

The Disability Council of NSW



Voicing Experiences:

People with disability from
culturally and linguistically
diverse communities and
service provision



Celebrating Difference

Acknowledgements

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Summary and Recommendations

As both the official adviser to the NSW Government on issues affecting people with disability and their families and an adviser to the Commonwealth Government on important issues for people with disability in NSW, the Disability Council is keen to develop a better understanding of service provision issues and experiences of people with disability from culturally and linguistically diverse (CALD) communities.

Voicing Experiences: People with disability from culturally and linguistically diverse communities and service provision is part of a developing strategy to improve our understanding of these issues. This report is based on consultations held by the Council from 2002 to 2005 with three hundred people with disability and their families from six culturally and linguistically diverse communities.

In both developing the project methodology and in its implementation, advice and assistance was sought from key organisations within each of the six communities. In addition, feedback from each community on the draft reports was actively sought and modifications made to reflect their comments.

We worked hard to make the consultations inclusive of people with disability from each community. We note, however, 80% of participants were family members of people with disability. We value the information received from participants at each consultation. However, we acknowledge that people with disability were under-represented. That is a concern we are committed to addressing in future consultations. Nevertheless, the comments of participants provided valuable insight into their experience of service provision.

There was consistency in the views expressed by all six communities on each of the issue areas covered by the consultations' focus groups. Each expressed a general appreciation for a range of formal support services they were using. This is particularly true of respite and ethno-specific services. At the same time we recognise that many people from CALD communities engage with whole-population disability services and generic service systems. Some of that engagement is valued, some is not. The key point is that we must listen to what people tell us.

There was also general consensus that service systems have not been established with people from culturally and linguistically diverse backgrounds at the forefront of planning. Despite increasing awareness and understanding, the service system is not yet fully culturally competent to respond to the diversity of expressed needs of people with disability and their families from a very broad range of backgrounds.

Participants in our consultations consistently identified commonly agreed aspects of service provision that presented barriers to people from culturally and linguistically diverse communities trying to accessing services, including:

Summary and Recommendations (continued)

- a lack of information in languages other than English about available services, rights and complaints processes;
- a lack of short-term, emergency and centre-based respite, supported accommodation, general support in times of crisis, early intervention or therapy services for children or enough bilingual workers and interpreters;
- waiting lists for home and community care services such as personal care, speech therapy, occupational therapy and physiotherapy;
- time-limited assistance;
- poor quality of services, for example, workers being late or not turning up; untrained staff; workers' cultural attitudes and knowledge of service; no relief staff; services inability to meet cultural and religious needs;
- limited resources available for services;
- lack of flexibility because of strict guidelines for services; and
- very high costs of activities, transport and equipment often paid for directly by families.

In addition to these barriers, participants spoke about two other important difficulties that stop them from using services. These were, feeling unable to ask for assistance and negative experiences with services in the past.

Participants reported both a lack of knowledge of where to go to get help if they have problems with a service, and a reluctance to make complaints if problems occur.

The difficulties experienced in using and accessing services were exacerbated by both communication difficulties and cultural differences, including a lack of information about services in plain English; difficulties communicating with workers in English; a lack of bilingual workers and interpreters, and a lack of culturally competent workers.

Overwhelmingly, people we spoke to said that accessible information and culturally sensitive as well as flexible service provision would help address the problems they identified. They said that this could be made possible by supporting:

- Parent/family groups and multicultural support agencies;
- A better flow of information to, and resources for, CALD workers;

Summary and Recommendations (continued)

- Culturally sensitive workers for assessment and casework management through Cultural Competency Training;
- Employment of CALD workers at decision-making levels to assist services develop culturally sensitive policies and procedures;
- Free and readily available interpreter services;
- More consultations and information sessions to strengthen networks across services and people with disability and their families from CALD backgrounds;
- Accessible centres for people with disability from CALD backgrounds and their families where they can access relevant information, specialists, support services and/or training as needed, and
- Community Education Campaigns to lessen the disadvantages of disability and increase their awareness of and access to available services.

Although the findings of this report are not new to many people working in the field, they do confirm that systemic barriers result in multiple disadvantages for people with disability from CALD communities. They not only encounter systemic barriers related to disability inequality when trying to obtain services but also suffer the effects of systemic barriers that result from a lack of cultural competency within the service system. As a consequence, to this day people from CALD backgrounds remain under-represented in their access to disability services.

It is not surprising that the kinds of services that work best for the people we talked to are those which are sensitive to people's cultural and linguistic needs. Why? Because they link them into mainstream services, assist them in their role as carers, give them an opportunity to socialise and provide a safe place to meet other families who are in similar situations and who share the same culture, language and religious beliefs. Such services make people feel connected, understood and accepted.

The first step then to improving access to services for people with disability from CALD communities and their families must deal with the additional disadvantages people face because of their cultural differences and language difficulties.

This highlights the need for us to look beyond issues of resources to face the real challenge of providing culturally competent services that respond to the needs of people from culturally and linguistically diverse backgrounds. With this in mind, the recommendations of this report are

Summary and Recommendations (continued)

predominately about taking responsibility in providing people with disability from CALD communities and their families with the support needed to reduce disadvantage. To do this successfully the Disability Council, government and service providers need to work together to support a more proactive approach to providing culturally competent service delivery.

For the Disability Council this means:

- Ensuring that its planning and activities adequately address the needs of people with disability from CALD communities
- Ensuring CALD community representation on the Council
- Working with CALD communities to raise their issues with the NSW Government
- Developing a strategy to work with government agencies and service providers to ensure that services provide culturally sensitive service delivery
- Working with CALD communities to develop community education and awareness campaigns that lessen the stigma and taboos associated with disability
- Acting as a catalyst between government departments (DADHC) and non-government organizations about the development of a CALD specific disability services forum to consult, inform and strengthen networks across services and people with disability from CALD communities
- Ensuring that any future consultations with people with disability from CALD communities investigate ways of facilitating the participation of people with disability from CALD communities so that their voices are better heard.

For Government this means:

- Listening closely to what people from CALD communities say about their experience of disability and other services;
- Developing and sustaining partnerships with key non-government organizations that are well connected to CALD communities;
- Ensuring government departments have policies that support culturally competent service provision;
- DADHC taking a lead role to develop infrastructure within CALD communities to develop supports for people with disability from these communities and their families;
- Ensuring and monitoring the provision of interpreting services in line with the NSW Premier's memorandum No: 98/22, which states:

Summary and Recommendations (continued)

NSW Government Agencies including Government Trading Enterprises are expected to ensure that contracts with private providers and funding agreements with non-government organisations identify a budget for interpreting and translation appropriate to the service provided and the needs of the clients of the service. In relation to state owned Corporations, I consider that this provision provides a sound approach when dealing with people from a non-English speaking background. Funding agencies are also expected to ensure through program monitoring that where such funding is made that language services are provided to clients who need them

- Ensuring that DADHC services and DADHC funded agencies establish a benchmark for a service access rate to match the population of people with disability from CALD communities in service catchment areas as well as ongoing monitoring and evaluation of services to ensure equitable access for people with disability from CALD backgrounds.

For service providers this means:

- Engaging with culturally and linguistically diverse communities to ensure their needs are being adequately met;
- Providing information in plain English and/or in languages other than English on services, rights and complaints mechanisms;
- Facilitating access to bilingual workers, interpreters and CALD support networks whenever possible;
- Ensuring and monitoring their provision of interpreting services in line with the NSW Premier's memorandum No: 98/22;
- Developing and working in partnership with CALD groups to ensure that information is widely distributed to both community workers and CALD communities;
- Ensuring that staff development programs provide a component of skills based training on culturally sensitive service provision or Cultural Competency Training;
- Ensuring equitable access to all services by measuring and monitoring the services access rate of people with disability from CALD backgrounds.

Introduction and Overview

People with disability from CALD communities are doubly disadvantaged when trying to obtain support as they face disability related and cultural and linguistic barriers.

There are no conclusive statistics about the number of people with disability within CALD communities in NSW but their number has been estimated at 314,335. . If this number is correct :

- 5% of all people in NSW are people from a CALD communities with disability, and
- 25.7% of all people in NSW with disability are from a CALD communities.¹

Although there have been attempts to document the experience of people with disability from CALD communities with regard to service provision there is a lack of precise data. It is clear, nevertheless, that under-representation by people with disability from CALD communities in disability services continues.²

It has been reported that in NSW, three out of four people with disability from a CALD communities miss out on receiving State or Commonwealth funded disability services simply because of their cultural and linguistic background.³ Barriers to accessing services have been identified in previous studies and include “fear, misconceptions or a lack of knowledge and lack of skills”⁴. These “barriers are created by systems, organisations, individual workers and also by people with disability from CALD communities themselves, their families/carers”⁵

As both official adviser to the NSW government on issues affecting people with disability and their families and an adviser to the Commonwealth government on important issues for people with disability in NSW, the Disability Council is interested in developing a better understanding of the issues and experiences of people with disability from CALD communities. This consultation project is the first step towards achieving this goal and is the basis upon which the Council will develop its planning and activities in relation to policy advice, systemic work and inclusive practice.

The consultations have also provided the Council with an opportunity to:

- provide information to people with disability from CALD communities and their families about key agencies and services that may be of assistance to them;

1. www.mdaa.org.au/publications/faqs/figures.html

2. 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.

3. www.mdaa.org.au/publications/faqs/key.issues.html

4. MDAA Ethnicity + Disability Factbook: The Factbook and How to Use It

5. MDAA Ethnicity + Disability Factbook: The Factbook and How to Use It.

Introduction and Overview (continued)

- increase the awareness of people with disability from CALD communities and their families about the role of the Disability Council;
- establish relationships and contacts with key networks and organisations involved with people with disability from CALD communities and their families;
- report and advise government on issues and themes emerging from consultations, make recommendations to government, where appropriate; and
- act as a conduit for the views of people with disability.

In total three hundred people with disability and their families from six culturally and linguistically diverse communities participated in a number of public consultations held between 2002 and 2005.

Although both people with disability from CALD communities and their families were invited to attend the consultations over 80% of participants were family members of people with disability. Whilst it is acknowledged that this represents an imbalance in views, the comments and experiences shared throughout the consultations nevertheless have provided valuable insight in relation to accessing services, problems encountered in using services and strategies for addressing these issues. The importance of recognising, valuing and respecting the views of people with disability has not been ignored. The Council acknowledges that any future consultations with people with disability from CALD communities need to look at other ways to ensure that their voice is heard.

In addition, it is also important to note that participants were largely approached through ethno-specific services. It is not surprising therefore that participants expressed preference for this type of services.

The role of the Disability Council of NSW

The role of the Disability is to:

- **Monitor the implementation of all Government policy in relation to people with disability and their families.**
- **Advise Government on the effect and relevance of services and priorities for services.**
- **Encourage diversity, flexibility and innovation in the provision of services.**
- **Promote the integration of people with disability in the community.**
- **Consult with people with disability and their families**

Introduction and Overview (continued)

This consultation project is not one that could, of itself, provide solutions. It has been our intention, however, to act as a catalyst for the development for better service provision for people with disability from culturally and linguistically diverse communities in the future. To that end we have faithfully documented the views expressed in the consultations as they were reported under each of the issue areas used for the focus group questions. We include recommendations for changes that will support a pro-active approach to providing culturally appropriate service delivery.



Chinese Consultation held at Burwood Council 2005



Chinese Consultation held at Burwood 2005

The Project and the Participants

This is a qualitative research project. With the exception of figures on the profile of participants, there is no quantitative data. Examples of personal experiences have been included to illustrate particular concerns.

People with disability and their families who participated in the project came from six CALD communities. . These six communities were selected for participation in the consultations because they represent the most commonly spoken non-English languages in NSW - Arabic, Chinese, Vietnamese, Greek, Italian and Spanish.⁶

The design and implementation of the project was undertaken with assistance and advice from key networks and organisations within each community. Their feedback on the focus group questions and consultation process used in the pilot was invaluable in developing the final methodology for the project. Their support with organising the consultations and with encouraging people with disability from CALD communities and their families to participate was crucial to the overall success of the project.

The consultations were held over a three-year period from 2002 to 2005. Each CALD group was allocated either one or two consultation days, which were open to all people with disability and their families from their community. Specific arrangements for each of the consultations were developed by taking into account the demographics of each community, including geographic locations, and significant cultural dates and times.

The consultations were advertised through:

- community organisations for each CALD group, particularly those for people with disability;
- newspapers such as Extra Informativo, El Espanol, the Spanish Herald, Chinese Heralds Daily News, Sing Tao, Australian Chinese Daily and La Fiamma;

6. Almost 19% of the population of NSW speaking a language other than English at home. Of those who speak a language other than English at home 12% speak Arabic, 10% Cantonese, 8% Italian, 7.5% Greek, 5.7% Vietnamese, 5.5% Mandarin and 4% Spanish. These statistics are sourced from the Community Relations Commission – For a Multicultural NSW at www.crc.nsw.gov.au/statistics/nsw_overview.htm

Consultations were held for each group at the locations and dates listed below:

- **Arabic: Liverpool 17 June 2002**
- **Greek: Roselands 19 February 2003 and Randwick 11 September 2003;**
- **Vietnamese: Fairfield/Cabramatta and Canley Vale 26 September 2003;**
- **Spanish: Eastlakes 5 November 2003, Dee Why 10 November 2003, Fairfield/Cabramatta 24 November 2003 and Gladesville 19 November 2003;**
- **Chinese: Burwood 18 January 2005 and 26 February;**
- **Italian: Haberfield 8 March 2005.**

The Project and the Participants (continued)

- SBS Radio;
- community television stations such as Channel 31, TVBJ (Chinese pay TV);
- community radio stations such as Sydney Greek Radio Stations, Radio Austral, radio 2AC, 2CR (China Radio Networks) and Rete Italia AM station;
- community churches, and
- CALD community workers approached to distribute information to their clients.



Greek Consultation held at Randwick Town Hall 2003

The consultations were conducted by way of face-to-face sessions, using focus groups of 10-12 participants and standard focus group questions. Focus groups were conducted in both English and in the community language, using either bilingual facilitators, or English speaking facilitators, supported by interpreters.

The focus group questions used in the consultations were designed to reflect the project objectives and the information

needs of the Council, and build on the knowledge already available related to the target group, service provision and access issues through a review of the literature undertaken for each group. The questions were piloted to establish whether they would be effective in eliciting the required information.

A report for each of the consultations, summarising and analysing the information obtained from each community was forwarded participants and key agencies and networks within each community for their feedback. These reports are now available to the general public.

In total three hundred people with disability and their families participated in the consultations. The highest percentage of participants came from the Chinese and Greek speaking communities, followed by the Vietnamese, Spanish, Italian and Arabic speaking communities as detailed in Table 1.

The Project and the Participants (continued)

Table 1 Number of participants by language spoken

Language spoken	Number of participants	Percentage of total number of participants
Arabic	14 ⁷	5
Greek	70	
Vietnamese	51	17
Spanish	42	14
Chinese	103	34
Italian	20	7
TOTAL	300	100

Not all people with disability and their families who participated in the consultations provided demographic data. Of the total number of participants, 85% completed the survey on participant's profile. Of the total number of participants in each language group, only the Spanish and Vietnamese had a one hundred percent response rate. The remaining groups ranged from 85% (Italians) to 50% (Arabic).

Table 2 Number of participants providing demographic data

Language spoken	Number of participants providing demographic data	Percentage of total in language group
Arabic	7	50%
Greek	55	78%
Vietnamese	51	100%
Spanish	42	100%
Chinese	82	79%
Italian	17	85%
TOTAL	254	85%

7. The sample of people with disability and family members from Arabic speaking background who took part in this consultation was very small and may not be representative of the broader population, thus some caution is required in interpreting the information provided by participants. However, Arabic-speaking community workers involved in this consultation indicated that the information obtained from participants is consistent with anecdotal reports from their clients.

The Project and the Participants (continued)

As can be seen from Table 3 the majority of people with disability and their families who participated in the consultations and who provided demographic data (81%) were family members/unpaid “carers”, friends or interested others.

Table 3 Status of participants providing demographic data

Language spoken	Status of participants providing demographic data	
	No of person with a disability	No of family members/unpaid carers, friends or interested others
Greek	13	42
Spanish	5	37
Arabic	1	6
Vietnamese	9	42
Chinese	17	65
Italian	4	13
TOTAL	49	205
AS A PERCENTAGE OF TOTAL RESPONSES	19%	81%

The primary disability reported by people with disability and their families who participated in the consultations and who provided demographic data was intellectual or developmental disability (67%).

The Project and the Participants (continued)

Table 4 Primary disability reported by participants providing demographic data

Language spoken	Primary disability reported by participants providing demographic data				
	Intellectual or developmental	Physical	Sensory	Psychiatric	Not stated
Greek	47	12	5	3	1
Spanish	10	16	6	5	0
Arabic	4	2	0	0	1
Vietnamese	47	2	0	2	0
Chinese	53	18	1	9	1
Italian	9	8	0	0	0
TOTAL ⁸	170	58	12	19	3
AS A PERCENTAGE OF TOTAL RESPONSES	67%	23%	5%	7%	1%

The majority of people with disability and their families who participated in the consultations (76%) indicated that their native language was their preferred language. Only 7% indicated that English was their preferred language.

Table 5 Preferred language of participants

Language spoken	Preferred language			
	Native language	English	No preference	Did not report
Greek	40	6	9	0
Spanish	31	3	7	0
Arabic	3	0	3	1
Vietnamese	42	2	7	0
Chinese	70	6	4	3
Italian	7	2	8	0
TOTAL	193	19	38	4
AS A PERCENTAGE OF TOTAL RESPONSES	76%	7%	15%	2%

8. Some respondents reported that there were two primary disabilities, hence the total number (262) of responses reflect this and is not consistent with the total number of respondents (254).

Barriers to Accessing Services

Although appreciative of formal support services, people with disability and their families reported there were many barriers they had experienced which led them to stop using services, limited their use of them or prevented them from initially accessing them.

These barriers related to issues of service availability, quality, flexibility, cost and administrative requirements. Other barriers included a reluctance to request assistance and previous negative experience.

Service Availability

Participants reported frustration with limited service availability. Examples included:

- lack of local respite services, particularly short-term, emergency and centre-based respite;
- long waiting lists for home and community care services, particularly personal assistance and support services;
- not enough supported accommodation services;
- very long waiting lists for services such as speech therapy, occupational therapy, and physiotherapy;
- not enough help during times of crisis;
- a general lack of early intervention and therapy services for children;
- time limited assistance (varying from six weeks to six months);
- a lack of culturally sensitive workers; and
- a lack of information in appropriate languages and formats about available services, rights and complaints process.

Lack of services and long waiting lists are major barriers for people with disability from CALD communities and their families in accessing services. The long delays often prevent timely service provision.

What are the things that make it hard for you to get help that you need or want?

Answer:

Service availability

Poor quality

Inflexibility

High costs

Administrative requirements

Reluctance to request assistance

Bad experiences in the past

Barriers to Accessing Services (continued)

Some participants said that delays often meant their children were assessed as too old to be eligible for services or could only access the service for a short time before the cut-off age. This, say participants, resulted in lost opportunity for early intervention and further delayed their children's development.

Some of the Italian people with disability and their families said that service providers often tell them that their requests for services and supports cannot be met due to the shortage of available disability equipment and resources.

Access to respite services was reported by many to be difficult, particularly at times of family crisis. Spanish, Vietnamese, Chinese and Italian speaking people with disability and their families indicated that they were required to book respite months in advance, and thus 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 who are being cared for by their adult children.

Arabic speaking people with disability and their families said that many families find it difficult to access respite services for their children with disability when they need to go overseas to tend to family responsibilities. The respite they need at such times usually extends the limits of formal services, and there is a lack of understanding from services that it is not feasible for families to take their children to countries that lack many support services.

A lack of culturally sensitive workers also prevented some people with disability from CALD communities and their families from accessing services. Some Greek and Vietnamese speaking people with disability and their families highlighted inaccurate or incomplete information from community workers as a problem, particularly where this resulted from assumptions by workers about the information needed by the family.

Several Chinese people with disability and their families experienced negative attitudes and stereotyping and felt that they had been discriminated against by services. An example was given where the local hospital did not provide any information on available services and support to a participant from a Chinese background, but this information was available to English speaking patients.

Many participants said they had experienced difficulty and frustration navigating the service system and finding the right services because of communication difficulties, such as a lack of plain English information about services, difficulties communicating with workers in English, and a lack of bilingual workers and interpreters. They had to ask for assistance repeatedly until they found the right service. One 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.

Barriers to Accessing Services (continued)

Frustration over the lack of interpreters available to provide assistance when needed, for example at medical appointments, was an experience many shared. 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. Others advised that there is a lack of interpreters to assist those who have no or minimal understanding of English.

“We did not get an interpreter in Vietnamese. We asked for a meeting with the Vietnamese interpreter but we did not get it.”

Parents of people with disability from a Vietnamese speaking background discussing their experience with a local service in their area

Participants repeatedly commented that their limited English is a barrier to accessing services as, when they try to speak English, people do not understand them. They reported feeling embarrassed and lacking sufficient confidence to try accessing those services again.

“We don’t understand the language. When I speak they don’t understand me. I get nervous.”

A person with a physical disability from a Chinese speaking background

It was noted that some Chinese people with disability and their families were not able to access Day Programmes due to the inability to verbalise their needs in English and to converse with others. Some also suggested that lack of English limits their employment opportunities, leading to a lower level of participation in the community and an increase in their sense of redundancy and inability to contribute to their community.

Participants commented on the importance of carers’ groups, disability support groups and disability advocacy 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’.

A number of people with disability from CALD communities and their families emphasised 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.

“I don’t know how many (services) there are. When I need anything I don’t ask, I just go to my daughter and the family.”

A mother of a person with a disability from a Spanish Background at a consultation in Dee Why

Barriers to Accessing Services (continued)

Poor quality Services

Quality of services was raised by many people with disability and their families as important to them. While supportive professionals are 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.

Others referred to the limited resources available for services, such as the impact of time limitations on the quality of cleaning assistance being provided, or the poor quality of care provided by workers in some accommodation and respite services.

Other issues of service quality raised by participants 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 or Meals on Wheels; and
- lack of worker sensitivity and lack of training for workers in cultural issues provided difficulties for a number of families. For example, workers who were judgmental or made decisions based on their assumptions about the person or their culture.

Participants reported that poor service quality prevented them from using existing services as it reduced the level of trust they held. A number of people were concerned about safety risks in respite due to the grouping of incompatible clients. This impacted on their level of use of the service.

Some Chinese people with disability and their families raised the issue of respite centres and day programmes being under-resourced and under equipped to provide adequate support. This was also seen as a barrier to accessing these services.

Lack of service flexibility

While the flexibility of respite was generally reported favourably, many participants expressed frustration with the lack of flexibility demonstrated by a compartmentalised care system with restricted guidelines for service delivery within individual agencies.

Barriers to Accessing Services (continued)

Examples included:

- frustration with in-home personal assistance and support guidelines that prevented the service providing assistance with tube feeding;
- Occupational Health and Safety guidelines which necessitated costly house renovations for one family;
- guidelines that prevented the service from managing medication and filling prescriptions;
- the inability to accumulate unused respite hours;
- 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.

“If you are not so severe or too severe, the resources aren’t there.”

A mother of a 25 years old man who has a physical and intellectual disability at the Spanish consultation in Gladesville

Others said 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. One Arabic participant reported that she had had little support to manage the age-related care needs of her father because service criteria prevented him from accessing aged day care services on the basis of his refugee status. Another Arabic speaking participant said that in-home services had been withdrawn when the service determined that the extended family were actively involved in caring for the person with disability.

Some participants noted that flexibility was determined by the service provider thus limiting its usefulness.

Many Greek speaking people with disability and their families also expressed a genuine fear of retribution if they pushed these issues too far.

High cost of disability

Additional costs associated with disability were raised by participants as particular barriers to accessing services. The most significant of these additional costs was related to transport.

Barriers to Accessing Services (continued)

Examples included:

- the costs of travelling to services that weren't available locally, such as medical and therapy services and
- the unreliability and lack of accessible public transport in certain areas within Sydney, where taxi transport becomes the only alternative available.

One example included the difficulty of paying for transportation in taxis 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 additional costs which presented barriers for people with disability from CALD communities and their families include:

- high costs of equipment, such as wheelchairs and incontinence pads;
- 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; and
- difficulties affording respite when it involves both taxi fare and service cost.

This resulted in families having to regularly subsidise the finances of the person with disability because the Disability Support Pension is not sufficient to cover the costs of services and daily living.

Greek speaking people with disability and their families were also concerned that about the lack of consistency of cost involved as even when involving the same activities the costs of services could vary substantially.

Chinese people with disability and their families identified that financial and other support services are not available to people with disability and their families who are not Australian residents.

Administrative requirements

Participants expressed concern about the amount of time that it takes to complete forms or provide statistical information for assessment and re-assessment on a regular basis when new workers/ coordinators and/or programs start. The paperwork required for the administration of case based funding was thought to be excessive and not contributive to the quality of service delivery. Forms, they noted, are not always provided in accessible and/or appropriate language.

Barriers to Accessing Services (continued)

Completing forms was in fact a key issue raised with services asking intrusive questions, and the forms being difficult to understand for people from a non-English speaking background. Many considered it to be an unnecessary barrier in some instances, particularly in relation to applying for the disability support pension, when they are asked to complete the same forms more than once although all information is already contained on a computer database.



Greek Consultation held at Randwick Town Hall 2003

Requesting assistance

People with disability and their families, particularly those from Greek, Arabic, Chinese and Italian speaking communities said they felt humiliated by having to ask for services or assistance. This, along with cultural expectations, prevented them from seeking assistance.

One Greek speaking 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 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.

People with disability and their families from Spanish speaking communities 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 misunderstanding of language and expression.

Past experience of services

Past experience of services often meant that many people with disability and their families were frustrated to the point that they gave up on trying to access services.

Barriers to Accessing Services (continued)

Examples included:

- not being given adequate information to choose an appropriate option to later find out that their children were eligible for certain services but had missed out;
- staff being arrogant, rude or unwelcoming when dealing with people with disability from CALD communities and their families; and
- being discriminated against and branded difficult when they complained about services.

One person noted that they had requested a financial report about how funding was spent and the issue was not resolved.

Many participants said that they feel ashamed and isolated from their community because of their experience of friends not being able to accept their children with disability. This also increased the expectation on the family to look after their loved ones in the home.

“I feel ashamed that my daughter has a disability and most of my friends feel embarrassed by her behaviour.”

An Arabic mother of a young woman with Autism

Services People Value

People with disability and their families who participated in the consultations expressed a general appreciation for a range of formal support services that they were using.

Respite services were viewed as particularly important because they provided time-out for family members from the 24-hour care of a family member with disability.

Specific CALD services, particularly carers groups were identified by participants as necessary and important in providing quality services because they provided:

- a link for them to mainstream services by writing letters on their behalf or informing them of assistance they may be able to access;
- an opportunity for socialisation;
- a safe environment where people are able to meet other families of similar circumstances, culture, language, and religious belief, and
- a place of solace for them to debrief and continue their push for more services that will meet their needs.

Some Vietnamese people with disability and their families said that they felt exhausted and often did not have the energy to fight for services. Only through the support of the Vietnamese Parents Support Group with Disabled Children in NSW were they able to continue to fight for more services.

Services that were appreciated included:

- respite
- accommodation services
- day programs
- in-home personal care services
- early intervention therapy services
- financial assistance for home modifications
- taxi subsidy scheme
- community transport services
- dental treatment
- playgroups
- Medicare
- government financial subsidies such as Carer Allowance, Family Allowance and Disability Support Pension.
- Autism Association
- Department of Housing
- government funded group homes
- House with No Steps
- Centrecare
- community access programs
- community transport
- interpreter services
- after-school care
- Downs Syndrome Association
- Multicultural Disability Advocacy Association
- CALD specific Parent Support Groups

What help do you get now that you really like?

Why do you like it?

Addressing Barriers to Access

Overwhelmingly, people with disability and their families 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 languages other than English would help them to understand what services provide so they could make informed decisions. Some said they would prefer access to bilingual workers to help negotiate the services they need.

Some said that services need to work in partnership with other groups such as culturally specific parents groups to ensure that information can be widely distributed across CALD communities.

Accessible information

Participants noted that information about rights and what to expect from services is vital to overcoming barriers facing people with disability from CALD communities.

“Families who have children with disability need to be given information and training to make sure that we have a better understanding about Disabilities (sic) and their rights in getting services.”

A Vietnamese parent of a child with Autism

As adult illiteracy is an issue for these communities, providing information via children and young people who speak English was seen as important, as was regular dissemination of information via language specific radio and television programs.

What would make it easier to get the help you need?

Answer:

- Accessible language formats.
- Accessible information
- Understanding and flexibility
- Access to language specific support networks
- Free and readily available interpreting services
- Cultural Competency Training
- More consultations and information
- Information, Referral and Training Centres
- Community Education Campaigns
- Longer respite hours and more accommodation options
- Affordable accessible community transport for people with disability
- Employment of CALD workers at decision making levels

Addressing Barriers to Access (continued)

Participants also said that they would like to see a better flow of information to community workers as they are their main point of contact for accessing information about CALD support services and 'mainstream' community and disability services.

Others said that CALD-speaking workers needed better resources to assist families.

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

Free and readily available interpreting services

Some said that interpreting services should be free and readily available.

Understanding and flexibility

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

Access to language specific support networks

Participants said that access to CALD support networks was important to help families negotiate the system.

Employment of CALD workers at decision making levels

While CALD workers and culturally sensitive workers were important, participants also said that the employment of CALD workers at decision making levels was needed to assist services develop culturally sensitive policies and procedures.

Cultural Competency Training

Some participants, particularly those from the Vietnamese, Chinese and Italian communities, identified the need for Cultural Competency Training.

Addressing Barriers to Access (continued)

Longer respite hours and more accommodation options

Longer respite hours and more accommodation options were suggested by people with disability and their families, particularly those from the Chinese and Italian communities. Italian people with disability and their families also suggested the need for more emergency respite centres.

Affordable accessible community transport for people with disability

People with disability and their families, particularly those from the Vietnamese, community suggested more affordable accessible community transport for people with disability to attend services.

Financial support for home and vehicle modifications

Vietnamese people with disability and their families suggested more financial support for home and vehicle modifications.

More consultations and information

Those from the Vietnamese, Chinese and Italian communities also identified the need for more consultations and information sessions to strengthen networks across services for people with disability from CALD backgrounds and their families.

Information, Referral and Training Centres

People with disability and their families, particularly those from the Vietnamese and Chinese communities indicated a need for a centre people with disability and their families that will provide:

- relevant information,
- referral to doctors and health professionals including social workers, psychologists, specialist therapists (speech, music, occupational therapy, physiotherapy, etc.),
- a space for people with disability and their families to access childcare services, daytime activities, facility for sports and entertainment,
- support and training for parents to understand and work better with their children with disability,

Addressing Barriers to Access (continued)

- support groups for siblings to accept having a sibling with disability,
- accessible transport to and from the centre, and
- English lessons to enhance communication and job opportunities, and
- counselling as needed.

Community Education Campaigns

Community Education Campaigns were highlighted by the Vietnamese and Chinese communities as a possible strategy to lessen the stigma associated with disability and enhance awareness of services to increase access. A similar campaign is needed to educate the community to empower CALD people with disability to participate in local and departmental committees providing opportunities to voice their ideas and needs.



Greek Consultation held at Randwick Town Hall 2003

Seeking Help and Problem Solving

Participants reported both a lack of knowledge of where to go for help if they had problems with a service and a reluctance to make complaints if problems occurred.

Lack of information about the complaints process

The majority of participants said that they did not know where to go to complain about particular matters. In addition, they said that they were unaware of their right to information about complaints mechanisms and complaint options. Several Arabic speaking people with disability and their families, linked their lack of information about complaints mechanisms to a general lack of information about support services.

Several Greek and Arabic speaking people with disability and their families indicated that they relied heavily on the services they used for a range of information though services didn't always tell them about their own services, other services or complaint options.

Participants said that they would often use a CALD worker in one service to find out about other services or for advice about dealing with problems with other services they were using.

Many, said that this lack of understanding of how to make a complaint leads to a feeling of helpless, of being overwhelmed and ultimately giving up on services.

If you are not happy with the help you are getting or you are having problems, what do you do?

Answer:

- **Don't know where to go to make a complaint**
- **Unaware of right to information about complaints mechanisms**
- **Rely heavily on services used though they don't always advise of complaints mechanisms**
- **Use CALD workers for information and advice**
- **Deal with problems on their own and cope as best as they can**
- **Services that they obtained were mainly due to the numerous complaints made**
- **Cultural expectations do not support complaining**
- **Previous negative experiences in trying to complain**
- **Fear of repercussions**
- **Get support from the Multicultural Disability Advocacy Association**
- **Get support from CALD Parent Groups**
- **Rely heavily on family members**
- **Ask their local Council, their doctors, hospital staff and friends for help**

Seeking Help and Problem Solving (continued)

“My father has had diabetes for many years but the doctor in the nursing home does not check this. How can I ask the nurses without being imposing to have this done. What rights do I have to ask information about my father. I would also like information in Spanish so that my father can be better informed. I am not happy that the doctor only checks him for 3 minutes and then the doctor goes. He does not ask my father anything or talk to him because he assumed that my father wouldn’t understand.”

A daughter of a person with a disability from a Spanish Background at a consultation in Dee Why

Many participants said that they deal with problems on their own and cope as best as they can.

A few Greek speaking people with disability and their families felt strongly that the services that they obtained for their children with disabilities were due mainly to the numerous complaints that they made to Government Departments, service providers, local members, independent advocates, case managers, etc.

Reluctance to complain

Participants noted reluctance to complain by people with disability and their families seemed to be linked both to cultural expectations and people’s previous negative experiences in trying to complain. Many also feared that their sons or daughters might suffer repercussions from service providers and it was easier to not say anything. A number of people noted that they were thankful for the services they got and would not complain about them.

Some noted they had complained to services to be told that the service cannot do anything about the situation, as that is how the system works.

One Arabic speaking family said that after complaining to a service provider about a reduction in therapy services, she was later told her case had been discussed and that she was hard to please. She did not take the complaint any further as a result.

Another said that when she complained about an aspect of service delivery, she felt she was blamed for creating the problem herself because of the way people dealt with her as a result of her mental illness.

Seeking Help and Problem Solving (continued)

Advocacy assistance

Some participants advised that they had received support from the Multicultural Disability Advocacy Association, and have found their assistance to be valuable in raising complaint issues with services on their behalf. Other indicated that they have approached other disability-focused advocacy services but had not been able to obtain their assistance. One 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.



Chinese Consultation held at Burwood 2005

Some people advised that they have received support from the CALD Parents Support Groups and have found their assistance to be valuable in raising complaints.

Most participants said they relied heavily on family members and rotate the role of primary carer which involved taking time off work to care for their sibling with disability.

A few people advised that they ask their local Council, their doctors, hospital staff and friends for help.

Conclusion

The views and experiences of the people who participated in this project are representative of a larger group of people with disability from CALD communities and their families. From their experience we are able to generalise about what assistance/support works or doesn't work and why, what makes access to services difficult, what would improve access and what they do about problems encountered with service provision.

What assistance/support works and why?

What assistance/support doesn't work and why?

The key issues regarding what assistance/support works or doesn't work related to service availability, quality, flexibility and cost. The findings of this report are summarised in the following points.

1. There is a general lack of information in appropriate languages and formats about available services, rights and complaints process is a major disadvantage for people with disability and their family in accessing services.
2. Short-term, emergency and centre- based respite are in short supply, as is supported accommodation, general support in times of crisis, bilingual workers, interpreters , and early intervention and therapy services for children.
3. There are waiting lists for home and community care services, particularly personal care as well as services offering speech therapy, occupational therapy and physiotherapy.
4. When assistance becomes available it is often unhelpfully restricted by sometimes arbitrary time limits.
5. Families are placed under stress being the primary source of support in the absence of available services.
6. Worker unreliability, inadequately trained staff, cultural attitudes and knowledge of service workers, a lack of relief staff and an inability to meet cultural and religious needs provide for poor quality service delivery as does limited resources.
7. Specific CALD services are necessary and important in providing a link to mainstream services, an opportunity for socialisation and a safe environment in which to share a similar culture, language, and religious belief.
8. The lack of flexibility demonstrated by a number of services is due to a compartmentalised service system with restricted guidelines for service delivery within individual agencies and services offered being determined by the service provider.

Conclusion (continued)

9. The costs associated with disability are very high and include costs associated with participating in activities, transport and equipment. Family regularly subsidise the finance of people with disability as their Disability Support Pension is not sufficient to cover the costs of both services and daily living.

Participants indicated that there are specific barriers to accessing services, including reluctance to request assistance and previous negative experience.

These barriers are clearly exacerbated by both communication difficulties and cultural differences, including a lack of plain English information about services, difficulties communicating with workers in English, a lack of bilingual workers and interpreters and a lack of culturally sensitive workers.

Overwhelmingly, participants agreed that accessible information, culturally sensitive and flexible service provision help address the identified barriers. Specifically, the people who spoke to us made the following observations.

- Parent's groups and multicultural support agencies are highly important in providing a support base for people with disabilities from CALD communities
- A better flow of information to, and resources for CALD workers is needed to assist and support people with disability and their families
- Culturally sensitive workers for assessment and casework management through Cultural Competency Training are highly desirable
- Employment of CALD workers at decision-making levels is needed to assist services develop culturally sensitive policies and procedures
- Interpreting services should be free and readily available.
- More consultations and information sessions are needed to strengthen networks across services affecting people with disability from CALD communities and their families
- A centre should be established, with accessible transport to and from the centre, where people with disability from CALD communities and their families can access relevant information, Social Workers, Psychologists, specialist therapists (speech, music, occupational therapists, physiotherapists, etc.), childcare services, daytime activities, facility for sports and

What makes access to service difficult?

What would improve access?

Conclusion (continued)

entertainment; or be referred to medical specialists.. The centre could provide support and training for parents, support groups for siblings, English lessons to enhance communication and job opportunities, and counselling as needed.

- Community Education Campaigns are needed to eliminate the stigma associated with disability and enhance awareness of available services to increase access.

Participants also reported both a lack of knowledge of where to go to get help if they had problems with a service, and a reluctance to make complaints if problems occurred. Specifically, issues around making complaints raised during consultations are documented below.

- People were unaware of their right to information about complaints mechanisms and complaint options.
- Some people use CALD workers to assist them while others said that they deal with problems on their own and cope as best as they can.
- Cultural expectations and people's previous negative experience affected willingness to complain. Many feared that they might suffer the repercussion from service provider if they complained.
- Some received support from the Multicultural Disability Advocacy Association and others indicated that they have approached other disability-focused advocacy services but had not been able to obtain their assistance.
- Some received support from the CALD Parents Support Groups but most rely heavily on family members.
- A few ask their local Council, their doctors, hospital staff and friends for help.

So what assistance/support does work? Not surprisingly, the type of assistance /support that works are those that are sensitive to the needs of those from culturally and linguistically diverse backgrounds. Why? Because they connect with them and provide an opportunity where they feel understood and heard and where their cultural differences are acknowledged and respected.

So what makes access to services difficult? Clearly, there are not enough services, not enough resources but more importantly accessing services becomes even more difficult when there is no or

What do they do about problems?

What is their 'complaint' behaviour?

Conclusion (continued)

limited understanding of need. The experiences of those who participated in this project highlights the importance of being able to communicate need and having these needs understood. Clearly the needs of those who participated are intrinsically tied to their cultural and linguistic background.

What would improve access to services? Overwhelmingly, participants agreed that accessible information and culturally sensitive and flexible service provision would improve access to services. Perhaps the first step to improving access to services for people with disability from CALD communities and their families is to provide opportunities to tell us what they need and by working with them to meet these needs. This means that we have to open up to culturally and linguistically diverse communities to facilitate a better understanding of their experience of disability.

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Arabic consultation

Name	Organization
Neamat El-Safty (Arablink Coordinator)	The Centre, Bankstown
Hind Saab	Rockdale Community Mental Health
George Habib	May Murray Neighbourhood Centre
George Ayoub	Multicultural Disability Advocacy Association
Mary Shalhoub	Dept. of Ageing, Disability and Home Cares (Met South West)
Edward Thomas	Carers Association, Inner West Carers Respite, Penrith Carers Respite, and Multicultural Disability Services (Macathur)
Rana Sayed (Family Counsellor)	Learning Links
Mia Zahra (Employment Consultant)	Commonwealth Rehabilitation Service – Parramatta
Sue Samad	Royal Institute for Deaf and Blind Children
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Peter Souleles (one of the facilitators)	
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Vietnamese Consultation

Name	Organization
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Name	Organization
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Yolanda Encina	Fairfield City Council
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Chinese Consultations

Name	Organization
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Italian Consultation

Name	Organization
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Celebrating Difference