costs associated with maintaining their culture in addition to the costs associated with disability, such as travel to countries of origin, sending money to family overseas and private education costs for children.

Participants also reported that cost to participate in activities is very high in some services. They were concerned that there is a lack of consistency of cost involved for participants, where they could be doing the same activities with two different services and one could cost substantially more. This resulted in parents having to regularly subsidize their children's finance as their Disability Support Pension were not able to cover the costs of both services and daily living.

Difficulties in navigating service system

All participants said they had experienced difficulty and frustration navigating the service system and finding the right services. For example, participants said that they had to ask for assistance repeatedly until they found the right service. Another

said that until they found a worker who knew the system and could make the right referral, they had not been able to access any services.

Participants felt that their difficulties finding services and negotiating the system were exacerbated by communication difficulties, including a lack of plain English information about services, difficulties communicating with workers in English, and a lack of bilingual workers.

A lack of culturally sensitive workers also prevented some participants from accessing services. Some participants highlighted inaccurate or incomplete information from community workers as a problem, particularly where this was a result of assumptions by workers about the information needed by the family. Aside from communication barriers, participants identified a lack of culturally sensitive services as a barrier to their using those services. Participants often sought the help of known bilingual worker to explain both written and verbal information about other services and negotiate on their behalf to obtain services.

Requesting assistance

Some participants said they feel humiliated by having to ask for services or assistance. This, and cultural expectations for some participants, prevented them from seeking assistance. For example, one participant said that although their daughter who has an intellectual disability was in her 30's, they would not seek assistance from a service as they felt strongly that it was their duty to care for her themselves and they felt a sense of shame that they have a child with a disability. Another said that they felt that they would be embarrassed to use some services, as it was both their personal duty and a matter of cultural pride to provide support to their family member themselves.

5.3 Addressing barriers

We asked participants what would improve their access to the support and assistance they want. Overwhelmingly, participants said that accessible information and culturally sensitive and flexible service provision would help address the problems they identified.

Accessible language formats

Participants suggested that information in plain English and/or Greek would help them to understand what services provided so they could make informed decisions. Some would prefer the access to bilingual workers somewhere to help negotiate the services they need.

Accessible information

Participants said that information about rights to support and what to expect from services is a vital component to overcome barriers facing people with disabilities from the Greek community. As adult illiteracy is an issue for the community, providing information to children and young people was important, as was regular dissemination of information via Greek radio and television programs.

Participants would also like to see better flow of information to community workers as they are the main point of contact with the support system and information about Greek support services for 'mainstream' community and disability services.

Understanding and flexibility

Participants stressed that services must be flexible to meet their needs both in relation to disability support and their cultural needs.

A few also suggested that they did not necessarily want a Greek-speaking worker due to concerns about maintaining their privacy within the community, but that it was important that workers have knowledge and understanding of the cultural background so that they could provide culturally sensitive assessment and casework management.

A number of participants also suggested the following would help to address the barriers facing people with disabilities, their families and carers from a Greek background;

- More community awareness education programs about people with disabilities within the Greek community
- Affordable pharmaceutical scheme
- More accessible venues

5.4 Resolving problems and making complaints

We asked participants what they would do if they are not happy with the support and assistance they are getting, or have problems with a service provider. Participants reported both a lack of knowledge of where to go to help if they had problems with a service, and a reluctance to make complaints if problems occurred.

Lack of information about the complaints process

Majority of participants said that they did not know where to go to complain about particular matters, nor were they aware of their right to information about complaints mechanisms and complaint options. A few participants felt strongly that the services that they obtained for their children with disabilities were mainly due to the numerous complaints that they made to Government Departments, service providers, local members, independent advocates, case managers, etc..

Many participants reported that they relied heavily on the services they used for a range of information, but services did not always tell them about their own services, or services' grievance procedures.

A few participants suggested that they relied on culturally sensitive bilingual workers and services for advice if they had a problem. Often, the same bilingual worker

would be asked to find out about other services or for advice about dealing with problems with other services they were using.

Reluctance to complain

Reluctant to complain seemed to be linked to cultural expectations and to people's previous negative experiences in trying to complain. A number of participants mentioned that they were thankful for the services they got and would not complain about them. Many also feared that their son or daughter might suffer the repercussion from service provider and it was easier to not say anything.

6. Discussion

People with disability of Greek-speaking background are doubly disadvantaged when trying to obtain support as they face both disability related and cultural and linguistic barriers. The issues raised in this consultation highlighted the need for the provision of accessible information by disability support services to Greek-speaking community to increase their awareness of the options available to them.

There is also a need for accessible information about the rights of people with disabilities and the various mechanisms available to people to protect their rights. The statistical information on the physical distribution of the Greek-speaking community in NSW can be used to target information campaigns to raise awareness of disability related issues and supports available.

One issue emerging from the consultation was that of the uncertainty of ageing parents or carers about the future of their sons and daughters when they are no longer able to provide care. It is important that parents are supported to plan for the future and ensure that permanent and appropriate arrangements are in place.

The consultation showed that there was an expectation from the Greek-speaking community that services should be culturally appropriate before they can be considered accessible and trustworthy. Participants provided some indication of specific cultural concerns in relation to the Greek-speaking community which will be useful in establishing culturally competent service provision.

Many of the issues raised by participants in this consultation are consistent with those raised in other forums by people with disabilities, their families and carers⁹. A more in-depth discussion of the findings from the six consultations intended for this project will be provided in the final report.

⁹ For example, the Parliamentary Inquiry into Disability Services received written submissions, heard evidence and held community consultations with people with disability, family members, advocates, service providers and government departments, including those of people from non-English speaking background. It found that people from non-english speaking backgrounds are under-represented in their access to disability services and made recommendations in its final report, *Making It Happen*, for addressing the imbalance.

7. What we learned from the consultation process

From this consultation we learnt a number of things about how to maximise the participation of people with a disability from Greek-speaking communities in a consultation process.

- Select accessible venues, which are located close to public transport, and which are considered central to groups of potential participants. Multiple locations may be required.
- Consult Greek-speaking community workers in order to determine appropriate consultation methods.
- Engage the support of community agencies to facilitate events and distribute information.
- In larger or non-ethnic specific agencies, make direct contact with the workers who work directly with members of the community wherever possible.
- Engage a community leader to provide a welcome at larger events to promote people's willingness to participate in the consultation process.
- Offer assistance with transport costs and provide appropriate carer support to participants.
- Provide culturally appropriate refreshments. This also provides an opportunity for participants and organising agencies to talk informally.

8. Where to from here

Further consultations with Spanish, Italian, and Chinese speaking people with disabilities and their families are being carried out in 2003-2004. Summary reports will be provided following each community consultation. A final report about the project is planned for the end of June 2004.

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.