

PROMOTING THE DISABILITY SERVICES STANDARDS

EXPLORING RESPONSES TO DISABILITY ISSUES

by

**CALD PEOPLE WITH DISABILITIES,
THEIR FAMILIES/CARERS,
ETHNIC COMMUNITIES AND
SERVICE PROVIDERS**

through

WORKSHOPS

on

THE “CALD PERSPECTIVES ON THE DISABILITY SERVICES STANDARDS”

2007-2008

Disability Services Commission

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- Ethnic Disability Advocacy Centre (EDAC)
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 - Jenny Au Yeong (Executive Officer)
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- Nulsen Haven
- Women with Disabilities WA
- Muslim Women's Support Centre
- Intework
- The Centre for Cerebral Palsy
- Disability Services Commission (Vic Park)

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- Annimac Consultants
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- Communicare
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- Disability Specialist Speech Pathologist (Dolly Bhargava)
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- Rocky Bay
- Sussex St Community Law Centre
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- WA Disabled Sports Association

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Finally, EDAC has taken more than the usual time with this Project Report since it became apparent that having the material available in the direct form of participant experiences makes it potentially a valuable grounded information resource to supplement the use of the *CaLD Perspectives on the Disability Services Standards* that are to be used in upcoming training by EDAC with all DSC funded service providers.

Also, although it was not the intention of the Project to develop Recommendations for consideration at all levels of disability service provision for CaLD people, the participants were of the opinion/expectation that improvements on a wider range of issues was going to be necessary if the beginnings of their working together with service providers was going to continue to be successful.

Zeliha Iscel and Maranda Ali

Project Officers, Ethnic Disability Advocacy Centre

2 Executive Summary

2.1 Issue of concern

The Disability Services Commission's (DSC) 2001-2 and 2004-2005 Annual Reports show that only approximately 2% and 3% of people with a disability accessing disability services in WA are of Cultural and Linguistically Diverse (CaLD) background. The CSDA Interim Report 1996 shows that also this is only 4.3% nationally. This contrasts with the fact that the ABS Surveys 1993 and 1998 identified that nationally 15.4% and 14.7% of people with a disability were from non-English backgrounds. Clearly this indicates that there is a critical disability service uptake gap by CaLD people with disabilities both here and Australia-wide that needs urgent and effective attention. EDAC has continued to report this concern, for example in its submission to the *Disability Sector Health Check* (EDAC Oct 2006).

Previous research reviewed by EDAC (*Supporting CaLD Carers* 2003), funded by the Disability Services Commission, has shown that this critical under-utilization of service access is primarily attributable to:

- CaLD cultural perceptions of disability and lack of knowledge and confidence about cultural, disability or carers rights; and also
- a continuing lack of engagement and involvement of the disability services sector with CaLD people with disabilities and their families/carers and communities - in the design, development and delivery of culturally appropriate disability services, and of suitable promotion of disability information and these services within ethnic communities.

The Commission and EDAC have since then worked on several initiatives with CaLD disability services consumers and providers to address these issues and close this services gap:

- ✓ Guidelines to assist service providers to implement the Disability Services Standards in culturally responsive ways (*CaLD Perspectives on the Disability Services Standards: Developing Culturally and Linguistically Responsive Approaches to the Disability Services Standards*).
- ✓ *Consumer Version (Easy English and Pictorial Version for Individuals with Complex Communication Needs)*.
- ✓ Training Manual and training staff of DSC-funded agencies in WA.
- ✓ This project - Workshops with both CaLD people with disabilities and their families/carers and communities and with their disability service providers, together. Outreach presentation of the outcomes of the Workshop series progressively on EDAC's *EthnicAbility* community radio program and website.

2.2 Project

Through this Workshop project, EDAC sought to contribute to addressing the issues underlying the services uptake gap. The project created working partnerships with disability service providers and CaLD people with disabilities and their families/carers and communities - through developing and facilitating Workshops to enable both to engage and better understand CaLD disability issues and the requirements for cultural perspectives in service design, development and delivery.

The series of Workshops was conducted over a 2 year period, using the *CaLD Perspectives on the Disability Services Standards* as a framework for addressing current issues of concern.

Overall, 10 Workshops were planned, developed and implemented. CaLD consumers, their families/carers, ethnic community leaders, and disability services providers - together learned about the Disability Services Standards from cultural perspectives and discussed their CaLD issues relating to those Standards. Overall this created improved mutual awareness of CaLD rights, issues and best practices relating to the Standards.

At the planning stage, the Steering Committee identified specific critical target groups and priority issues of concern for the 10 Workshops:

1. Special disability groups – CaLD women with disabilities, and CaLD people with Cerebral Palsy, Intellectual and Developmental Disability, and Autism.
2. Special regional areas of concern – Mirrabooka, South Eastern Perth, Northern Perth.
3. Special community ethnic groups – Muslim community.
4. Special issues of concern – Accommodation, Independent schools.

Each workshop was facilitated utilizing a process involving:

1. Guest speakers - assisted to address CaLD/disability issues impacting each identified target group and area of concern;
2. Participants sharing their actual experiences of accessing services; and
3. Discussion addressing carer and consumer issues and concerns - facilitated within the *CaLD Perspectives on the Disability Services Standards*.

A total of 152 people attended the 10 workshops.

2.3 Outcomes

Some common issues were identified across all the Workshops that were experienced as barriers for people from a CaLD background who were accessing/trying to access disability services. Each was explored by participants in relation to the different Standards to which they apply.

Each issue was addressed as a challenge for positive constructive improvement. The Workshops engaged CaLD consumers and agencies in the beginnings of relationships on the basis of which they can further continue to work together – toward achieving mutually informed understanding of culture and disability, and, on that basis, build inclusive services that engage and appropriately support CaLD consumers with disabilities and their family/carers and cultural communities.

2.4 Dissemination

The outcomes of the Workshops were made available to the ethnic and general community and the professional disability services sector by regular broadcasts throughout this time on EDAC's weekly *EthnicAbility* program on 6EBAFM ethnic community radio.

Also, from the outcomes of the Workshops an integrated summary report was developed with CaLD examples of the Standards and their cultural aspects. This was translated and narrated in 7 languages, recorded to be broadcast on the *EthnicAbility* radio program.

There is ongoing accessibility to the broadcasts and translations on the EDAC website.

2.5 Participant support

EDAC also provided support to the Workshop participants by referral to its individual and systemic advocates who followed up issues arising that required attention.

2.6 Project evaluation

Feedback indicated that both CaLD people with disabilities and their families/carers and communities, and service providers, found that participating in the Workshops provided them with a practical understanding of CaLD disability services and support issues within the framework of the Disability Services Standards.

In all, the project was successful as about 65% of participants obtained support to access disability services, and service providers expressed how they have learnt more about CaLD carer needs from their experience in the Workshops – and appreciated the initiative to provide a sustainable CaLD/disability information resource created from the Workshop outcomes through the *EthnicAbility* radio broadcasts and through their accessibility in summary translations on the EDAC website.

2.7 Recommendations

The aim and purpose of the Project was to engage CaLD consumers, family/carers and ethnic communities together with disability service providers, around their main issues of concern, to begin working together to implement the Disability Services Standards in culturally appropriate ways.

To enable and support this, they developed constructive recommendations and expectations for improvements they felt necessary at all levels

Overall Recommendations

From the experiences of both consumers and service providers, across all Workshops, it was clear that;

Firstly, there is a need to raise awareness, of both ethnic communities and disability and other services, on the lived experience and issues of CaLD people with disabilities, and also, secondly, that of their families/carers.

Secondly, importantly this needs to continue to be done within the development of a better awareness and understanding of the basic human rights to substantive equality of CaLD people with disabilities, and this be explicitly informed by current disability and multicultural policy and legislation.

Thirdly, this must be enabled to be implemented in demonstrable and accountable/monitored ways into actual practice, at all levels, within awareness of the Disability Service Standards and guided by consumer experience as expressed in the *CaLD Perspectives on the Disability Services Standards*.

Fourthly, to achieve that, CaLD people with disability must be engaged and resourced to provide the leadership, management and development and delivery of all services to CaLD people with disability - at all levels, from legislation and policy through to practice.

A number of more specific recommendations were made, arising out of and supplementary to the immediate main objective of the project.

Overall, the recommendations support the continued engagement of CaLD consumers and carers with their service providers in further working together toward reducing the critical gap in service uptake of CaLD people with disabilities.

3 Project Outline

3.1 Implementing the DSC Strategic Plan for CaLD people with a disability

The vision of the DSC Strategic Plan is that *all people live in welcoming communities which facilitate citizenship, friendship, mutual support and a fair go for everyone*. DSC has Strategic Objectives to fund services that encourage and support people with disabilities, regardless of their ethnicity to interact and build partnerships within all areas of society, including family and friends, their communities and service providers. The funding for this particular project by DSC is based upon promoting these Objectives for CaLD people with disabilities.

3.2 Issue of concern: critical gap in service uptake for CaLD people with a disability

People with disabilities from Cultural and Linguistically Diverse (CaLD) backgrounds and their families are generally reticent to use disability services because of their own cultural understanding, values and practices regarding disability; lack of understanding and unfamiliarity with disability as it is regarded and supported in Australia; language and support difficulties in navigating the complex disability services system; and also because the generic nature of the services are generally not responsive to their cultural and language needs.

Although nationally CaLD people represent approximately 15% of the disabled population (1993, 1998 ABS Surveys - CSDA Report 1996), their rate of access to services in WA continues to be only about 2-3% (DSC Annual Reports 2001-2, 2004-5) and at 4.6% much the same problem exists nationally (CSDA Report 1996).

In previous research by EDAC (*Supporting CaLD Carers* 2003) consumers attributed this shortfall in CaLD access of disability services to the fact that they as a group have the least understanding of government policies, disability standards, strategic plans, goals and their citizenship rights. It is also due to the fact that they are also not comfortable with the mainstream nature of disability services in terms of both satisfaction and outcomes, citing the need for cultural consideration as the key element and for improved understanding of how an individual's cultural practices may impact on the nature of the service they need.

EDAC has drawn attention to this critical service uptake gap again in its submission to the *Disability Sector Health Check* (EDAC Oct 2006).

3.3 Integrated initiatives to close the gap

The Disability Services Commission and EDAC since then have been working together on several initiatives to address these issues and close this services gap:

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- ✓ In 2006 EDAC was provided with Service Improvement Project funding from DSC to work with CaLD disability services consumers to develop guidelines to assist service providers to implement the Disability Services Standards (including the new Standard 9) in culturally appropriate ways (*CaLD Perspectives on the Disability Services Standards: Developing Culturally and Linguistically Responsive Approaches to the Disability Services Standards*, EDAC 2006).
- ✓ In 2007 EDAC was funded under the Substantive Equality Project of DSC to develop a Training Manual based on those CaLD guidelines suitable for training DSC-funded disability service providers throughout the State in the provision of culturally appropriate services within the Disability Services Standards framework.
- ✓ In 2007 EDAC received a Quality Systems Improvement Grant from DSC to work with a disability communications specialist to produce a Consumer Version of the *CaLD Perspectives on the Disability Services Standards* based on easy English, graphics and augmented communication strategies.
- ✓ In 2008 EDAC has secured DSC funding to commence using the above specially developed resources in training the staff of DSC-funded agencies in WA.
- ✓ Recognising the importance of improving disability services to CaLD people in its Strategic Plan, DSC provided EDAC with Strategic Plan Implementation Grant funding to work with both CaLD people with disabilities and their families/carers and communities and with their disability service providers, together, in building mutual understanding of appropriate services for CaLD people - through addressing current areas and issues of concern. Doing so within the Disability Services Standards, the *CaLD Perspectives on the Disability Services Standards* were used as a guide.

As an important part of the outreach of this overall strategic initiative, EDAC was also funded to present the outcomes of the Workshop series progressively on its *EthnicAbility* community radio program.

This project was consequently one of several that together comprise a cooperative and ongoing integrated approach to this service development and access problem for CaLD people with disabilities and their families/carers and communities.

3.4 Summary overview of the project

3.4.1 Aim

To contribute to closing the persisting critical gap in access, satisfaction and effectiveness across the range of disability services to CaLD people and their families/carers and communities.

3.4.2 Objectives

- ✓ to enhance mutual understanding regarding disability and its cultural aspects - among consumers and carers, service providers and the ethnic communities; and
- ✓ to promote inclusion in disability service development, delivery and evaluation.

3.4.3 Method

The project centred on the development and delivery of a series of Workshops for CaLD people and their families/carers and communities, involving disability service providers. The Workshops targeted key areas of concern identified beforehand. They encouraged all participants to work together to constructively explore addressing each issue within both cultural approaches to the understanding of disability and also cultural approaches to the Disability Services Standards. Each Workshop used the *CaLD Perspectives on the Disability Services Standards (2006 revision)* as a guiding framework.

The project incorporated three main elements, each addressing these desired Objectives:

- **Creating opportunities for engagement and working partnerships** between disability service providers and CaLD people with disabilities, their families/carers, and ethnic communities - through their being the hosts of the EDAC Workshops:
 - ✓ to promote improved CaLD involvement in the development of mutual understanding and in addressing the cultural aspects of providing disability services.
- **Developing and implementing 10 Workshops** catering for an average of 15 participants each, including CaLD consumers, their family carers and their ethnic community and service providers. Each Workshop provided a forum for CaLD consumers to “have their say” about their experiences in accessing disability services, for service providers to raise their difficulties providing services to CaLD clients, and for both to engage these issues constructively together:
 - ✓ to develop better mutual understanding about disability and its cultural perspectives; and
 - ✓ to explore together desired service improvements in terms of cultural responsiveness.
- **Disseminating outcomes to the wider multicultural community**
Workshop outcomes were reported on EDAC’s *EthnicAbility* community radio program through interviews with guest speakers and CaLD consumers and their families/carers and others; and an integrated summary of the overall

outcomes from the workshops was translated into the main ethnic community languages. Both were also posted on the EDAC website for public access:

- ✓ to create wider awareness in the community of culture and disability and of how service providers, ethnic communities and CaLD people with a disability can work in partnership to ensure service delivery meets cultural needs.

Overall, it is expected that these workshops will increase the percentage of CaLD consumers accessing disability services, through having facilitated mutually more informed and constructively engaged consumer/provider relationships.

4 Project planning and development

4.1 Project Plan

A Memorandum of Understanding (MOU) was created between EDAC and the National Disability Services (NDS) of WA (then ACROD) for a Steering Committee to be created consisting of representatives from EDAC (as Chair), NDS, DSC, CaLD person(s) with a disability, service provider(s) - and the Project Officer. The Memorandum outlined the roles/resources which EDAC and NDS would contribute towards the project, the requirement for the Steering Committee to meet at monthly intervals, and detailed reporting required by the Steering Committee, including outcomes of each Workshop on its completion.

For the 2 year timeline for the project, EDAC and NDS developed a project management schedule with the following progress objectives, subsequently ratified by the Steering Committee:

1. Recruit Steering Committee members and finalise MOU – 1 month.
2. Create a Project Plan to enable process objectives to be achieved in an orderly manner – 2 months.
3. Determine the target groups/issues for each Workshop, from background research and consultation – 2 months.
4. Develop a generic program agenda for each Workshop, allowing for adjustments according to the theme of each Workshop - 2 months.
5. Recruit service providers to host each Workshop, canvass participants, implement the Workshops, report outcomes of each progressively to the Steering Committee and the *EthnicAbility* radio program – 12 months.
6. Produce and disseminate summary outcomes of the Workshop series translated and narrated in the main community languages, through both *EthnicAbility* and the EDAC website – 3 months.
7. Report – 2 months.

4.2 Background research and creating working partnerships

For most of the 10 Workshops, each was preceded by a minimum of 3 planning meetings of the Project Officer with the host agency and Guest Speakers (usually CaLD persons with a disability or family/carer) relevant to the identified topic.

- An initial meeting with the host agency reviewed background research and experience within the Workshop theme, regarding issues typically impacting CaLD consumers.
- Guest Speaker(s) were then identified, who were appropriate and experienced, to address these issues in the Workshop, and were invited to attend a final 2 planning meetings where the Workshop agenda was finalised.

These planning meetings were seen to be beneficial not only for planning the Workshops, but also for creating the opportunity for service providers to establish to the beginnings of ongoing working partnerships with representative consumer spokespersons and their ethnic communities, toward working together to establish improved mutual understanding of the issues impacting CaLD consumers accessing disability support services.

4.3 Workshop development

Through consultation with the Steering Committee, Workshops were developed for 10 critical target areas (3 reserve). It was determined that the Workshops would cater for target groups within the following categories. [The initial Workshop (Mirrabooka) acted as a trial to guide further adjustments to the program outline, advertising/canvassing and bringing in other agencies].

Special disability groups	<ul style="list-style-type: none"> ➤ CaLD women with disabilities ➤ Cerebral Palsy ➤ Intellectual and Developmental Disabilities ➤ Autism
Special regional areas of concern	<ul style="list-style-type: none"> ➤ Mirrabooka (Pilot workshop) ➤ South Eastern Perth ➤ Northern Perth ➤ Mandurah*
Special community ethnic groups	<ul style="list-style-type: none"> ➤ Muslim community ➤ Vietnamese Community (as a backup option)* ➤ New emerging communities (as a backup option)*
Special issues of concern	<ul style="list-style-type: none"> ➤ Accommodation ➤ Independent schools (as a backup option)

* not actioned.

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Each Workshop operated to a generic 4 hour Program Outline ensuring the objectives identified for the project were achieved and yet enabled enough flexibility to focus the program according to the topic of each Workshop. The Program Outline ensured that the following areas were addressed in each Workshop:

1. Guest Speaker(s) provided information appropriate to each Workshop-specific theme.
2. Education on the Disability Services Standards, relative to the Workshop theme, with their application to CaLD people - guided by the *CaLD Perspectives on the Disability Services Standards*.
3. Participants sharing their experiences relative to the issue(s) and relating these to the Standards and CaLD guidelines.

A generic Powerpoint presentation was developed for the Workshops. This enabled participants with English language or sight/hearing difficulties opportunity to access combined visual/verbal representation of the Disability Services Standards. Recently EDAC had developed a pictorial consumer version of the Standards which was utilized as a guide for the presentations. The Powerpoint also incorporated the Program Outline, which usefully maintained structure within the Workshop when sometimes several different people would be presenting.

An information and resources table was organised for each Workshop where service providers and EDAC provided information for consumers relevant to the topic. This included translated information in ethnic community languages relevant to the participants (prepared in advance from knowing the language and culture of those who registered for the Workshops). EDAC also made available copies of the *CaLD Consumer Perspectives: Developing culturally and linguistically responsive approaches to the Disability Services Standards* (EDAC August 2006).

4.4 Overcoming barriers to Workshop participation

From its previous Workshop experience EDAC identified and addressed the several barriers that tend to preclude people with disabilities who are from CaLD backgrounds from participating in Workshops. EDAC planned ahead to address these obstacles at least a week before each Workshop by identifying participant support needs during their registering of interest to attend.

A transport subsidy was provided to individuals who indicated that they would only be able to attend if some assistance with transport could be provided.

Interpreters were provided where CaLD people indicated that they would be keen to attend but had language support needs. Addressing this early also enabled forward planning to allow the Workshop process to incorporate strategies to enable adequate time for the participating interpreters to relay the information in the relevant languages.

Workshop process supporting complex communication needs. Using a Powerpoint presentation to support verbal information and discussion in the

Workshops provided the opportunity for participants to also visualize key points relating to the services of EDAC, to the topic of the Guest Speaker, and how their cultural beliefs and/or practices relative to the issues they raised could be incorporated within the Disability Service Standards.

One of the advantages in utilizing a Powerpoint presentation was to provide augmented communication in view of the fact that some of the CaLD participants had compromised communication capabilities due to either or both the nature of their disability and/or being new to the English language. They were assisted with Easy English access to the Standards and to be able to visualize each through the use of key practical images. Also, in culturally accessible ways the images portrayed cultural aspects of the Disability Services Standards, from the *CaLD Perspectives on the Disability Services Standards*. Images that were used were similar to *Consumer Version (Easy English and Pictorial Version for Individuals with Complex Communication Needs)*.

Approaching the Standards through participants own current key issues. It was not appropriate to try to attempt to cover all of the Disability Services Standards and their cultural aspects in each Workshop. Also, to maximise Workshop relevance and outcomes for both consumers and service providers it was decided that, after a brief overview, to concentrate of those Standards most relevant to the issue(s) of concern being addressed in that Workshop or being raised by each particular group of participants.

For example, some Workshops required a specific focus on some Standards: such as Standard 9 (Protection of Human Rights) during the Gosnells workshop and Standard 5 (Participation and Integration) during the Autism Workshop.

The advertisement strategy involved a flyer being developed for each Workshop (see *Appendix C*). In addition to the purpose and details of each Workshop it also:

- ✓ informed potential participants that both transport and interpreter supports would be made available as required;
- ✓ indicated that they would have opportunity to share their own issues about disability services with each other and raise their concerns and ideas directly with relevant service providers in a constructive context;
- ✓ was translated into the main expected participant languages, such as Arabic, Dari, Chinese and Vietnamese; and
- ✓ was distributed not only by mail and email but also by hand/word of mouth through EDAC's well developed disability and ethnic community networks:
 - Personal invitation of EDAC clients by the individual advocates.
 - Via email through EDAC's service provider database, to those for whom the topic of each workshop was most relevant.
 - Via email to DSC's Local Area Coordinators.

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- Within DSC's LAC newsletters.
- Via EDAC's website.
- During the EDAC *EthnicAbility* community radio program on 6EBAFM.
- To clients of the host agencies and Guest Speakers.
- To subscribers of Carers electronic newsletter.
- On the Department of Communities online courses guide.
- Via the AussieMuslim website (for the Muslim Workshop).
- On OMI's website for Harmony Week (for the South Eastern Perth Workshop).
- In the newsletter for Shelter WA (for the Accommodation Workshop).

[One of the biggest difficulties identified with advertising the Workshops through the disability service providers to their CaLD clients was that they were not required to include an individual's ethnic background when a client registered for services. This made it difficult for the service providers, especially the Local Area Coordinators, to identify which individuals on their databases would fit the CaLD eligibility criteria for the Workshops (see *Recommendation 7.3*)].

Facilitating direct constructive engagement of consumers with their disability service providers as host organisations and as participants. The focus of the Workshops was to get CaLD consumers and carers to begin talking constructively with each other and their service providers to enhance consumer understanding of disability and services in WA, to articulate the cultural aspects of their disability support needs relative to currently critical issues, and to engage them in assisting agencies to develop and provide services in culturally accessible and effective ways – with the expectation that these inclusive working relationships would further develop and continue along these lines.

The Workshop process provided the opportunity for attendees to participate in group work where consumers and service providers both had the opportunity to discuss their experiences and could then work together to address any cultural difficulties. The informal nature of the Workshops allowed and encouraged the discussions to continue through the lunch break as an appropriate opportunity for individuals to network and pursue further meetings with each other and with their service providers.

[In obtaining agencies to host the Workshops at least one month's notice was necessary in order for them to obtain approval from their management committees and to plan for the time within their staff work-load schedules, and in some cases for access to agency venue].

Engaging Guest Speakers to provide up-to-date issues-focussed information. Guest Speakers were organised for a number of the Workshops. The objective here was to provide up-to-date information on disability issues and aspects of disability services to both consumers and their families/carers and their service providers, in a forum where there could then be direct and cooperative discussion on working on those issues together.

[Again at least one month's notice was necessary each time in order for them to obtain approval from their organisation and for the Workshop and its planning to be accommodated in their work schedules].

Facilitating personal outcomes. It was planned that participants at each Workshop would be given the opportunity to bring out their concerns, how they would like to see the issue improve, and together find ways that each might be addressed. This included who they could subsequently contact further to obtain assistance from to resolve their issues, such as the organisational representatives participating in each Workshop.

Alternatively, for some a referral was suggested to EDAC's individual advocates. While encouraged and supported to contact EDAC themselves, the Project Officer did facilitate referral where it was necessary.

After the implementation of a few Workshops where some participants seemed to be hesitant to obtain advocacy assistance on their own initiative from an EDAC individual advocate with whom they were unfamiliar, one of EDAC's individual advocates was invited to briefly attend the Workshops. This strategy was found to be successful as participants were able to raise their issue of concern and leave the Workshop feeling that it was taken seriously and that someone was following up arrangements that had been put in place to assist them to resolve the matter.

Participant evaluation enabling progressive improvement of the structure and process of the Workshops throughout the series. Participant evaluation of each Workshop enabled ongoing adjustments to be made as necessary. Each Workshop was evaluated utilizing written and verbal feedback. All participants identified the parts of the Workshop they enjoyed most and what needed to be improved. Having both of these options for evaluation enabled feedback to be obtained from all participants, including those who have difficulty with reading/writing English. This information was then evaluated and incorporated each time into the Project Officer's report for the Steering Committee. With explanation and the permission of participants, the Workshop proceedings were audio-taped. This assisted with accurately compiling each Workshop report.

A short standard Evaluation Form was developed for the Workshops (*Appendix A*). The questions were structured to enable participants to provide feedback on the Workshops in a qualitative form to identify what they hoped to achieve from the Workshop, what they had learnt from the Workshop, the quality of the Workshop, what they liked and disliked about the Workshop. The form also allowed individuals to make recommendations regarding how they would like the Workshop to improve. The Workshops provided for individuals to give verbal feedback, especially those who had difficulty with written language skills. [This feedback was conducted in an informal manner during the lunch break].

The feedback from each Workshop was incorporated into the report for the Steering Committee where adjustments were made to the planning, advertising and structure of the remaining Workshops where necessary.

Facilitating consumer engagement in systemic advocacy – in addition to personal individual advocacy participants were also encouraged to look at their issues in a wider perspective in terms of others who they knew who were similarly affected, or people in their situation generally. Both participants and service providers were made aware of the nature of systemic advocacy and the value of their participation. CaLD consumers were encouraged to seek opportunities to represent CaLD and disability issues and contribute to improvements in the sector developing culturally appropriate services. Examples included initiatives that consumer and service provider participants could consider together, such as engaging or developing informed consumer reference groups.

Also, participants were informed that EDAC's systemic advocate, facilitating the Workshops, would take up issues and pursue suggestions they raised that were found to be common among them and illustrated the importance of their inclusion and support in how that would be done. After each of the Workshops EDAC advocated for those desired systemic changes as and where appropriate.

Participant inclusion in creating wider awareness of CaLD /disability issues. The project incorporated planned strategies to enable other CaLD consumers, ethnic communities and service providers the opportunity to also improve their awareness of the issues impacting people from a CaLD background in accessing disability services and how these issues might be resolved through mutual participation together with service providers within a cultural understanding of the Disability Services Standards.

Ethnic community radio and the EDAC internet website:

- ✓ Permission was negotiated from Workshop participants and Guest Speakers to use the Workshop outcomes as material for EDAC's *EthnicAbility* radio program.
- ✓ Also, a number of participants and Guest Speakers were invited and interviewed live on air and others taped for air.

After each Workshop the outcomes were broadcast on EDAC's *EthnicAbility* program on 95.3 6EBA FM on the first Tuesday of each month. These broadcasts enabled other CaLD people with disabilities or their family carers and service providers to learn about how to include an individual's CaLD practices and beliefs appropriately within services and support, as guided by a cultural approach to the Disability Services Standards.

- ✓ At the conclusion of the Workshop series, case studies from across the Workshops were compiled into integrated examples illustrative of addressing CaLD/disability issues within cultural approaches to the Disability Services Standards. This was translated into 10 languages and narration of each was recorded for subsequent broadcast during EDAC's *EthnicAbility* radio program.

- ✓ These examples in the main current ethnic community languages were also posted on the EDAC website for public access and promoted in EDAC's Newsletter and through it's community and professional networks.

The languages translated included: Dinka, Arabic, Italian, French, Swahili, Croatian, Tagalog, Spanish, Bahasa Malaysian, Mandarin, Vietnamese and Turkish.

For the Muslim community it was narrated in Arabic by a religious leader, as this would not only reach people from Arabic speaking countries but a number of ethnic Muslim communities who choose Arabic as their second language, being the original language for their religious texts, the Quran and Hadiths.

[Each translator/narrator signed a copyright agreement to enable EDAC to utilize this material on it's radio program and website].

5 Project implementation

The total of 152 individuals attended the 10 Workshops, representing various cultures and disabilities. The largest cultural participation was from the Vietnamese, African and Muslim communities.

A generic 4 hour Program Outline was created for the Workshops. This was outlined for participants in the Introduction to the Powerpoint presentation for each session (*See Appendix B*).

All Workshops were audio-recorded with the permission of participants and summary outcomes, as below, were provided each time to the Steering Committee and made available to the Coordinator of EDAC's *EthnicAbility* community radio program.

5.1 Individual Workshops and their outcomes

5.1.1 Mirrabooka

The Edmund Rice Centre (ERC) agreed to be the host agency for the first Workshop. Preparatory background consultation by EDAC with ERC identified that the following issues would impact individuals who would access the Workshop from ERC:

- The ERC has only a few CaLD clients with disability and not many seek help through the Centre for a family member with a disability. This is due to several factors including - religious ramification on the parents of having a child with disability; and the Immigration Department's selective approval of those who migrate to Australia screens out people with a disability.
- Some ethnic families hide the family member who has a disability because it reduces the marriage prospects of other members.
- The concept of mental illness does not exist in some ethnic communities. It is not seen as a disability. Mental illness is understood (best explained to) these communities through parts of the body such as head and brain.

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- In some rare cases there are issues where families who have a member with a disability take advantage of the allowances the person is entitled to but neglect the person, and so tend not to come forward.

These points were incorporated into the notes for the Workshop. The facilitators were mindful of the sensitivity of these issues and decided to use examples from personal experience as a strategy to reduce the sensitivity. Standards 2, 3, 6, 8 and 9 were marked as the main points of focus for this Workshop.

Although attended by ERC staff, during advertising and promotions for this Workshop some difficulty was experienced in engaging LAC's and contact persons from other not-for-profit organizations.

Participants raised some important issues from their experiences, which were identified together in terms of the Disability Services Standards, and solutions discussed with reference to the recommendations made by CaLD consumers in developing the *CaLD Perspectives on the Disability Services Standards*:

Standard 2 - Individual Needs:

- Service provider staff across many agencies are experienced by clients as often making assumptions regarding their cultural needs according to their cultural background or appearance – rather than negotiating with and being guided by them as the CaLD persons concerned.
- Extra utility allowance from Centrelink should be provided for households where a family member has a mental illness.
- Incentives need to be provided by Centrelink to encourage individuals with disabilities or mental illness to obtain and retain employment, especially in cases where they have difficulty ensuring a stable income from both Centrelink and the employer, when their illness impacts their ability to maintain employment.

Standard 3 - Decision Making and Choice

CaLD participants expressed concern that service providers often do not include the family in decisions made for the member with a disability. They advised that especially in ethnic families, decisions made for an individual implicate and can have an impact on other household members so the family unit as a whole must be included and taken into account in considerations and decisions. Families also hold complex cultural responsibilities for care that should be respected and constructively supported.

Standard 6 - Valued Status

The experiences of participants suggested to them that the mental health sector needs to be better trained to deal respectfully and in a more informed way with CaLD people with mental conditions and their families/carers and cultural communities. For example, one participant reported that hospital staff treat CaLD patients inappropriately and see that as racist. The client's

veracity has also been doubted at times because of her ethnic appearance. Some of her friends have also shared with her that they have had similar experiences and recommended to her not to go to certain hospitals.

Standard 8 - Service Management

Participants reported the frustrating experience that mental health disability services are both disjointed and duplicated between the mental health and disability sectors and different providers, giving the impression that the government does not seem to view mental illness as being a disability.

No participants had been included in evaluation or development activities of any of the disability services they had utilised. One had to use her own time to inform and educate staff individually on recognising and responding appropriately to the needs of CaLD people, especially those with mental health conditions.

Standard 9 – Protection of Human Rights and Freedom from Abuse and Neglect

From the example raised by the host agency from preparations for the Workshop, further types of issues were raised by participants of instances where providing protection and raising of awareness and expectations under this new Standard 9 was seen as a significant improvement. Cultural competency is essential by providers and advocates to ensure that pre-existing 'cultural practice' does not entail 'sharing' essential disability support resources for the use of others; withholding those resources because of cultural devaluation of the person with a disability; or neglecting to access resources available on their behalf.

Feedback regarding the effectiveness of the Workshop identified that the use of an interpreter in the Workshop meant that there was much more limited time to effectively discuss a range of issues and relate them to the Standards. It was apparent that where this is the case the educational component the Workshop needed to be abbreviated and the consultation and discussion component closely targeted to/driven from the key issues of the participants, rather than attempting to achieve full coverage of the Standards exemplified through discussing a diversity of participant examples.

Feedback also indicated that future Workshop flyers needed to incorporate information that a transportation subsidy would be available for potential participants attending the Workshop. This would increase access and participation in the Workshops and remove this as a possible barrier as participants would be aware at the outset that the subsidy was available, not just when they rang to register for the Workshop.

5.1.2 CaLD women with disabilities

Women with Disability WA (WDDWA) agreed to host the second Workshop and invite its membership. In pre-Workshop consultation it was identified that, in

particular, a number of women with disabilities from CaLD backgrounds have difficulties with identifying their abilities and opportunities in both business and community participation. From this, together it was decided appropriate to bring in a motivational speaker/facilitator. From EDAC's prior experience, the one chosen was Annimac Consultants

A second pre-Workshop meeting was then accordingly conducted with the Project Officer, WWDWA and Annimac Consultants, where the key issues were identified:

- Isolation and loneliness of women with disabilities, generally, but also particularly in some ethnic communities where they can tend to be hidden away.
- Lack of support for males who care for their wives or mothers or other females with disabilities, including difficulties of this nature within some cultural settings.
- The individual needs of women with disabilities are not always met, generally, but particularly so for CaLD women with disabilities.
- Women with a disability sometimes are not given the opportunity to choose regarding important life matters - for example, some are sterilised without their consent - and cultural values and roles are frequently not adequately considered and taken into account.

It was determined that the workshop should provide particular focus on Standards 2, 3, 5, 6, 8 and 9 by assisting individuals with discussions regarding these issues.

To assist individuals with transport for this particular Workshop the Multicultural Services Centre assisted by providing one of their buses to pick up and return participants.

Those present were open and engaged at quite a personal level in discussions, indicating that they were glad to be part of this Workshop as a small and intimate group, as they would not have been as open if more women or others had attended.

The issues raised by participants centred around the lack of services to fulfil their social needs. Below is a summary of the issues that were raised and how they were related to the Disability Services Standards.

Standard 2 - Individual Needs

- The greatest need identified by participants was the isolation, loneliness and lack of confidence they felt when -
 - they were not able to obtain assistance with social support outside the usual office hours;
 - the minimal support they could access to network and practice their social skills; and
 - lack of support with transport.

This had progressed to result in depression for some participants.

Of core concern for CaLD women with disabilities was also the isolation from family members from their home country to support them.

- Some service providers assume that all disability can be discernable by a person's behaviour and/or physical appearance. This was compounded by either ignoring culture or making cultural assumptions. These experiences have deterred participants from using certain services as they have felt prejudged, misjudged and less credible as their own experiences and opinions and understanding of this within their cultural values and gender practices was not sought or respected.

Standard 3 - Decision Making and Choice

Participants felt as women they were not accorded full individual rights in decisions made about their lives, and particularly, as CaLD women, this was often even worse.

- Two of the participants reported that service providers didn't always give them all the relevant information they needed to themselves be able to make an informed decision.
- They also reported how their families were more engaged in the decision making process than they were, which limited their ability to have control of their own lives.

There seemed to be a significant need here for awareness of gender and disability issues to be negotiated as appropriate to achieving individual rights within the Australian context, cognisant of cultural gender and disability practices.

Standard 5 - Participation and Integration

- The participants reported that as CaLD women with disabilities they haven't had the confidence to make friends and socialise in community settings due to limited services to assist women with disabilities to learn social skills and obtain social support. On the occasions when they have obtained enough confidence to try to socialize within the general Australian and their ethnic communities they have felt as if they were not accepted and were subjected to negative attitudes and lack of understanding of their disabilities, which caused them to become further isolated.
- None of the CaLD women at the Workshop were employed, and only two said they were looking for work. They did not have much in the way of expectations, due to both their limited self-confidence of their abilities and their fear of being subjected to negative attitudes because of their disability, and not understanding where they could obtain appropriate disability support to assist them with preparing, gaining and retaining employment.

Standard 6 - Valued Status

The participants identified that due to them feeling that Standards 2, 3 and 5 were not being adequately met when trying to obtain disability services support, this has caused them to feel that society, and even their own families and ethnic communities to some extent have given a low value to them as women with disability and especially as CaLD women with a disability.

Standard 8 - Service Management

Participants observed that women with disabilities, particularly CaLD women, are poorly represented on staff in disability service organisations and also the low levels of consultation and inclusion in service development and delivery are seen as significant aspects of poor understanding and neglect of their issues.

Standard 9 – Protection of Human Rights and Freedom from Abuse and Neglect

Women with disabilities, particularly CaLD women, saw that their difficulties in participating in society and the workforce, especially with any sense of equality and being valued, amounted to a deficiency in respect for their basic human rights as people. They also felt that it was an issue of neglect.

Overall in this Workshop, participants identified difficulties with attaining the self-confidence to be their own self-advocates, especially when initiating social interactions and in gaining employment. They identified that they felt valued in participating in a Workshop such as this, and would appreciate others which could teach them how to develop confidence and skills and to do so appropriate to their particular cultures.

Participants provided feedback on how they enjoyed the Workshop and, like the previous group, how they enjoyed having a small intimate group to enable interaction. They commented that they would have been less confident to interact openly in a larger group.

Also identified by the participants was that many CaLD women who were informed of the Workshops could have been reluctant to register and attend because of lack of confidence and feeling they had low value. It was also noted that no family or community members attended the Workshop, thus further demonstrating the social isolation and lack of social support of these women.

5.1.3 Cerebral palsy

The Centre for Cerebral Palsy (TCCP), formerly the Cerebral Palsy Association, agreed to be host for the EDAC Workshop. The Centre reported they had a significant number of CaLD clients, both children and adults, and were keen to hear from them about the services they receive and how that related to the Disability Services Standards and the cultural guidelines in particular (*CaLD Perspectives*) as TCCP had produced its own recent manual on culturally

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responsive services. This was taken into account in the preparations and discussions for the Workshop, supporting the TCCP initiative and integrating it into the Workshop.

The preparatory consultation with TCCP's Speech Pathologist and Social Worker identified the following issues which would be most likely to be related by the participants during the Workshop in relation to exploring their experiences within the Disability Services Standards:

- Isolation of CaLD PWD's;
- Their lack of participation in social events; and
- CaLD PWD's and their families not being sure of services available to them.

Hence it was agreed that the Workshop focus on Standards 1, 2, 3, 5 and 8.

Also, the Workshop was opened to all people with cerebral palsy, not just the clients of TCCP.

The session was very well attended, where participants were quite interested to learn about their rights in accordance to the Disability Services Standards and had a number of comments in regards to the Standards about particular issues that impacted their lives and their ability to obtain appropriate services - such as:

Standard 1 - Access to services

- Participants commented that although there are many venues that offer a variety of cultural activities and services, many are inaccessible to people with Cerebral Palsy, particularly wheelchair users. As a result, many people with Cerebral Palsy (CP) cannot participate in quite a lot of social activities.
- Also they were aware of many cultural activities and services but those who cannot speak English well found that they could not access them to gain a good understanding of what they do.

Standard 2 - Individual Needs

- Participants raised concerns that playgroups often don't have toys and activities that are appropriate for the needs of a child with CP and rarely any appropriate multicultural activities. Frequently children with CP, CaLD children in particular, can be found alone just playing by themselves, and unhappy about and resistant to going to playgroup for that reason.
- The adult participants with CP commented that although there are a number of services for children with CP there are few services for adults with CP and even less in their local ethnic communities. They expressed their concern that this lack of services was causing them to become isolated and lose their social skills.

Standard 3 - Decision Making and Choice

- Concern was expressed by parents regarding the future of their children with CP when they were no longer around to care for them. In some cases this is because the child/adult with CP cannot communicate verbally and the parent has little or no social support outside her family.

In discussion, the other carer participants agreed that this issue is common amongst all carers, especially when the traditional option of support from their extended families was unavailable to them as it would have been in their country of origin, but they were now isolated from negotiating that normal option of transitional care now that they were here, and they were concerned to continue to provide culture-based care rather than have their child/adult removed to a mainstream care facility.

- Participants also commented that due to waiting lists for medical treatments at public hospitals they were too fearful of trying to access respite or vacations in case the child's name was withdrawn from the waiting list.
- They also commented that their care choices and decisions were often limited by concern about the costs of services – such as daily massage/therapy for a child being hard to afford at times.
- Most participants reported they have accessed services that had not used an interpreter, especially when the service was a small agency or private company and were not aware of the Telephone Interpreter Service.

They also reported that some agencies, although aware of the service were reluctant to use it, even though this would assist with the way the agency would be able to deliver their service to them as CaLD clients.

Standard 5 – Participation and Integration

- Integration of children with CP into school activities continues to be an issue, especially also for those who are from CaLD backgrounds. For example, one of the participants has a daughter who is currently going to a mainstream primary school. The teachers have been briefed about her disability but the information has evidently not been imparted to the other children. The children do not play with her much.

She also does not get invitations to visit the homes of other children. She has only once been invited to a birthday party, and the mother feels this may be due to the other children's parents also not being made aware of the actual nature of her daughter's condition.

- Participants wanted more programs to integrate people with cerebral palsy into their local community. Another participant, for example, stated that he had been invited to a community function and was embarrassed when he got

there with his carer to find that all the other attendees were children with their parents. He said "There must be many adults with CP who have this problem." (This issue also comes under Standard 6 - people with disabilities and their families not being recognised as valuable community members).

- The 'Streets Alive Program' that some local Councils have now adopted was raised as an example of a successful initiative, where street parties are organised and open to everyone in the neighbourhood. These cater for people with disabilities and residents who are from different cultural backgrounds. They provide a positive and friendly atmosphere for them to socialise with able-bodied members of their local neighbourhood community. Some people with CP reported now being visited by and visiting neighbours, and feeling more included in their community.

Standard 8 - Service Management

- Discussion included issues of recognition of the capabilities of people with Cerebral Palsy, particularly those from CaLD backgrounds, and their capacity for employment to contribute to disability services at all levels. Workplace and language support, with writing in particular, should enable enhanced levels of participation and leadership at management, policy and service development levels, and enable agencies to better meet equal opportunity requirements.
- From the playgroup examples given above there was concern expressed that there seems to be a lack of staff trained to manage children with disabilities, those with CP, and CaLD children in particular.

The feedback from the Workshop was very positive, a majority felt that this had shown them that they had rights just like everyone else and felt empowered by this knowledge. They also said that they had benefitted from hearing of other people's concerns and suggestions, which had enabled some of the carers to leave the Workshop feeling they were better able to obtain support within their caring role.

The staff of TCCP also provided feedback on the Workshop, commenting that it had raised their awareness about locating resources and helped them discover ways to ask for more support and resources. TCCP staff suggested simplifications to the Powerpoint presentation for participants and more detail beforehand for the staff regarding what would be discussed at the Workshop to assist them with leading discussion and drawing out issues, - although consumers reported being informed and empowered by the consumer-directed nature of how discussion was facilitated.

5.1.4 Intellectual and developmental disabilities

The Disability Services Commission office on Hillview Tce, East Victoria Park agreed to host this Workshop as during the background preparation consultations

it was determined that the most suitable participants for the workshop would be carers and appropriate DSC-funded disability service providers.

The Guest Speaker engaged for this Workshop to present and co-facilitate discussion was Dolly Bhargava, Disability Specialist Speech Pathologist, as she has extensive experience working with people with complex communication needs. Her expertise has also been utilized in writing with EDAC the Easy English and pictorial Consumer Version of the *CaLD Perspectives on the Disability Services Standards*. This new Consumer Version for CaLD people with disabilities was incorporated into her presentation at the Workshop and subsequent discussion.

Accordingly the Workshop process focussed on caring roles. The concerns identified as those most likely to be raised included:

- Lack of involvement of family carers in disability support decision making processes for individuals.
- Lack of inclusion of people with intellectual and/or developmental disabilities in the community - and related to this the communities limited ability to deal with challenging behaviour.
- Lack of awareness of disability rights, by all concerned.
- Difficulty for individuals with intellectual or developmental disabilities to adapt to changes in situations.

Accordingly, it was determined that the Workshop encourage discussion particularly on Standards 1, 2, 3, 5, 6, 8 and 9 to assist participants to bring out their main issues of concern. A presentation would also be provided by Dolly on alternative ways to assist people with complex communication needs to cope with changes in various situations.

The session was well attended with all having adequate English skills, this led to many in-depth discussions. Although participants were informed that all information brought up at the Workshop would be kept in confidence where individuals wouldn't be identified, some did express that they were not comfortable with the facilitator using a tape recorder during the Workshop so this session was not audio-recorded.

In lieu of this, a few participants who were OK with recording were later approached and agreed to participate in an interview for the EDAC *EthnicAbility* community radio program to discuss the issues and outcomes from the Workshop.

The issues raised at the Workshop included:

Standard 1 - Access to services

- Some CaLD parents/carers found that their own lack of English skills and cultural restrictions prevented them from asking for help from outside resources. This was especially so for women and caused them to have

limited knowledge on the types and availability of services to support the family member they are caring for.

Standard 2 - Individual Needs

- Challenging behaviours. Some CaLD parents caring for their children reported that they experienced being excluded from services because of their child's challenging behaviour. Explanations given related to service provider's occupational health and safety regulations. Parents felt that service providers should instead be required, encouraged and trained to look further at the specific needs of the child to enable strategies to be put in place to address the perceived risk.
- Respite. There was a general perception amongst the participants that service providers are not adequately acknowledging the need for CaLD parents/carers to obtain more respite support. Parents end up feeling guilty for mentioning to service providers that they need such support, and particularly that the arrangements also need to be culturally appropriate.

For example, one parent with six children was invited to take respite from her caring role, the problem she found in being able to do so was that the service provider wasn't able to also help her with finding someone to care for the other children.

Many of the carers agreed that they are unable, for his reason, to avail themselves of respite. For CaLD carers availability of culturally supportive care for the other children they also care for at the same time in the family can also be an issue.

- Transition support. All parents felt that there is very little help available to people with profound disabilities during times of transition, such as transition from school to employment, from employment to retirement or from a parent's home to other accommodation. These times can be difficult for anyone, parent or child, but are particularly traumatic for a person with a severe disability and their family carers, and especially where continuation of cultural support is not maintained or also is changed.

Standard 3 - Decision Making and Choice

- Service providers not providing adequate information for service users to enable them to make informed decisions they tend to be those agencies who are short staffed or have a high staff turnover and the staff themselves not having the necessary information or time available to work effectively with CaLD people.
- The participants also identified that services need to take a "holistic approach" when decisions are to be made. In particular with CaLD families, family dynamics and shared responsibilities for care need to be recognised, respected and taken into account and the family supported to be involved in a negotiated decision making process.

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- This was experienced as applying at times even to the mother as the primary carer. For example, one mother expressed her distress at having decisions made for her child by service providers where she wasn't involved in the decision making process. For CaLD families, in particular, this is profound disrespect of her responsibilities and cultural care role.

Standard 5 – Participation and Integration

- Employment. During the Workshop participants commented how individuals with disability, especially intellectual and developmental, were not obtaining appropriate skills to assist them with obtaining employment, maintaining employment and avoiding being chronically under-employed. Employers and agencies have reported that jobs are available for people with disabilities, particularly in the current climate of manpower shortage, but training programs are not creating the necessary skill levels. [Participants in other Workshops, even those without intellectual and developmental disability, are still reporting discrimination from consideration for employment when any disability is made known, but most are reluctant to pursue the matter formally].
- Social isolation was an issue also raised at this Workshop. Parents were concerned that their child has little, if any, social skills due to isolation from their able peers. For example, one mother added that the social isolation also means that her daughter has not had the social environment to help her to develop control of her emotions.

Standard 6 - Valued Status

- Devaluation through chronic under-employment. For example, one mother said her son is not being recognised as a valued member of the workforce. He is not being taught the skills to make him eligible for advancement or even an expansion of his role.
- Parents reported their concern regarding the social exclusion of people with disability, which they see and feel on a day-to-day basis as demonstrating society's negative attitude towards people with disability. The negativity keeps people with disabilities imprisoned in a frustrating and debilitating low valued status.

Standard 8 - Service Management

- Individual people with intellectual and developmental disabilities may have capabilities and potentials that enable them to perform valuable organisational duties at all levels, and they expect their service organisations to seek to engage them accordingly and also to supportively promote their capabilities to participate in other organisations.
- CaLD people with disabilities generally, and those with intellectual and developmental disabilities especially, say that they need support to be invited

to participate in and effectively contribute to organisations in their own ethnic communities.

Standard 9 - Protection of Human Rights and Freedom from Abuse and Neglect

- Participants felt that each of the above issues amounts to an abrogation of the natural human rights of people with disabilities to participate in society in all ways to the full extent of their capabilities, and, to be specially supported to be able to do so. Their feelings expressed were that this continues to be not only neglect but also abuse because the exclusion is still consciously perpetrated in all areas of the life of people with disabilities. Inadequate provision for consideration of support of cultural identity and belonging for CaLD people with disabilities simply adds to this picture, whereas, like improvements in the other issues of concern, it has the potential to significantly improve their situation toward enjoying a quality of life to which they have equal right.

The feedback obtained during the workshop was extremely positive. The participants reported that they valued the opportunity to discuss their concerns and what they experienced when accessing services. They said they benefitted from the presentation on teaching people with complex communication needs ways to adapt to different situations. The techniques covered in the presentation were actually utilised during the group activities/consultation and were seen as useful in attracting and retaining participants' attention even though they were the carers themselves. They requested an opportunity to participate in a more in-depth workshop on developing those skills themselves.

5.1.5 Muslims with disabilities

With the objective of linking with local ethnic communities it was decided that this Workshop should be developed for one of the new and emerging cultural communities in WA, the Muslim community. It is a religious grouping that comprises many ethnic communities. A number of these are recent refugees and migrants from countries - like Somalia, Afghanistan, Iraq, Sudan and Burma.

The Muslim Women's Support Centre (MWSC) agreed to be the host organisation for the Workshop, appropriately as being one of the main Muslim organisations in WA that support Muslim women and their families. Pre-Workshop consultation with MWSC identified some of the issues facing Muslims with disability, particularly Muslim women with a disability and also Muslim women who are carers of one of their family (or Muslim community) with a disability. The issues identified as those which would be most likely to be raised by participants and need to be given consideration in the Workshop included:

- The concern that their cultural/religious practices may not be respected or upheld when accessing services.
- Muslims feeling that their needs would not be valued due to the negative stereotyping of Muslims within the media and government.

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- Difficulty with for Muslims with disabilities to be valued and included within the Muslim community itself.
- The issue of disability is rarely discussed in the Muslim community. When it is discussed people tend to talk about it with just sympathy and the need for charity.
- Family members who have a person with a disability tend to keep the issue to themselves. It has been reported how some family members are ashamed of having a person with a disability and are also fearful that it will diminish the prospects (such as marriage) of other siblings.
- The notions of disability in the Muslim community are as diverse as the ethnic groups involved. Some Muslim cultures had difficulty in particular in identifying with the concept of intellectual or mental disabilities.

These issues were taken into account with the preparation of the Workshop, where it was determined that Standards 1, 2, 3, 5, 8 and 9 should be focused on. As the issue of double discrimination, because of cultural/religious beliefs and disability, was expected as the biggest concern for the participants, it was decided that the participants would benefit from having a Guest Speaker from the Equal Opportunity Commission to talk about their cultural/religious rights in legislation and as incorporated in the national policy *Multicultural Australia: United in Diversity* and also in this State under the *WA Multicultural Charter*.

Due to the difficulty for Muslims to openly discuss disability issues this Workshop was designed to be conducted in a friendly and informal manner. It was decided that a BBQ would attract more attendees and encourage better participation. It was also decided that advertising should utilise the local Muslim community resources as well as the general advertising also used for the Project. Accordingly, appropriately culturally designed flyers were sent to local Muslim businesses, distributed within the Muslim schools and sent to Muslim newsletter/papers, as well as spreading information about the Workshop through informal networks personally - such as at family functions and small community events and by volunteers and staff of MWSC.

Attendance was smaller than previous workshops, attributed to disability being a relatively new concept for the community to recognise and address. The number of people who did attend was still adequate enough to enable small groups to be formed for group discussions regarding prevailing issues and for these to be addressed with regard to the cultural guidelines for the Disability Services Standards and information on available services provided.

Two personalized interviews were conducted after the Workshop due to participants wanting to attend and contribute their issues and concerns but having difficulties because of illness. One interview was conducted over the phone, while the other was face-to-face.

The relaxed environment of the workshop was found to be quite successful and a number of in-depth conversations were continued past the Workshop scheduled

time. Some issues brought out from the Workshop and personal interviews, relative to the Standards, included:

Standard 1 – Access to Services

- Participants mentioned concern about the limited information and support provided for a person with a disability accessing post-school options such as further education or employment. Most didn't understand the options available within DSC funded employment assistance. There was a reluctance to seek help, for fear the person with a disability would be tricked into entering a sheltered workshop.
- It was mentioned also, for example, by one participant with a disability that they didn't know what services would be available assist them to obtain a driving license.

Standard 2 – Individual Needs

- Some of the participants voiced their concern about their inability to obtain effective transportation assistance. A particular example was where a service provider made last minute changes to their transport arrangements and didn't assist the person to access other transportation arrangements, and also didn't inform the carer that they themselves were expected to re-arrange transport assistance for the family member.
- Transport services tend to prefer taking a number of patients at a time, which becomes a problem when a patient may have uncontrollable offensive reactions to these always different and changing arrangements. This can create stress for the person with a disability, who feels that their condition is not understood and their needs respected and who they are as a person is devalued.
- Although participants appreciated the assistance of interpreters in times of need, the carers feel that when both themselves as the carer and the interpreter are present the interpreter should enable the carer to take the leading role in the meeting and enable the carer to obtain assistance from the interpreter when required. Otherwise the carer feels their role of caring is devalued. The training of interpreters to relate only and directly to the client and the service provider, and exclude all others, is seen as culturally inappropriate, disrespectful and offensive.
- The issue of carer migration was also raised at the Workshop. For example, one participant was in a predicament experienced also by many others. She hasn't been able to find a carer that can cater for her cultural/religious needs in Australia, and has applied for a family member to migrate as a carer, but that family member has been denied access into Australia. This had caused the participant to feel even more isolated, depressed and lonely with no-one culturally appropriate available to assist her in her caring role.

Many migrants and refugees have to come here with no extended family and also not always is there a cultural community here, or that it is supportive especially concerning care for a person with a disability.

- Concern was raised regarding government service providers, other than disability services, who are not appropriately recognizing the needs for people with disabilities. One example given was that the Department of Housing and Works hasn't recognized the need for the family member with a disability to have equipment installed, like air-conditioners, to reduce the instances/severity of a person's medical condition.
- Male Muslim carers report feeling isolated in their caring role. It was identified by one that he felt isolated due to the inability to speak to other male Muslim carers about the difficulties and issues relating to caring for his family member with a disability. He felt this support could improve his ability to make more effective, informed and confident care decisions.

Standard 3 – Decision Making and Choice

- Concern was raised by CaLD participants about decisions being made for the family member with a disability without consulting them as their family carer. This can create a situation that is difficult for the client, carer and family. It can cause distress to the person with a disability in terms of responsibility relative to their capacity to self-manage. Also sometimes it can make them feel that they should not be a burden on the carer. They can show anxiety and insecurity at the cultural disrespect this demonstrates, in which they are then implicated, for the carer and family's care roles.
- Although protection and promotion of the rights of the individual is always paramount, in some cases individual decision making and choice is too rigidly imposed without negotiation with the client as to who he/she might like involved in the process, and with the family. Services excluding all others on principle even despite the client's wishes, are felt not to be according appropriate consideration and respect to family cultural care roles and responsibilities that are primary for the client and that they live with.
- Both persons with a disability and carers state that they prefer a situation where time and opportunities are made available to allow them to consult with one another and the family, and on the basis of being mutually fully informed, before any decisions are made. Although this extends time taken in providing client services, it tends to produce sustainable and effective outcomes and client satisfaction.

Standard 5 – Participation and Integration

- A number of participants mentioned the lack of culture-specific disability support services to uphold / support their Islamic belief system and also the problems in getting their cultural values and practices understood, valued and taken into account in services generally.

- The group of mainly women Muslim carers cited the isolation in their role of not having people they can socialize with and obtain support from who share the same values as themselves. They mentioned how they felt that in other groups they felt that their religious values seemed to always be in question and that they frequently needed to explain their actions and beliefs.
- On the other hand, some of the participants also commented on the limited ability for Muslim people with a disability to be involved within the Muslim community, causing them to feel socially excluded and that the Muslim community has little need or value for them as people with disability. Overall, together with their problems with inclusion in the general community, this felt like a double exclusion.

Standard 8 - Service Management

- The host organisation - which had been developed in response to the general and cultural issues requiring extra need for mutual support among Muslim women as carers for family members with a disability - recognised and discussed the value to them of their recent incorporation, collaboration with associate organisations and ethnic community stakeholders, and current development of articulated organisational policies and practices.
- Participants expressed the need for ongoing cultural awareness among service providers about the different Muslim communities and their disability practices, and conversely the need for service providers to make their services known and accessible to culturally supported by those communities.

Standard 9 - Protection of Human Rights and Freedom from Abuse and Neglect

- Participants felt that the current political climate was sensitive and difficult for Muslim people such that they had to work harder to gain their rights to social and community inclusion. While there was trust and respect at a personal level there seemed to be some reticence and withholding of engagement at service levels. This currently adds to the problems of CaLD people with disabilities and their family carers in terms of being able to fully access their natural human rights to all aspects of citizenship and services to which they like everyone else are entitled.
- On the one hand Muslim carers and people with disabilities need culture-specific inclusion and support, and, on the other, also need to be able to fully participate in the wider multicultural community and within that have access to culturally respectful and appropriate services.

Due to the informal nature of the Workshop it was decided that it would be more appropriate to obtain verbal feedback from the participants. This was quite positive, with them finding the workshop informative and they were also appreciative of having the opportunity to openly discuss their concerns, particularly the cultural aspects. On reflection on the Workshop, more people

from the Muslim community may have attended if the venue had been arranged in a place that Muslims would normally frequent. This will be a strategy to pursue for future workshops with the Muslim community.

5.1.6 South Eastern Perth

An email was sent to all Local Area Coordinators (LAC) within the overall Perth Metropolitan area informing them of this Project and inviting them to provide feedback on what they identified as areas of concern for people with disabilities who were from Culturally and Linguistically Diverse (CaLD) backgrounds. The South – Eastern district provided the most responses and interest in learning about how to improve the opportunities for CaLD people with a disability and their carers.

A meeting was then organized with the LACs and District Managers within this area to talk about the option of running a Workshop in their area. This meeting identified that there could be significant value in addressing a range of issues, which included:

- CaLD communities not creating opportunities for people with disabilities and their carers within their community to participate in their own ethnic community activities.
- The difficulty LACs find in trying to effectively disseminate information within ethnic communities about options available for persons with disabilities.
- LACs having difficulty not being able to identify from their records which consumers are from a CaLD background due to the DSC statistics not providing the option for ethnic details to be included on their database.

Regarding the latter, EDAC's systemic advocacy has made recommendations to DSC in its previous *Supporting CaLD Carers Report* (2003) and to the Minister for Disability more recently in the *Sector Health Check* (2006) regarding the issue of developing adequate ethnic details for required inclusion on the databases of DSC funded services to enable more effective DSC reporting on services to CaLD people in line with ABS population statistics.

In terms of organising the Workshop, Gosnells Community Legal Centre (GCLC) was suggested by the LACs as being the best organisation for EDAC to approach to be host organisation for the regional Workshop due to their proven commitment of supporting people from an ethnic background during previous projects. GCLC accepted and during the pre-Workshop planning meeting from their experience they helped identify that CaLD/disability participants from this area would probably find Standards 1, 2, 3, 6, 8 and 9 of the biggest concern. With these Standards in mind several Guest Speakers were obtained this time to address these concerns. They included Communicare, Sussex St. Community Legal Centre and the DSC District Manager in Gosnells.

The structure of the Workshop was more formal but relaxed enough to enable participants to feel comfortable in discussing their experiences. They benefitted

greatly from participating in the group work where they had opportunity to explore their perceptions of disability rights with service providers. They provided encouraging suggestions on how to see the full rights of a person with a disability extend past just basic human needs.

One participant provided quite positive feedback regarding the services they have received on behalf of two of their grandchildren and commented that the grandchildren have been “well cared for” by the services. However, two CaLD participants didn’t wish to talk about their issues at the workshop, leaving early as they felt their issue was too confidential to talk about at the Workshop. This was respected and EDAC’s individual advocate contacted them after the Workshop to assist them with the problem with which they were concerned.

The disability issues of current concern that the CaLD participants raised at the Workshop were:

Standard 1 - Access to Services

- Residence status. One participant, for example, was a mother of CaLD background in Australia on a Student Visa. She has a 6 year old daughter who was diagnosed with an intellectual disability. Her daughter has been denied access to disability services due to her residence status. The daughter has also been denied entrance to the school system as they need provision of a Teachers Aide for the daughter, which the mother cannot afford to pay. Without the opportunity to provide early intervention and access to education for her daughter she is concerned about the future prospects of her later in life.
- Delay in access to disability services. Another mother of CaLD background, for example, has a 5-year-old boy who has been having difficulty obtaining disability service support. He has now been waiting for 7 months to be accepted by DSC and obtain other services, where he’s been on a number of waiting lists. She commented that no one had provided her with an interpreter to explain the waiting list process or assist with understanding the requirements.
- Age of access. As an example of this issue, another mother of two sons, adult twins both diagnosed with Autism, mentioned how DSC has refused one of her sons to be registered with them because he was diagnosed at a later age, even though that son went to a special school for his disability. This was largely because the mother who is of CaLD background had not realized the degree of disability of that son because her other son presented more serious attributes of Autism than he did and so required her more immediate attention and priority and she had spent most of her time trying to get support for the more seriously affected son. The other son that has been refused DSC registration is unable to read or write.

Standard 2 – Individual Needs

Restrictive service area boundaries. One person with a disability giving an example of this as an issue of concern, commented about her local agency that is providing her with a Support Worker. The restrictions on the agency prevent the Support Worker from attending appointments outside the local area. She finds the process unnecessarily rigid and restrictive and has difficulty getting another Support Worker just so she can attend appointments outside her area, particularly one who is appreciative of her cultural needs.

Standard 3 - Decision Making and Choice

Devaluing and inappropriate interference with client decisions. For example, a CaLD participant with a disability mentioned her concern about the agency where her Carer is employed. The Manager there has a habit of overriding her own independent decisions with other service providers. For example, the Manager contacted an agency with whom she had arranged to provide extra security for her home and told them that “he knows her better than anyone else” and “she doesn’t need it”, preventing them as external service providers from taking action on her behalf as she had herself requested.

Standard 6 - Valued Status

Derogatory behaviour instead of support. One of the CaLD parents/carers gave an example of her distress on how her son had been treated at an employment agency. He was devalued and subjected to derogatory statements about his inability to read or write. They placed a paper in front of him and asked him to find a job and laughed at his inability to read the paper, making the statement “If we give you a shovel would you shovel shit for us”, while laughing. This comment affected the man so much that he threatened suicide if he was forced to go there again.

Standard 8 - Service Management

- There was general concern about the level of professionalism experienced also in relation to cultural respect, and expectations that there should be explicit standards of behaviour of staff trained in dealing with clients with disabilities and especially those clients from CaLD backgrounds.
- There seemed to be a need for disability services staff and organisations to develop more effective liaison and working relations with ethnic communities. Improved understanding could generate more cultural respect in service provision.

Standard 9 - Protection of Human Rights and Freedom from Abuse and Neglect

All of the other Standards explored in the Workshop inevitably led to the overall concern, as in the other Workshops and addressing all of the other Standards, that the basic human rights of CaLD people with disabilities are in many ways being addressed far less than adequately and equitably. Each of the issues raised was felt to be at base an abrogation of the rights to

recognition of full personhood, to all aspects of citizenship and to valued social inclusion and participation.

As feedback, participants commented that the biggest thing they enjoyed and had learnt during the workshop was where to get support for people with disabilities, especially that which was CaLD-friendly, within the various organisations that were represented by the Guest Speakers. Some people also commented about their enjoyment of the Workshop having an inspirational video of someone with a disability being a valued community participant. Others commented on the relaxed and friendly environment the Workshop provided that encouraged positive exchange.

5.1.7 Independent schools

Public school systems are provided with various government programs and support mechanisms to assist students, parents and teachers meet the needs of a student with disabilities. These opportunities have been found to not be as readily available to students in independent/private schools. Some of these schools felt they haven't been as well included and represented regarding information and resourcing support for issues of students with a disability.

The Ethnic Disability Advocacy Centre (EDAC) was contacted, for example, by the Principal of the Primary School of the Australian Islamic College (Kewdale) because of their concern about students with a disability. On this basis they agreed to host the EDAC project to conduct an informal disability issues Workshop within the school.

In pre-Workshop consultation, background information was obtained of some of the issues impacting Islamic students and their parents in obtaining support for a child with a disability. It was mentioned that they were not aware that the Disability Services Commission existed and the types of services that were available for a person with a disability - other than Teacher's Aides and Psychologists (from Therapy Focus).

The majority of children attending the Australian Islamic College (AIC) have a CaLD background. A number of new migrants and refugees are from areas such as Iraq, Afghanistan, Somalia and Malaysia.

With the Principal, some barriers were identified that were faced by parents and teachers when trying to obtain appropriate services and support for Islamic children with disabilities within the school. These difficulties included:

- Religious and cultural perception of disabilities. This especially concerned recognition of the more "hidden" disabilities such as those that are intellectual or psychological.
- Limited resources, such as psychological testing, available at the school for parents to obtain a preliminary diagnosis. Parents tend to see the school as their primary resource to identify learning difficulties. The school has not the capability and also has limited knowledge of other outside resources to support parents in obtaining the diagnostic support that they seek.

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- Concern that their child will be segregated from the Islamic community and family members if they obtain a diagnosis, and their child taken out of the culture-based school to a “special” mainstream school.
- Limited knowledge by the school staff of available disability services support for the families, such as Local Area Coordinators.
- Parents having a large number of children, limiting their ability to divide their time and resources to prioritise the extra needs of their child with a disability.
- Parents having a perception that a child labelled as having a disability will have reduced prospects within both the Australian and their own cultural/religious society.
- The Principal also mentioned they have had to refuse enrolment of a number of students with a disability due to the limited State funding available to independent schools to provide Teacher Aides and support resources for students with a disability. This caused the financial burden to be carried, if possible, by parents, most of whom suffered from limited financial resources.
- It was also reported to the Principal by parents that excluding their child with a disability was creating great stress on each family as it was taking away their choice of ensuring their child with a disability was able to obtain the same religious (and general) education as their siblings and other community members and that it further excluded their child from the ability to feel like included members of their cultural/religious communities.

The Principal agreed during the initial meeting that it would be viable for both the parents of a disabled (or suspected disabled) child and the teachers to learn about disability services through an “informal” EDAC Workshop. This would assist the school to link with disability services agencies and enable the families and children with a disability to know about their rights and obtain better support. It was decided that the “informal” workshop would be best delivered in two stages:

- The first, with the Primary School staff of all 3 campuses. Here they would learn about the basic services available for a person with a disability, including EDAC’s advocacy service and learn about the need to uphold the Disability Services Standards such as Standard 5 (Participation and Integration) and Standard 6 (Valued Status) and their cultural aspects.
- Then, holding an “informal” Workshop during the Kewdale Campus parent/teacher meetings (on April 10, 2008), where parents could drop in while meeting their child’s teacher. They could meet the Project facilitator, an EDAC individual advocate and another Muslim with a disability to learn about the Disability Services Standards and discuss potential improvements to services in upholding those Standards and their cultural aspects.

The advertising of this Workshop required the use of resources within the school and promotion was in two stages.

- Firstly, during a staff meeting the teachers were advised of the Workshop and were encouraged to engage relevant CaLD parents to talk about their concerns regarding of their child, and those of their child themselves; and

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- Secondly, letters were sent to relevant parents about the parent/teacher meeting, informing and reminding parents of children with disabilities about the informal EDAC Workshop.

Approximately 50 staff members attended the pre-Workshop meeting - Primary School staff, Principals of all 3 campuses, the Director, and religious leaders (Imams). During the meeting the staff didn't make any comments or raise any questions, which may have been due to the pre-identified cultural/religious barriers in understanding and discussing disability issues within the Muslim community.

After the presentation it was mentioned that this was the first time that the issue of disability had been raised in a formal staff meeting. Many of the staff were not used to talking about disability issues so openly. Usually discussions about a child with a disability occurs between the Principal, teacher and parent. The Kewdale Primary Principal mentioned that she was happy to have this discussion as it was the beginning of a process that may enable a better understanding and recognition of disability issues within the school. This suggested that Standard 8 (Service Management) could also be a useful focus for the Workshop.

It was also reported by the Principal for all 3 campuses after the staff meeting that the staff were happy to hear the issue of disability being discussed in an open manner and this meeting would be a catalyst to enable a more positive perception of disability within the Muslim community. The Principal also mentioned that the Dianella campus has about 12 students with a disability, causing a lot of concern for the school and the students.

The Project Officer made attempts to initiate a meeting with the Dianella Principal, but there was difficulty organising mutually suitable times within the limited timeframe of the current project. It is recommended that this option be pursued after the project to establish a working relationship with staff at the AIC Dianella campus.

One of the difficulties presented at this type of more "informal" Workshop was that parents had limited time to learn about all the Disability Services Standards and the cultural guidelines, as they needed to also talk to different teachers within the allocated time frame for the parent/teacher meetings. Due to this limitation, one participant elected for a phone interview later to enable her to have time to meet with the teachers then later address her CaLD disability concerns with Project staff.

A man who is Muslim and quadriplegic was engaged to attend the Workshop as a Guest Speaker and Co-facilitator. A pre-Workshop meeting considered that this would provide the staff and parents of the school a first-hand opportunity to talk with him about his issues and experiences as a person with a disability from the Muslim community. This was to serve as an example to encourage participants to begin to share and examine their own experiences – on the one hand those with disabilities and their families/carers sharing their lived experiences and their support needs, and on the other hand school staff to look at recognition and

community support for people with disabilities. He had previously expressed an interest to do so because he himself had experienced the cultural difficulty of the Muslim community in talking about disability. He was keen to help by talking about how his religious belief has helped him with his disability to become a valuable member of the Muslim community. The main focus within the Disability Services Standards was then Standards 1 (Service Access) and 6 (Valued Status). [The option was explored also with the Principle of the Kewdale campus for the Guest Speaker to also talk with the Primary students as well].

In the actual Workshop the participants didn't know of the Disability Services Standards and those with disabilities and their families/carers did not have a lot of confidence in their rights in relation to the Standards. However they did identify a few issues that they were able to then relate to the Standards. Overall, participants mentioned that they were happy with the disability services they were receiving but that the primary issue that was affecting them was related to obtaining appropriate support and understanding within their own cultural and religious community, like their child's school. Both they and the school were pleased that the difficulties were now being raised more openly and they were on track to be able to continue to work together to improve recognition, understanding and support for their members with disability.

The following issues that impacted on Muslim people with disabilities were raised during the Workshop and were explored within the Disability Services Standards with a view to improving community support as well as access to culturally appropriate services:

Standard 1 – Service Access

- School-based support.
 - Disability support in schools is limited because private schools are allocated only limited funding for Teacher Aides. One participant, for example, expressed her concern that her son wasn't obtaining assistance at the school through access to the services of a Teacher's Aide as he has only a mild intellectual disability.
 - Support with challenging behaviour. There was a concern from another of the parents, for example, about obtaining appropriate services to assist her son at school with his challenging behaviour. Due to his Autism he would frequently get frustrated with other students at school and home and start fights. The parent has had difficulty accessing the School Psychologist. The parent wasn't aware of suitable services outside the school environment to obtain support.
- Disability services support for out-of-school activities.
 - Residency status. One issue of this nature was identified, for example, by a parent who is a New Zealand resident and is legally blind. She mentioned her difficulty in obtaining disability services to assist her to learn to travel on public transport and to learn English. She has

approached a number of disability services, (such as the Association for the Blind WA) and was told she cannot access their services because she wasn't an Australian resident.

- Culturally appropriate carer and social support services. One parent, for example, mentioned that although she felt that mainstream service providers were respectful of her cultural and religious needs in practice she still felt uncomfortable accessing mainstream services for support, such as obtaining female carers for her daughter and also getting culturally appropriate social support. She has found that the process of having to ensure services are culturally appropriate has caused extra stress on herself and her family.
- Awareness of services. As one instance, a participant commented that although she was receiving adequate services from her disability-specific provider (the Centre for Cerebral Palsy) she wasn't aware that the Disability Services Commission also had support services available within her local area such as a Local Area Coordinator.

Standard 6 – Valued Status

- It was reported that some of the student's with disabilities were subjected to being teased and bullied at the school. It may be that this is to some extent due to the negative perception of disability within the Muslim community. It is one objective of this Workshop to begin a process to correct that attitude.
- It was also reported that religious leaders were refusing children with challenging behaviours to attend the Mosque during religious prayers, which was creating an environment that was reinforcing the perception that Muslims with disabilities don't have the same value as other Muslims. This is a notion that other religious leaders dispute. It is important that this receives careful consideration and that beginnings are made to successfully promote a positive religious basis to valuing people with disabilities. Rights under Standard 5 (Participation and Integration) were also raised as a key practical concern here as inclusion of people with disabilities is not only a goal but also part of the means to promote their acceptance and Valued Status.

Standard 8 - Service Management

- One of the main issues was that disability had not been discussed as an issue of focus at the school, and informed support strategies explicitly developed, despite the difficulties being experienced. Although disability and educational practices are recognised within the mainstream education system, in faith-specific schools with children and their families drawn from diverse cultures, a need was expressed for these issues to be formally considered within the decision making and planning processes of the school and include representation from those religious and cultural communities.

Both the College Primary Principal and the Kewdale campus Primary Principal, provided feedback that they were happy with the way the Workshop was run and that it enabled parents to discuss issues relating to their child's disability within an environment they felt comfortable with. They said they would like to invite EDAC to attend similar parent/teacher meetings in the future.

The facilitator also felt that the Workshop was successful in providing information to staff and in reaching parents that normally don't openly discuss issues relating to caring for their child with a disability. Holding the Workshop informally during the parent/teacher meeting period was successful as a way of beginning to open people to talking about disability issues in their school and community. There could be a follow-up Workshop structured in a more formal manner to target strategies to achieve specific outcomes on the main issues of concern. Alternatively a series of Workshops could now be convened, outside the parent/teacher times, with one for each campus, to enable full participation by the whole college.

5.1.8 Northern Perth

Initial pre-Workshop consultation by the Project Officer and some of the District Managers within the Northern Perth area identified the issues impacting people with disabilities and their carers in that general locality. For this the District Managers had compiled and distributed a questionnaire for their LACs to respond to regarding consumer trends. The feedback showed that the most prevailing issues for people with disabilities and/or their family carers from CaLD backgrounds were:

1. Language barriers - they had difficulties getting information about services because of language and problems in access to interpreters and translators.
2. Self-advocacy difficulties - they felt intimidated by government services, which could be attributed partly to their experience of government agencies in their country of origin. They tend to rely on the Local Area Coordinators and local non-government organizations, such as Ishaar, EDAC, the Edmund Rice Centre, Carers WA and the Migrant Resource Centres, as advocates for all their communication with and to obtain assistance from government departments such as Centrelink, Homeswest and Education.
3. Cultural perceptions of disability – they experienced barriers within their own cultural communities that limited their social interaction.
4. Recognition of qualifications – family carers reported difficulty having their qualifications from their country of origin recognised. This was hampering their ability to obtain suitable employment for themselves to complement their carer role and to assist resourcing the additional expenses of providing care.

It was identified through this background research that the Workshop would most profitably focus on Standards 1, 2, 5, 7 and 8.

The questionnaire also identified that the largest ethnic language groups in the North Perth area were Vietnamese, Somalian, Arabic, Romanian and Filipino - who were canvassed for participation in the Workshop.

Carers WA agreed to host this Workshop. Guest Speakers were invited from government services - Centrelink, Education Department, Police Department and Department of Housing - to provide information on how they support people with disabilities, particularly CaLD people, including their own complaint procedures. Unfortunately the Department of Housing wasn't able to be represented at the Workshop due to management restructuring at the time.

This Workshop had the largest turnout for the Project. A Vietnamese interpreter was provided for the Workshop as they comprised the majority of attendees and requested this assistance. As experienced at Mirrabooka, this required the facilitator and Guest Speakers to modify their presentation time and procedure to allow for the information to be conveyed progressively to participants through the interpreter.

At the Workshop, participants showed a lot of interest in the topics discussed, but seemed to be reluctant to ask questions openly about the information being presented or to participate in discussion. This could be attributed to the Workshop being conducted in a large group because of the need for interpreter support. This may have prevented the discussions being more personable like during the previous smaller Workshops. Also it may have been a reflection of cultural practice.

In terms of feedback, a number of participants commented that they were quite happy with the disability services they were receiving. However, it was later pointed out by one of them that some may truly be happy with the services, but cultural practice of politeness and respectfulness would have precluded others from speaking out negatively. They would have felt too embarrassed or shamed to raise issues about services in front of other members of their community. Also their past experience has been that they obtained no support in their country of origin as a person with disability and they didn't want to appear ungrateful for the services they are now receiving. Experience here also had made them anxious that they would be putting the services they did receive at risk if they spoke out.

From the participants that did comment about their experiences when accessing disability services, they identified the following areas of concern about service providers meeting the Disability Services Standards in ways that were culturally appropriate:

Standard 1 - Access to services

- Many of the participants expressed their difficulty with obtaining information about services suitable to their needs; this was attributed to –
 - much of what they needed not being translated into their language; and
 - agencies not providing interpreters during appointments and meetings.

For example, several participants said that were not aware that they could apply for Carer's allowance or Carer's payment until service providers utilized the services of interpreters and they were able to fully discuss and understand the disability support services that were actually available and how to apply for them.

- Narrow one-off information provision, in problem-focussed rather than person-focussed casework, and not addressing whole-of-life needs, was also a concern that was raised. For example, one participant mentioned they had contact with an LAC where they obtained assistance for the person they were caring for with an intellectual disability a few years ago, but were not informed then that they could go back to their LAC to obtain assistance with any subsequent concerns.
- Similarly, inadequate consideration of client capacity to utilise information provided was also an issue. For example, one participant raised their concern about not being given adequate information about the Post School Option service and didn't know where to find out more information about it or where she could find someone to translate it for her.
- Insufficient evaluation of client needs was another concern. Another participant, for example, mentioned that they have been assisting the care of their grandchild who has a disability and neither they or the child's mother has been informed of the different types of services they could obtain to assist with the care, so the family has struggled on their own for a number of years without suitable support when all the time it was in fact available and they could have accessed it if they had been properly informed or had interpreter assistance to more fully inquire and inform themselves at the time.

Standard 2 – Individual Needs

Transport assistance seems to be frequently raised as a problem. One participant, for example, voiced her concern about not being provided with adequate transport assistance. She had requested transport assistance to take the person she was caring for to hospital for a check-up after an operation, but had to cancel the appointment due to no transport. She later went to another appointment at the hospital where the staff got angry with her for not being present at the previous meeting, even though she explained the situation to them. People of different cultural backgrounds have enough of a problem with community attitudes without matters like this, such as inadequate transport provision, unnecessarily causing conflict.

Standard 5 – Participation and Integration

Other participants mentioned they are interested to find out about services and events (and Workshops like this) within their local area, but they are missing out on this information because agencies are not advertising them within their local sources of information such as ethnic community newspapers/newsletters and are also not providing suitable translations of

information into community languages. The participants also mentioned that they would like to access information about services from ethnic radio programs, and appreciated *EthnicAbility*.

Standard 7 – Complaints and Disputes

It was commented that there is a reluctance to make complaints either informally or formally – for many reasons that are cultural as well as related to the client's previous experience and expectations of governments and service providers.

- For example, one of the participants who said in public in the Workshop that she was happy with the services she was receiving, explained this to the facilitator personally after the Workshop on the basis of her own experiences as a refugee. She had had to struggle to survive civil war in her country and found that obtaining services for the person she was caring for there was out of the question. So when comparing that experience in her country of origin to the service she is receiving now she is here, she feels bad about making any complaints, even though she actually isn't obtaining services suitable to her needs. She felt that providing feedback or making a complaint to be equivalent to her showing ingratitude for what she is receiving, and that receiving something, even though not suitable, is better than receiving nothing.
- Participants in other Workshops expressed their fear of making a formal complaint as they had suffered discrimination by service providers when they questioned entitlements or raised any issues of dissatisfaction. They queried the enforcement, in the Standards, of non-retribution, and regarded preventative education of service providers as more likely to be effective, but that formal complaints procedures still needed to be there but they needed help with taking action under those provisions, both to the agency concerned and if necessary to DSC as their funding body.

Standard 8 - Service Management

Participants expressed and illustrated concerns they have with the level of understanding and practice of government departments, as well as the concerns with disability services agencies, which they see as matters of informed policy and staff training.

For example,

- With the Disability Services Commission, their concerns in this Workshop and others have been the difficulties understanding the complexity of disability determinations and entitlements; which services are DSC funded and therefore are subject to the Disability Services Standards; low levels of liaison between LACs and ethnic communities and consequently being poor informed of services; reactive rather than promotional proactive early engagement by LACs and services; and poor involvement of CaLD people

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with disabilities in DSC itself at all levels, especially in CaLD/disability issues, both employment of CaLD staff with disabilities and consultation of CaLD people on matters affecting them in developing policy and practice.

- With Centrelink, the concern for the negative organisational 'culture' and practices tends to be ongoing. Whereas there is excellent feedback regarding the few Multicultural Services Officers, the main problems seem to be with systemic practices that cause perpetual difficulties and disadvantages for CaLD people with disabilities – ranging from continual complex documentation requirements that seem to always require considerable support to complete, to automatic termination of allowances without any consultation or support where those submissions are deemed insufficient; and lack of any sense of responsibility, duty of care or assisted proactive planning in instances where there are potential or actual gaps in financial support provisions where there are changes in life circumstances.
- With the Police Department, there was a sense of concern about levels of training regarding understanding and responding appropriately to disability (particularly mental health) and cultural differences. For example in the Workshop the way information in one instance was provided by the Police Department. This concerned the well-intentioned explanation of arresting perpetrators of family violence - by "showing him how he needs to change his ways to be more like us". While police protection and intervention is appreciated in this and other matters, the specific comment was perceived (possibly misperceived) as a generalised assimilatory statement and as such to devalue an individual's right to cultural identity while upholding Australia's laws in our multicultural society. This experience was indicative of the sensitivity of CaLD people to the cultural denigration that they experience - perpetrated in this way by the cultural mainstreaming of disability and other services - that is deeply felt and expressed at times as 'cultural genocide'. They naturally then seek to avoid contact with such services and avoid accessing them, even at considerable personal cost and hardship.
- With the Education Department, staff were also experienced as having a limited understanding of CaLD issues, particularly regarding disabilities and educational support practices. In particular, in the Workshop the representative had difficulty answering the question of how people from a CaLD background who couldn't speak English very well could obtain assistance from their Teachers/Teacher's Aides. This deficiency of understanding how to address cultural needs such as language support within the Education Department was acknowledged by the Education Department Guest Speaker who suggested that more work should be done with the Education Department to enable them to more appropriately address these barriers. This opportunity for constructive engagement on this matter was pursued after the workshop.

At the end of the Workshop participants were encouraged to provide individual feedback using an Evaluation form, or alternatively, which suited most, with an interpreter provide feedback as a group. Participants were interested when learning about their rights in relation to the Disability Services Standards and they keenly attended to information provided by the various government departments.

5.1.9 Autism

The Autism Association was recruited as host agency for this Workshop. During the initial meeting with them they advised that they had only a small number of CaLD clients within their agency and that it would be most valuable to involve as well in the Workshop other organisations, who also tend to have very low CaLD client membership/participation, particularly those services associated with post-school employment and alternatives to employment.

Accordingly, Intework was suggested, as the limited opportunities for CaLD people with disabilities, especially autism, to participate in employment was the biggest barrier for social inclusion and development of independence. Given this, and the relatively greater relevance of engaging in Post-School Options that were alternatives to employment, or which could supplement partial employment, Volunteer WA (*Take 2 Program*) and the WA Disabled Sports Association also agreed to participate as Guest Speakers. The task of the Guest Speakers in the Workshop was to actively engage the participants to explore the various practical and realistic opportunities for community participation, how to access options suited to them individually and how they could also ensure care for their cultural needs.

As well as Standard 5, Standards 1, 2, and 6 also seemed a necessary and relevant focus for the Workshop given the nature of the issues identified. Both Volunteer WA and the WA Disabled Sports Association reported that they don't have many people access their service who are from a CaLD background and would like to work with EDAC in the future to address this concern. The small numbers of people with a disability from a CaLD background who are accessing recreational services may be indicative of an underlying theme of CaLD communities in general seeing little value in their people with a disability participating in recreational activities – a matter which perhaps can be pursued promotionally within the ethnic communities themselves and serve as an opener to moving toward CaLD people with disabilities achieving greater active inclusion and developmental opportunities in all other areas of life.

During the pre-Workshop consultations a number of issues impacting their CaLD consumers with conditions such as autism, were identified, which included:

- Developing realistic employment and social expectations for a person with Autism – within both the cultural and wider community.

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- In terms of realizing the need to make future plans on what their child will do once they leave the education system, CaLD parents not being informed and supported effectively regarding Post School Options.
- Carers taking on too much of the responsibility, thus limiting the development of independence of the individual with disability – resignation and acceptance of the condition in some ethnic families/communities, with consequent non-developmental and dependency entrenchment care practices.
- Various cultural perceptions regarding disability which cause difficulties for agencies at times to find ways to address those practices when providing support to an individual.
- Difficulty to relay service information to CaLD people even with the support of interpreters/translators.

To ensure the participants were able to stay engaged positively throughout the workshop the Powerpoint presentation was dispensed with and the host organisation and Guest Speakers talked directly and briefly about the work they do in their agency and then encouraged the participants discuss what they wanted to achieve from the Workshop and what their experiences have been in obtaining social support with Autism.

The issues identified by the participants showed aspects of the Standards that need to be more effectively addressed in culturally informed ways when implementing the rights of persons from CaLD backgrounds:

Standard 1 – Service access

- Services are not readily accessing their local ethnic community resources to assist with getting their information out to CaLD consumers. For example, one participant commented that although it is good that some information is translated in various languages, the translations are not being utilized effectively if not promoted the ethnic community newspapers, radio programs or within their places that are frequented by ethnic community groups.
- The Disability Support Pension and the recent reduction of working hours to qualify for the pension was raised and discussed in the Workshop. One participant, for example, said that volunteer work was viewed by Centrelink as evidence of their ability to participate in regular employment. Some participants commented that this issue had prevented them from doing a little volunteer work. The issue was raised that although volunteer work required the participant to fulfil a task for an organisation, many people without disabilities engaged in volunteer work as a form of socialization and that it helped with a feeling of being valued participants in society. They felt that this option of social volunteer work was being taken away as an option for many people with disabilities. This was especially so for CaLD people with disabilities like autism who may engage in voluntary work as they find engagement in work problematic because of English language difficulties on top of their other communication issues.

- Current intelligence tests used as access tools were also questioned at the Workshop in terms of their validity when an individual's cultural environment is not appropriately recognised and taken into account in that process. One participant, for example, voiced their concern about their foster child who undertook the tests and found difficulty with the content of a number of questions because of the discrepancies between European and ethnic experiences.

Standard 2 – Individual Needs.

- Lack of male Support Workers was identified as a major concern for the participants, causing men and boys from a CaLD background constant feelings of guilt and worthlessness as they permit female Support Workers to attend to their needs - forbidden within some cultural and ethnic belief systems. Their only other alternative is to maintain their reliance on their family for social support and care and they feel guilty when they see they are wearing their family out because of limited alternative options that maintain cultural respect for them and their families.
- Likewise, there is also the need for Support Workers to ensure that females are made to feel comfortable when accessing services. Particularly, their religious and cultural beliefs should be upheld in terms of interacting with members of the same sex. Their experience had been that services had difficulty with understanding and valuing this view and this had in one instance caused the father to become overprotective and limit the opportunities for the daughter to receive services due to his fear of the service staff in this way not upholding the family's religious/cultural beliefs.

Standard 4 – Privacy, Dignity and Confidentiality

Cultural inappropriateness of interpreters was identified as at times being a cause for concern. For example, one participant commented about an issue where an interpreter was brought in for assistance and the interpreter and the consumer were from conflicting groups in their country of origin. The interpreter initiated a dispute during the interpretation service which caused the consumer to feel vulnerable and lose trust also that the interpreter would maintain confidentiality of the information they were there to interpret.

Standard 5 - Participation and Integration

- Participation in employment was identified as the biggest barrier for people with Autism in developing a sense of social inclusion and personal independence.
- Post School Options were regarded as the main area of possible participation, with CaLD parents needing to be better informed and supported in planning and engaging in these alternatives to employment for their child with autism after leaving school.
- Total dependency care attitudes and practices in some ethnic families/communities toward individuals with disability such as autism were

identified as limiting the development of social participation and independent living skills.

Standard 6 – Valued Status

- Impacts on carer support. It was reported that there is a negative image of people with disabilities in some ethnic communities. There isn't recognition that people with disabilities are able to succeed in life. The job of caring for such a person is put solely on the family carer, such as the mother, and the ethnic community is not actively involved with supporting either the person/child or her as the carer. This stress is multiplied when they are usually required to also attend to the needs of their other children and family. Frequently this causes them to have to choose between the care of the person/child with a disability and their other children and family members. This typically results in family stress and discord and the carer feeling that their role as parent/carer is also devalued in their community. It was suggested that current disability service providers need to be more proactive in creating good working relationships within the various ethnic communities and be more active in promoting respect and encouraging support for people with disabilities and their family carers.
- Hidden people with disabilities. Negative perceptions and devaluing of people with disabilities within some communities means that not only the persons concerned and their carers are affected but the family as a whole. For example, one participant reported how two brothers came to Australia because the other sibling in their home country had a disability and that had caused their marriage prospects there to be much reduced. It is commonly known that some ethnic families tend to hide away the person with a disability, and this severely limits the opportunities for community and social participation not only of the person with a disability and the family carer but of the family participating as a family the community and having other families or people in the community visit their home.

Adjustments made to the structure and presentation of this Workshop were successful and still enabled individuals to learn about the Standards and discuss their experienced issues and cultural concerns. Also group management skills to facilitate cooperative participation were a necessary ingredient in the success of the Workshop given the challenges for people with autistic disorders in these contexts. Overall feedback from the Workshop indicated that it was seen as successful, with one participant expressing their desire to attend the subsequent Accommodation Workshop.

5.1.10 Accommodation

Nulsen Haven agreed to participate as host agency for the Workshop and Guest Speakers were from Rocky Bay and Sussex St Community Legal Centre.

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Pre-Workshop consultations and planning initially with Activ Foundation Accommodation Services, and subsequent feedback on these from Nulsen Haven, determined that a number of family carers and people with disability are currently reporting considerable distress with accommodation support, identifying issues raised by CaLD families with a family member with a disability making transition into supported accommodation, such as:

- Being on long waiting lists for Accommodation Support Funding.
- Family carers from a CaLD background having limited understanding of the various Accommodation Support options.
- CaLD family carers feeling guilty because of a sense of abandoning the person with a disability to residential care, and coping with a sense of personal and moral failure in one's duty in the eyes of others as continuing care within the family is a strong expectation in most ethnic cultures.
- A perception that a person with a disability will have limited life options once placed in residential care, such as accessing their ethnic and religious community, participating in social and recreational activities or obtaining employment.
- Finding a culturally supportive accommodation environment for their family member with a disability.
- Concern about the security of the accommodation support for their family member, especially as family carers commonly enter into accommodation support arrangements for them because they themselves are ageing and no longer able to provide adequate home-based care. There is some anxiety about relying on government support, particularly concern about what may happen with their family member with a disability if the DSC funding for accommodation support is taken away and they as the parents are no longer living or perhaps themselves in aged care.

The Workshop was structured to target both people in accommodation support and those currently exploring accommodation support options. Guest Speakers provided information on the various accommodation options, including those identified in the DSC Community Living Plan. Standards 1, 2, 4 and 6 were indicated as the appropriate focus areas for the discussions according to the issues raised in the pre-Workshop consultations. Also opened for discussion was importantly the natural range of emotions family carers could expect to experience when assisting their family member to make the transition to supported accommodation, including the importance of a positive outlook and sharing confidence in the arrangements once they know what they want for them. Also covered was basic information on guardianship and inheritance law where a person with a disability is the recipient.

In the Workshop some CaLD consumers discussed their experiences when they have tried to access services, and others their experiences in supported accommodation, and both offered suggestions on ways to assist CaLD consumers in particular. CaLD consumer comments and feedback from Guest

Speakers and the host agency were able to be framed by EDAC staff to illustrate the Disability Services Standards requirements and the usefulness of the guidelines provided by the *CaLD Perspectives*.

The Workshop turned out to be both quite emotional and inspiring as participants talked about their experiences. The issues brought forward highlighted the major gaps currently with accommodation support where people with disabilities and family carers are feeling they cannot access these services unless they are on their last legs of being able to cope with their current living situations. This was found to be extremely stressful for participants who come from a CaLD background. The following issues were raised, as considered in relation to the Disability Services Standards and cultural aspects of providing accommodation services:

Standard 1 – Service Access

- Delays in assessment for supported accommodation. For example, one participant described how she had made a CAP application 7 years ago for accommodation support for her 28 year old daughter with a disability. She is becoming quite distressed as the care for her daughter is extremely demanding. Her daughter has sleeping problems and will stay awake most nights. This has caused respite agencies to charge her extra fees for the extra services of attending to a child with behavioural problems of a night time. She also commented that when Support Workers come to their home they have difficulty with understanding and taking into consideration the family's cultural practices. Cultural appropriateness of care also concerns her for when her daughter is accepted into supported accommodation.
- Participants also discussed their feelings of insecurity in temporary accommodation support, being very uncertain of their future due to the fear of maybe not being able to continue staying there while waiting for a more permanent arrangement with their CAP application. Security, certainty and being able to rely on routine and the familiar are often important aspects in the life of people with disability, with anxiety and worry easily caused by ongoing uncertainty and unpredictability of their personal living arrangements. This is particularly so for CaLD people and especially during their first experience of being separated from the direct care within their families.
- Difficulty accessing accommodation support, especially that which is culturally supportive, has caused many families to try and obtain a Carer from their country of origin, often from within the extended family or a close family friend. However, the current migration laws don't allow people to migrate as a Carer unless they are a direct family member. A participant relating an example of their own experience of this said that they didn't have any direct family members who would be able to take on the caring role but a person in their community close to the family who could do so, but was not approved for migration.

Standard 2 – Individual needs

- Meeting important cultural needs in supported care was an issue. One example raised by a participant was that they were appreciative of how their accommodation service provider was trying to make adjustments to meet their individual cultural needs, however they found that when it came to obtaining culturally appropriate food they had to change their eating habits and eat food which was deemed not appropriate to their religious beliefs. Although services can obtain religiously appropriate food he mentioned that it is usually frozen and not fresh and he wanted to be able to enjoy fresh food like others at the centre.
- Another issue raised concerned adequacy of information access for CaLD residents. For example, one family member obtained official letters from accommodation service providers but they were always in English. The service provider wasn't able to translate the letters for her. This caused difficulty as they needed to keep going out to get letters translated to know what was happening to their family member accessing the service.

Standard 4 – Privacy, Dignity and Confidentiality

The confidentiality policies of accommodation service providers was raised as being another area of concern for family members from a CaLD background, where culturally the head of the family is still seen as the main person to be consulted during major decisions, even if the individual family member is accessing accommodation support. Yet, these family members with family/cultural responsibility are denied information regarding the care of the individual due to the confidentiality practices of agencies. This issue also relates to Standard 3 - Decision Making and Choice. Taking the time and care to develop culturally respectful negotiated solutions, involving client agreement and observing cultural care role responsibilities, are recommended for consideration in these circumstances.

Standard 6 – Valued Status

It was commented that accommodation services are currently employing more staff from a CaLD background. The main reason has been the difficulty getting people to work in this sector in the current employment market. While this could be seen as fortuitously helping to address the cultural needs of CaLD residents, it was questioned, from examples of poor attitudes and treatment, what training and provisions are put in place to enable these individuals, who are sometimes new migrants, to appreciate the value that people with disabilities have in this society, especially if they come from countries that don't value people with disabilities.

Overall the feedback from the Workshop was quite positive with most people saying that they had enjoyed learning about the various accommodation options available, and about the rights of a person with a disability and how with some informed consideration these can be achieved in culturally respectful and appropriate ways.

5.2 Promoting uptake of Workshop outcomes

5.2.1 Systemic advocacy

Issues raised during the Workshops identified needs and opened opportunities for changes to be considered at many systemic levels. It began a process of engagement of consumers, family carers and service providers that was intended to encourage further consultation and cooperation to work together towards improvements for CaLD people with disabilities not just individually but also in general across the sector.

Across the Workshops, common themes identified were:

- Sharing culture/disability awareness: services and ethnic communities
- Culture in care practice
- Engaging families
- Supporting CaLD family carers
- Promoting inclusion
- Working with interpreters

The Workshops provided suggestions of how the wide range of issues raised might each begin to be addressed. EDAC in its systemic advocacy role provided encouragement and direction for agencies and their consumers, during the Workshops and subsequently, to develop practical strategies to pursue initiatives of mutual priority interest and concern.

A number of participating agencies expressed interest to work further with EDAC towards providing support for CaLD people with disabilities and their family carers. For example, the Education Department organised a meeting with EDAC's Systemic Advocate directly after the Workshop in which they were involved, to discuss ways they can be more proactive in addressing the needs of CaLD people with a disability. Also others expressed interest, for example Volunteer WA and the WA Disabled Sports Association in the possibility of developing a project to enable CaLD consumers to be more active in social activities, and the Muslim Women's Support Centre were interested in possible initiatives to enhance the self-esteem of their family carers.

EDAC itself is continually engaged in advocating for systemic change on a wide range of issues and its activities have been enriched and informed by the contributions made in the Workshop series of this Project.

[EDAC also attended to a number of cases of individual advocacy as a result of the Workshops, and also consumers, carers and service providers also followed up on issues in individual cases].

5.2.2 EthnicAbility

To set the context for the series of radio broadcasts promoting the outcomes of the Workshops, the first was an interview with the Australian representative to the

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United Nations regarding the new UN Convention on the Rights of People with a Disability, to which Australia is a signatory, as recently 'human rights' was added to our Disability Services Standards (WA) Standard 9 (Protection of Human Rights and Freedom from Abuse and Neglect). EDAC has been active in promoting the new version of the Standards with CaLD communities and in assisting service providers with their implementation appropriate to CaLD consumers.

For the rest of the Workshops, some of the participants, Guest Speakers, host agencies staff and the Project Officer were interviewed on the radio program - by either pre-recording at the Workshop or live at the station - to discuss the main issues and outcomes and to generally promote awareness of culture and disability within the framework of the Disability Services Standards.

In all, 13 programs were broadcast progressively on EDAC's program *EthnicAbility* on 6EBA ethnic community radio, throughout 2007-8, in direct relation to the Workshops, to widely disseminate and promote the outcomes, especially to engage and inform the ethnic communities.

27/02/2007	UN Convention on Rights of People with a Disability	01/04/2008	South Eastern Perth: people with disabilities and their family carers
17/07/2007	<i>CaLD Carers Speak Up</i> (Mirrabooka)	06/05/2008	Northern Perth people with disabilities and their family carers
21/08/2007	Women with disabilities	03/06/2008	Accommodation services
27/11/2007	Cerebral Palsy	01/07/2008	Schools and students
11/12/2007	Developmental Disability	08/07/2008	Making complaints to make change
05/02/2008	Muslim people with disabilities and their family carers	04/08/2008	Autism
04/03/2008	CaLD people with challenging behaviour	Commencing Sept 2008	Case study narrations of integrated outcomes of the Workshop series.

5.2.3 Translation and narration

A composite statement of outcomes (Appendix E) was compiled after all the Workshops were completed, to illustrate the prominent issues that were raised and how service providers can engage with CaLD people with disabilities and

their family carers and communities to incorporate the diversity of individual cultural and religious practices within the Disability Services Standards.

CaLD community members with previous translating experience volunteered their services. Translations were verified by an independent community member. Although this strategy proved viable, in future projects should include funding allocation to have documents professionally translated. (see *Recommendation 7*).

The integrated outcomes were translated into 7 languages: French, Italian, Croatian, Spanish, Bahasa Malaysia, Vietnamese, Somali, Arabic and Tagalog.

One of the Workshops, as an example of the value of potentially also working separately within different ethnic communities, was directed at a specific ethnic group; the Muslim community. A separate translation and narration was also compiled for that community, addressing the issues that were presented by them at their Workshop. This was translated into Arabic, being the prominent language that most Muslims utilize when reading the religious texts they have in common. A religious leader (Imam) was culturally the most appropriate person to do the narration, being a leading figure guiding and advising the community about every-day issues.

Both the written translation(s) and narration(s) have been made available on EDAC's website www.edac.org.au (*Disability Services Standards*).

EthnicAbility will commence broadcasting these narrations from September 2008.

6 Outcomes

A total of 25 organisations participated in this Project, as host agencies and providing Guest Speakers for the Workshops. Feedback was positive and encouraging - appreciating being informed about the Disability Service Standards; the nature of the issues CaLD people with disabilities and their family carers and communities have with being able to access culturally appropriate service provision; and the opportunity and encouragement to begin working engagement with their consumers toward their involvement in developing culturally effective practice. There was considerable interest also in the ongoing availability of EDAC to provide assistance and guidance in this process through its systemic advocacy role.

Overall, 152 participants attended the 10 Workshops. Verbal and written feedback from them showed that the majority felt they had learnt something new about how an individual's cultural needs can be incorporated within the Disability Services Standards. They also appreciated learning about other services and the information provided on specific topics by Guest Speakers at the various Workshops.

One over-riding concern people expressed was that they generally had difficulty in distinguishing what services were funded by DSC and tended to raise issues relating to services of all government and non-government agencies. Funding is

not usually public and their expectation anyway was that the Disability Services Standards should apply universally, not only to services funded by the Disability Services Commission. This caused them difficulty at times to know where they could legitimately pursue their experiences of cultural gaps in services.

Around 65% of attendees utilized the opportunity to obtain individual advocacy and support on specific issues identified at the Workshops, either from EDAC's individual advocates or from the other organisations present.

Some participants were motivated into learning how to self-advocate after having the opportunity to raise their issues in the Workshops, especially those who were subsequently interviewed on/for the radio program. This had enabled them to feel they were empowering themselves. (They were advised of EDAC's Self-Advocacy resource for CaLD people with disabilities: *Let Me Speak*)

Broadcasting the radio programs also proved a useful systemic advocacy strategy, as it raised awareness of some specific CaLD issues relating to the Disability Services Standards that other service providers who had not been able to attend the Workshops were able to look at addressing in cultural ways. For example, after hearing the radio program, one agency requested to participate in the subsequent Workshops to assist the service in meeting CaLD consumer's cultural needs.

Work has begun by agencies and their CaLD consumers on systemic issues related to cultural aspects of disability issues identified in the Workshops. EDAC is also pursuing arrangements with some organisations towards addressing various systemic issues. EDAC will continue itself to follow through on issues through future submissions to government on policies and legislation, and opportunities in research, training and service development.

6.1 Summary of issues and relevant Disability Services Standards

Some common issues were identified across all Workshops that were experienced as barriers for people from a CaLD background who were accessing/trying to access disability services. Each of these was addressed as a challenge for positive constructive improvement, with agencies and CaLD consumers now engaged with the beginnings of relationships on the basis of which they can work together to achieve mutually informed understanding of culture and disability and build inclusive services that engage and appropriately support consumers and carers in need.

The more general common issues such as these tend to impact across several of the Standards. They do so also across different domains of disability services and the different types of disability and different cultural groups wishing to access services. The various different aspects of each broad issue are therefore here related to some of the different Standards to which they apply.

- 1. Cultural competency and disability awareness** – CaLD consumers reported that service providers generally tended to neglect or make stereotypical assumptions regarding their needs as individuals from CaLD

backgrounds and their disability - based on their 'ethnic' appearance or their cultural background, as well as on their appearance in regard to their disability (see *Recommendation 6*).

- CaLD people with disabilities and their family/carers may refuse access to a particular service or eventually to ALL services if their repeated experience is that services either don't consider or else make assumptions about them and their individual needs, especially their personal cultural identity and family cultural care practices and also their disability support needs. (**Standard 1**)
- CaLD people with a disability need to feel that they are treated as an individual, their cultural nature recognised but not stereotypically as 'representative' of a specific culture. It also needs to be respected that their individual needs may be different from what is perceived as acceptable within their ethnic community. Similarly their actual disability support needs need to be appreciated on an individual basis. (**Standard 2**)
- When a service makes assumptions about what an individual can or cannot do and what they think is best for them, without consideration of their culture or else pre-conception of their ethnic beliefs/practices, or generalised notions of their disability, it is not providing the individual the opportunity to themselves make decisions and choices about the type of disability support services they receive and negotiate appropriate cultural and individual need considerations. (**Standard 3**)
- Support for participation and integration that neglects cultural needs purposefully or inadvertently promotes the discredited policies and practices of assimilation. That based on cultural preconceptions and stereotyping also disrespects an individual's right, and their family's, to negotiate their own cultural participation and integration in our contemporary multicultural society. Participation and integration is a highly individual matter even for people with a particular type of disability, as it is for people from different CaLD backgrounds, and should be negotiated accordingly. (**Standard 5**)
- Services that ignore or make assumptions regarding the cultural aspects of an individual's disability support needs can cause them to feel that the cultural aspect of their identity and personhood has no valued status. (**Standard 6**)
- Services that do not employ staff who are CaLD people with disabilities, nor provide cultural competency training for staff, nor engage their CaLD consumers and families/carers and ethnic communities in the management of those services and in the design and development of culturally appropriate services – are seen and frequently experienced as perpetuating the outmoded (and disgraced) cultural assimilation practices of the past. Such service management practices are not in accord with

international, national and State disability, multicultural, citizenship and equal opportunity legislation, policies and guidelines. (**Standard 8**)

- Cultural neglect or assumptions, which may limit an individual's options regarding the cultural considerations in type of service they receive, can be conceived by them, either way, as indirect racism. Similarly, neglect of adequate consideration of individual aspects of disability support needs can be felt as an abrogation of equal opportunity. (**Standard 9**)

2. **Interpreters/translators** - Service providers not valuing the need, or understanding how to use, interpreter and/or translator services, (see *Recommendations 7 & 8*).

Without the support of interpreters and/or translators a service provider will find they will have problems with meeting the CaLD needs of consumers in relation to the Standards in the following ways:

- CaLD consumers will not know about services and how to access them. (**Standard 1**)
- CaLD consumers will have difficulties communicating to and negotiating with the service about how they can best meet their needs. (**Standard 2**)
- They would feel they don't have full control regarding decisions to be made. (**Standard 3**)
- Service providers will have difficulties with helping them understand how using a professional interpreter will respect their privacy. (**Standard 4**)
- Without interpreter support the individual will have difficulty with actively participating in general Australian society and will feel excluded, especially so if their own ethnic community doesn't encourage it. (**Standard 5**)
- The individual will feel that disability service providers don't value them or respect their culture because they don't provide communication support in their language. (**Standard 6**)
- Individuals would be inhibited from and disadvantaged in making a complaint about a service. (**Standard 7**)
- Without language support, there would be limited opportunities for them to provide feedback to or participate in service management or to contribute to service developments. (**Standard 8**)
- Due to the lack of interpreter/translator support which impacts the first 8 Standards, CaLD people will not feel their human rights are being upheld. They may also be reluctant to raise issues of abuse and neglect. (**Standard 9**)

3. **Family carers and decision making** - Service providers were excluding the cultural needs of family carers to be involved in the decision making processes. (see *Recommendation 9*)

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- Service providers need to acknowledge that some individuals, particularly those in CaLD families, may have a strong/traditional family connection that needs to be included within the service delivery; and that they may forego access to services that do not involve their family carer(s) in the process. (**Standard 1**)
 - In planning the service to meet the individual needs of CaLD people with disabilities, because of cultural care roles involvement of family carers needs to be negotiated with the client, and the cultural care responsibilities of the family carer taken into account. (**Standard 2**)
 - Although the needs and individual rights of any person with a disability is the main focus of service delivery, service providers need to ensure that if their traditional cultural practice involves major decisions being made in a collective manner with stakeholders in the family and community, this process should also be supported. (**Standard 3**)
 - Some service providers are using confidentiality policies rigidly to prevent family carers discussing with them issues/concerns relating to the person with a disability who is accessing the service. They are excluded rather than their involvement negotiated, with the client, in a culturally informed way. This has caused extreme stress in some CaLD families in particular and family ties to be broken, alienating the person with a disability from the family and even further from their traditional cultural support networks. (**Standard 4**)
 - Family carers tend to provide a majority of the support for a CaLD people with a disability. When they have been excluded from the decision making process, they begin to feel their cultural care role isn't valued by the service and the person with a disability is also thereby encouraged to think, feel and act likewise. (**Standard 6**)
 - Basic human rights in a contemporary multicultural society such as ours involves respect for diversity of values and practices, and where these conflict there is responsibility to seek negotiated solutions within the overall framework of the governing laws and policies of the day. Imposed solutions without constructive and mutually informed engagement of the parties affected in each case is considered an abrogation of those rights. (**Standard 9**)
4. **Social participation** - CaLD people with disabilities and their carers find they have limited social opportunities to help them integrate in both the general Australian community and their ethnic community. (see *Recommendation 10*)
- Currently, CaLD people with disabilities don't have many opportunities to access services that enable them to participate in social activities within their ethnic and the general Australian community (**Standard 1**)
 - Many CaLD people with disabilities identify with both their ethnic and Australian communities, but services find it difficult to meet their individual cultural needs within the broader community and their individual needs

within their ethnic communities, tending to neglect or disregard both. (**Standard 2**)

- If services don't try to work with an individual's ethnic community and the broader community to encourage social participation both ways, they won't provide them with opportunities to have 'real' choices appropriate within our contemporary multicultural values and policies. (**Standard 3**)
 - CaLD people with disabilities may find themselves participating in Australian society, but this isn't 'true' participation if the individual nature of their ethnic cultural identity, values and practices are not respected; and conversely if participation in their own ethnic community does not also respect both their wider cultural involvement and disability. (**Standard 5**)
 - A number of ethnic communities don't see a person with a disability as having a valued status in the wider community, especially so if they are of CaLD background. If service providers don't work with both the ethnic and general communities there is little opportunity for the individual to feel 'real' value within their own culture and also to seek valued status within the wider society (unless they alienate themselves from their own cultural community to do so; or, alienated from both, settle for a devalued life). (**Standard 6**)
 - It is imperative that all disability service providers include commitment to recognising and working with the broader issues of social/community participation in their policies and practices for all CaLD clients, regardless of their specialised areas of service (**Standard 8**)
 - It's a fundamental human right for all people, with or without a disability, to be valued in as individuals; and in a multicultural society to have some flexibility of choice in the diversity of their social, cultural and community participation; and in terms of substantive equality be provided with the appropriate support to do so. (**Standard 9**)
5. **Adult cultural/social support** - Limited cultural or social support services for adults with a disability (see *Recommendation 10*).

A number of programs are designed for school age people with disabilities, but there is a relative absence of services for CaLD adults with disabilities.

- In the absence of adult social access support, it is difficult for CaLD consumers to access cultural and social activities in society generally, and particularly within their local ethnic communities, support that those communities could provide if resourced. (**Standard 1**)
- Those that may access mainstream social support for people with disability find the service insufficiently flexible to meet their individual cultural needs. (**Standard 2**)
- The small number of services that may assist CaLD adults with disability in terms of social support, tend not to provide the opportunity for individuals

to have a 'real' choice especially when they have specific cultural needs. (**Standard 3**)

- Adults with a disability from a CaLD background tend to find themselves facing 'double exclusion', from general Australian society because of their ethnicity and from their ethnic community because of their disability. They tend to be fearful of trying to participate and integrate in either community without extra social support. (**Standard 5**)
 - Due to the 'double exclusion' of CaLD adults with disabilities from both general and ethnic communities, they tend to feel they don't have valued status whichever way they turn. (**Standard 6**)
 - CaLD consumers and their families/carers report the need for disability service providers to be more mindful in their policies and practices to proactively help to avoid the problems/gaps that can arise in life transitions, especially from child at school to adult isolated at home without adequate social support (**Standard 8**)
6. **Temporary residents** - No information for temporary residents, including many who are from CaLD backgrounds, regarding how or where they can obtain support for a family member with a disability. (see *Recommendation 11*).
- Temporary residents are not being provided information on what disability services they can access, or the standard costs involved with accessing these services. (**Standard 1**)
 - Temporary residents, like all Australian residents, also have specific individual needs regarding types of services that can assist them with managing their disability, which they need to negotiate with appropriate providers. (**Standard 2**)
 - Currently, temporary residents tend to feel that they and/or the family member with a disability isn't valued in Australia because only permanent Australian residents with disabilities are valued enough to be provided with access to services. (**Standard 6**)
 - When a temporary resident wants to complain about not being able to access services, they are unsure of where to go to make a complaint (**Standard 7**)
 - CaLD people with disabilities who are temporary residents require special attention in service strategies - as they tend not to be as readily or as easily included in consumer consultations by disability services agencies, and also require early proactive contact with information and service promotions (**Standard 8**)
 - Temporary residents tend to feel that they are being subjected to government neglect from the current absence of policy and information on how they can access disability support services. (**Standard 9**)

7. **Information for parents of students in independent schools** - Information regarding disability services for parent carers and/or students with disability is not being disseminated to all independent schools, in particular those that are ethnic-specific (see *Recommendation 7.12*)
- Parents of CaLD students, particularly at ethnic-specific independent schools, are not being provided information on the types of DSC-funded services and how to access those services. (**Standard 1**)
 - The school environment has been identified by a number of CaLD parents as the only valued source of disability support to meet individual needs. DSC-funded services should recognise and support this and work to support the student and/or parent within their school. (**Standard 2**)
 - Without information and support from services within a student's school the CaLD students and their parents will not be provided the opportunity to have appropriate choice on the services they receive as for children and parents in other schools and the community. (**Standard 3**)
 - If ethnic-specific independent schools and all others also, are not provided information on types of services available and/or those services are not appropriate for CaLD parents/students, they will not have the opportunity to learn to participate in both the general Australian society or their own ethnic community. (**Standard 5**)
 - As a consequence of not being provided information on disability support services to meet their individual needs and so have choice and be able to participate effectively in the school and their ethnic community and wider society, they do not feel they are valued as people or as school and community members. Also lack of support for their parent carers likewise leaves them also feeling unvalued. (**Standard 6**)
 - Disability services as part of their funded contracts should be required to ensure and demonstrate that they provide appropriate information and contact to all sectors of the community, especially proactively with schools, and, that within their multicultural commitments, this should include culture/faith-specific independent schools (**Standard 8**)
8. **Culture and gender-appropriate support workers** - CaLD people with disabilities were finding that service providers had difficulty meeting culturally gender-appropriate support - male care or social support for men with disabilities; and female care and female social support for girls/women (see *Recommendation 14*)
- CaLD people with disabilities are finding it difficult to access gender-appropriate support workers in services, in accordance to their cultural/religious practices, and sometimes accordingly refuse services, putting extra pressure on the family. (**Standard 1**)

- The cultural aspects of the individual needs of males and females of some cultures who have a disability are not being met when services are unable to provide a support worker of appropriate gender for them. (**Standard 2**)
- If there are no gender-suitable support workers, an individual of some cultures isn't able to make 'real' choices about services, and sometimes needs to make the difficult and unsettling decision to disregard their cultural/religious practices in order to meet their support needs, or to forego that support altogether. (**Standard 3**)
- CaLD people with a disability who need to compromise their religious/cultural beliefs and utilize a support worker from the opposite gender tend to feel they have lost their privacy and cultural dignity especially if that support worker needs to attend to their daily hygiene needs. (**Standard 4**)
- Similarly, in that situation they feel that they have no valued status to the service or to the wider society providing that service. (**Standard 6**)
- Policies and practices of all agencies should include commitment to gender equality, that this include the gender respect practices of different cultures in all aspects of service provision, and that staff training in cultural competence includes such (**Standard 8**)
- Worse, it can be felt not only as inadvertent cultural neglect, but also as cultural abuse when and if it is raised as an issue and the person is obliged to accept the service provided in a gender-inappropriate way or to forego the service. (**Standard 9**)

7 Recommendations

The aim and purpose of the Project was to engage CaLD consumers, family/carers and ethnic communities together with disability service providers, around their main issues of concern, to explore ways of working together to implement the Disability Services Standards in culturally appropriate ways within the guidelines of the Disability Services Standards – i.e. toward best practice solutions for disability services for CaLD people.

Whereas mutual awareness-raising regarding the Standards, and their implementation in culturally appropriate ways, was the Project aim, the constructive approach that was adopted motivated participants to also appreciate the importance of the wider context.

Consequently both consumers and service providers became aware that for their mutual efforts to begin to bear fruit at the level of service delivery they also needed to develop constructive recommendations and expectations for improvements all levels that would support and enable this.

Overall Recommendations

From the experiences of both consumers and service providers, across all Workshops, it was clear that;

Firstly, there is a need to raise awareness, of **both** ethnic communities and disability services and others, on the lived experience and issues of CaLD people with disabilities, and also, that of their families/carers.

Secondly, importantly this needs to continue to be done within the development of a better awareness and understanding of the basic human rights to substantive equality of CaLD people with disabilities, and this be explicitly informed by current disability and multicultural policy and legislation.

Thirdly, this must be enabled to be implemented in demonstrable and accountable/monitored ways into actual practice, at all levels, within awareness of the Disability Service Standards and guided by consumer experience as expressed in the *CaLD Perspectives on the Disability Services Standards*.

Fourthly, to achieve that, CaLD people with disability must be engaged and resourced to provide the leadership, management and development and delivery of all services to CaLD people with disability - at all levels, from legislation and policy through to practice.

The new UN Convention on the Rights of People with a Disability, to which Australia is a signatory, now becomes related to our Disability Services Standards (WA) developed under our Federal and State Disability Services Act legislation, since recently 'human rights' was added as our new Standard 9 (Protection of Human Rights and Freedom from Abuse and Neglect).

Funded by DSC to do so, EDAC has been active in promotion of the new Standard 9, integrated within the overall Disability Services Standards, within CaLD communities and in developing cultural guidelines for its implementation by service providers with CaLD consumers and their family carers and ethnic communities.

Opening the *EthnicAbility* broadcast series on the Workshops by setting the context and overall framework as 'human rights', was also consistent with and promoting EDAC's recommendations that:

- 'human rights' be relocated from Standard 9 to be instead an overall principle that governs all aspects of each of the 9 Standards;
- the valued and active inclusion of CaLD people with disabilities be encouraged as a matter of their basic human rights to be involved in decision making and choice in all matters affecting the quality of their lives;

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- that additionally the existing guiding principle of ‘individual human rights’ be extended in explicit practice provisions in all matters to respect, engage and support the cultural and care roles of CaLD families and communities;
- that people with disabilities are supported to direct and manage disability matters at all levels in government and all services;
- that within this, CaLD people with disabilities are supported to direct and manage CaLD disability matters at all levels in government and all services (with the same applying to Aboriginal people with disabilities);
- that to enable such quality of life outcomes, effective inclusion and leadership, the principle of substantive equality be applied to resourcing and capacity building through active and accountable strategic planning for progressive change.

(EDAC submissions to the Disability Sector Health Check, Review of the Disability Services Act (WA) and to the Disability Services Commission 2025 Futures Plan).

These recommendations derive from over a decade of engagement in CaLD disability matters by EDAC as their peak body in WA, representing and promoting their interests and concerns at all levels through its systemic advocacy. Each of the above was further substantiated by the nature of the issues and solutions discussed and progressed during the Workshop series and accordingly form the main recommendations from this Project.

The Workshops have contributed to the beginnings of the journey out of dependent client status for people with disabilities, and especially for those from CaLD backgrounds. The positive ‘coming out’ has been encouraging especially in view of the fact that, as the Workshops identified, those from CaLD backgrounds who come to Australia, especially as refugees from war-torn countries and others still or newly emerging from colonial and local oppression, tend to be fearful or apprehensive to even access services let alone make complaints or seek inclusion to contribute constructively to improvements to better meet their needs. Taking back an element of control in their own lives and a sense of shared responsibility in service development and delivery, is clearly the critical element in successfully ‘closing the gap’ in service access, contributing to which has been the main objective of this Project.

Supplementary recommendations

At a different level, a number of more specific matters came to attention during the consultations in planning the Workshops, and also then in the Workshops themselves, that were considered as warranting consideration by the Commission to support the commitment of consumers and service providers in working together towards progress in addressing matters affecting the overall issue of the low service uptake for CaLD people with disabilities.

Supplementary recommendations arising from planning and consultation:

1. Provide disability awareness training for new migrants in Perth southern districts.

The Local Area Coordinators within the Mandurah area identified a current concern regarding the absence of people from a CaLD background accessing their services, even though there is both a large developed ethnic community in Mandurah and also an increase in new migrants.

Some of the disability service providers mentioned that Mandurah has become one of the preferred options to locate new migrant communities but their isolation had caused them to become more focused on addressing their basic needs while adapting to Australian society, with disability issues less of an urgent priority. They also mentioned that due to the absence of settlement services within that area there had been an increase in family violence cases.

They felt there needs to be a considerable program of building community contacts and promotions, which is beyond the scope of this current project. However, general disability awareness training, regarding support services and lifelong positive prospects for a person with a disability, is needed in the area to encourage CaLD people with disabilities in those communities to begin accessing support. EDAC has previously identified that cultural stigma and exclusion associated with people with a disability in some ethnic communities tends to discourage them and their family/carers from obtaining appropriate support for their disability. This issue was again raised during several of the other workshops.

2. Seek to improve the cultural responsiveness of disability services to CaLD people with mental health issues.

This was a persistent issue of concern arising not only in pre-Workshop consultations but also throughout the Workshops themselves.

The Commission is encouraged, in partnership with the Division of Mental Health, to investigate the nature of this matter and to consider developing and providing appropriate capacity-building training to enhance the cultural competencies of disability services staff at all levels and across all areas to address the difficulties they are experiencing in the provision of services to CaLD people with mental health issues and so help those clients receive disability support services in an appropriate, effective and supportive manner.

EDAC is currently commencing such a Project for its individual advocacy staff and its CaLD consumers who have mental health issues. The outcomes may prove informative for a sector-wide approach that both providers and consumers have raised as necessary and currently feel is a priority.

3. Encourage agencies to include an client's cultural and religious background in databases, along with language(s) and country of birth.

One of the biggest issues presented at the workshop was consumers not having access to information and events that were relevant to their cultural or religious background. This concern was identified during advertising the workshops where LACs and other DSC funded organisations were unable to identify and so contact potential CaLD consumers who would have been interested to attend the workshop. (Contrary to Standard 1: Access).

Not asking for and including an person's cultural and/or religious background within the database of services has the tendency to portray to consumers that their cultural/religious background has no value or significance within the service they are receiving from DSC and DSC funded organisations, (Contrary to Standard 6: Valued Status).

4. Utilize ethnic community resources to disseminate information on disability services and on activities

This issue was a common concern raised during the Workshops. Participants mentioned they rarely get information about upcoming events for a person with a disability or information regarding the services they can access for support. They commented that this is especially so if the individual requires interpreters/translators. This has caused a number of individuals to miss out on opportunities of disability support and can be contributing to the low CaLD consumer involvement rates.

Some of the participants commented that they spend more time within their local ethnic community than in the general Australian community because of their lack of English skills. They would be more likely to access information if made available there. These local community resources include ethnic businesses and community centres, and utilizing ethnic radio and newspapers as they have people who can translate some of the information for their community.

5. Disability Services Standards be incorporated and monitored with all Disability Access and Inclusion Plans (DAIP) for government services and promoted widely for all other services to people with disability.

During these Workshops many individuals had difficulty in separating disability service providers and the more general service providers. In particular many had problems with distinguishing which services were funded by DSC, especially as some organisations (also) obtain funding from outside DSC to support a person with a disability, such as local government programs or health professionals. This directly affected consumer expectations and understanding of the entitlement and enforceability of their rights under the Standards.

Responses from some of the participants showed that some other government service providers are not appropriately valuing or responding to the needs of a

person with a disability, which has caused some participants to feel that their disability is only valued within the confines of DSC funded services. They expressed concern that this continues to confuse CaLD consumers regarding their rights. Also they were concerned about the absence of uniform enforceable standards within other (non-DSC funded) government agencies, their unsatisfactory experience with whom tends to reinforce the current negative perception and non-valuing of people with disability found in some ethnic communities themselves.

It has been suggested that if all government agencies were to include the Disability Services Standards within or along with their DAIP it would enable consumers to have a more concrete understanding of their rights and feel better equipped in self-advocating their disability rights within non-DSC funded government agencies. They suggested that the Disability Services Standards be provided in a generic form for all service providers dealing with people with a disability, such as, in particular, promulgated widely within the Health Department, Education Department, Homeswest and Centrelink, and that this necessarily be accompanied by a positively culture-friendly version/presentation.

Finally, participants suggested that this should also be provided and promoted widely by DSC through all sections of the community and private enterprise, showing leadership with a view to helping society develop a positive 'culture-change' generally toward people with disabilities and their rights to inclusion and full participation in citizenship, and especially so for CaLD people and their families/carers.

Supplementary recommendations arising from the Workshops:

6. Provide ongoing training on cultural/disability awareness and accountable implementation of the cultural guidelines for the Disability Services Standards – to all DSC funded services, and extend to other government services, community organisations and ethnic communities

The feedback from the Workshops showed that people from an ethnic background with a disability have a number of difficulties also accessing services outside those that are DSC-funded. They are feeling that their cultural or religious practices are not respected or supported, which then causes them to feel degraded, intensifying their lack of self-confidence because of their disability, especially if they come from an ethnic background that has a negative perception of disability.

Cultural and/or disability awareness training can help to reduce these barriers for CaLD people with disabilities and their family carers, enabling them to feel they belong and are valued by both the general Australian society and their ethnic community.

7. Encourage and support services to incorporate funds for professional interpreting and translating services within funding applications and provisions

Throughout the project participants identified the limited availability of information translated into their primary language as being the biggest barrier for them to access services. This is especially important for family carers and people with a disability with limited English skills. Agencies report limited funding to get their material translated into the main ethnic community languages.

This applies also to projects seeking to engage CaLD consumers, carers and communities. Fortunately this Project had the support from many qualified individuals from a number of CaLD backgrounds who were willing to assist with translating information at a minimum cost. Their support was greatly appreciated by EDAC, but this isn't a sustainable option for EDAC or other agencies, particularly those who may at the moment be considering initiatives resulting from these Workshops and their continuing engagement with CaLD consumers will require effective dissemination of their promotional and outcomes information within ethnic communities.

Information needs to be available in languages relevant to consumer needs. Funding applications need to ensure they incorporate the costs of obtaining professional translation of basic information for consumers and this element needs to be recognised and accepted as essential by funding bodies.

The same concern applies to funding for interpreters. CaLD consumers report experiencing reluctance by service providers to engage the services of professional interpreters. Inadequate level of funding is frequently given as a reason.

8. Encourage and resource service providers to undertake training on how to access and work with interpreters and translation services

Again, many respondents at the Workshops voiced their concern about service providers not valuing or appreciating the need for individuals to obtain interpreter/translator support. This has caused CaLD consumers and carers to have a limited understanding of the support they were accessing and how this service would meet their needs.

It was also found during this Project that some service providers felt uncomfortable using interpreting and translating services due to their lack of experience. If practical training was made available to service providers regarding using translators/interpreters, they would have more confidence and less hesitation in using the service and there would be more services actively working towards meeting the linguistic needs of consumers.

9. Encourage services to include family members in decision making processes.

In some cultural practices all family members discuss an issue and consult with the head of the family before decisions are made. This decision making process enables the whole family to feel valued and included if changes are made, and prevents further conflict and distrust from family members.

However, some service providers are having difficulty understanding and/or respecting this practice and tend to focus only on the rights of a person with a disability and not also considering the responsibilities of the family carer and authority of the head of family. Services need to ensure they find out if an individual with a disability has traditional ways that decisions are made in their family and engage with this process to assist the individual with making a decision. This may involve encouraging the individual talk to their family before a decision is made, consulting with the family to determine their concerns about a decision, and supporting the individual and family to find resolution of those concerns before a decision is made.

Although individual rights remain paramount, participants felt that there is often room for respect and negotiation with others in cultural roles of responsibility toward clients.

10. Provide social support for CaLD people with disabilities, especially adults, and in particular assist CaLD communities to provide social support services.

During the schooling years a person with a disability has opportunities to access social support within their school environment (at the least), but these are limited outside school, especially in their cultural community, and also once they leave the school system as adults.

The social support that is available in view of their disabilities isn't always appropriate for CaLD people in terms of meeting their cultural/religious needs, limiting their active and valued participation and inclusion in both their ethnic community and the wider society.

Improved social support is necessary for CaLD people with disabilities to engage effectively in the general community in culturally appropriate ways, especially for adults.

It has also been suggested that ethnic communities be supported to become funded providers of social support services, such as Alternatives to Employment - by working closely with these ethnic communities to assist them with funding applications and the initial establishment of their service.

11. Provide standardized information on temporary resident's disability service rights and alternative options to access services.

Temporary residents may come to Australia with a healthy family member who acquires a disability in Australia, or may enter Australia with the prior knowledge that a family member will need extra disability support services while in Australia. These temporary residents enter Australia with full knowledge that they will be required to pay for these support services and are informed that the Australian services will be able to provide them with appropriate support.

Once in Australia however, they find they are provided conflicting information by service providers regarding their rights to service access, what they are expected to pay, and who they can make complaints to if they are having difficulty accessing services.

There is a need for this information to be standardised, translated into the main ethnic community languages, made available as part of entry pre-application information, and be available from all disability support services here.

12. Provide for migration of carers for CaLD families.

To enable culturally supportive disability care, the government be encouraged to approve migration of extended family or local community members as carers for CaLD people with disabilities – to ease the stress on families who culturally do not wish to access mainstream carer services or accommodation for their child/adult with disability care needs.

13. Encourage all Local Area coordinators to work especially closely and proactively with independent/private ethnic-specific schools.

The project identified the close relationships that CaLD parents form with schools regarding support for their child with a disability. They view the school as their prime connection to their ethnic and/or local community and see the school as the main resource supporting their child with a disability.

A number of Local Area Coordinators have developed strong relations with government schools where the staff have a good understanding of the role of LAC's and DSC. However the background consultations during this Project showed little progress has been made with some culture-based independent schools, as staff were unaware that DSC existed and what support services the Commission could provide for a student with a disability. This has caused many CaLD students to miss out on appropriate support, especially if there tends not to be the culture of valuing disability and promoting disability rights in their ethnic community.

It would help to diminish the current shortfall of CaLD people with disabilities accessing support services if LAC's were to establish close relationships with ethnic independent schools. Especially, to inform school staff about the types of services students can receive outside the education system, and also to ensure

the school felt they could approach the LAC if they had concerns regarding where a parent could go to get appropriate support for their child. There is a need to help parents assist and plan for their child with a disability to have a future outside the education system.

14. Encourage services to provide and allocate support by staff suitable as necessary to each CaLD person's gender

Individuals with a disability need to feel their cultural beliefs are respected and taken into consideration when accessing all types of services. One area that has caused great concern has been the unavailability of gender-appropriate staff or the service providers simply not being aware of the need to take into consideration the individual's cultural gender-related prohibitions when providing support. Services need to be encouraged to ensure they have both male and female staff available to support consumers and obtain feedback from the consumer about any cultural considerations regarding interacting with people from a different gender and ensure they work towards meeting those needs.

8 References

EDAC submission to the *Carers Recognition Act 2008*.

EDAC submission to the *Disability Sector Health Check 2006*.

EDAC submission to the Disability Services Commission *2025 Futures Plan*.

EDAC submission to the *Review of the Disability Services Act (WA)*.

Let Me Speak: Self-advocacy training for people with disabilities who are from culturally and linguistically diverse backgrounds. 2005 EDAC.

Supporting CaLD Carers 2003 EDAC.

9 Appendices

Appendix A: Evaluation Form

Appendix B: Training Package (including program outline)

Appendix C: Sample Flyer

Appendix D: Workshop photos

Appendix E: Translation and Narration of Summary Issues

Appendix A: Evaluation form

The Ethnic Disability Advocacy Centre (EDAC) would like to thank you in advance for completing this form.

Please feel free to make comments and suggestions. Your constructive criticism of the good and bad aspects of this workshop will help us improve future workshops.

1. What were you hoping to get out of this workshop? _____

2. Did the workshop meet your expectations? Yes No

Comments _____

3. Did you learn anything new at this workshop? Yes No

If yes, what did you learn? _____

4. Was the workshop well presented? Yes No

Comments _____

5. Were the presenters well informed about the topics covered? Yes No

Comments _____

6. What did you like most about the course? _____

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7. What did you like least about this workshop? _____

8. Can you suggest ways to improve future workshops? _____

9. Would you recommend the workshop to others? Yes No

Comments? _____

10. Any other general comments? _____

Appendix B: Training package (including program outline)

(not available)

Appendix C: Sample flyer

PEOPLE WITH AUTISM (*and/or your family carers*) FROM AN ETHNIC BACKGROUND HAVE YOUR SAY!



People with a disability from an ethnic background, your family and friends, are valued contributory members of the Australian community, who have important things to say about your experiences in obtaining the right support and appropriate services.

The Ethnic Disability Advocacy Centre (EDAC) will be holding a workshop that focuses on your rights and obligations to ensure that people with a disability and those that play significant roles in their lives receive services in a culturally appropriate manner.

The benefits of attending this workshop include:

- An opportunity to have your say in a confidential and safe environment about services you receive
- A chance to meet other agencies to assist with participating in community activities
- Making friends with others in a similar situation



When: Monday 12th May
Time: 10:00am – 2:30 pm
Where: Bassendean Memorial Library (Room 1)
46 Old Perth Road
Bassendean

LUNCH SHALL BE PROVIDED ON THE DAY

A small transport subsidy available upon request

Outcomes from the workshop will be explored on EDAC's radio program EthnicAbility, which airs every Tuesday, 11:30-noon (95.3 6EBA FM World Radio)

PLACES ARE LIMITED SO BOOK IN EARLY. **RSVP by 2nd May 2008**

More information or to register, contact: Maranda Ali on 9388 7455 or email maranda@edac.org.au



Supported by: Autism Association & Intework



EDAC
Ethnic Disability Advocacy Centre

Intework

Funded by the Disability Services Commission

Appendix D: Workshop Photos

(not available)

Appendix E: Translation and Narration of Summary of Issues - as raised from the workshops.

Experiences and rights of people from cultural and linguistically diverse communities accessing disability services

People who access services funded by the Disability Services Commission (DSC) are protected by the Disability Services Standards, a total of 9 standards which ensure that a person with a disability and their family/carers receive the best quality support from an agency.

Agencies also need to ensure that people from an ethnic background are able to feel they are obtaining the best quality support by ensuring a person's language, cultural and religious practices are considered in their service delivery as proposed by the 9 disability services standards.

The Ethnic Disability Advocacy Centre (EDAC) is an agency that works towards ensuring the rights of people from a Cultural and Linguistically Diverse (CaLD) background are protected. EDAC recognizes that a person from a CaLD background with a disability can only feel like a valued Australian citizen when an agency respects and responds to an individual's linguistic, cultural, religious and disability needs.

EDAC ran a number of workshops on disability awareness, related services and obtaining feedback from consumers and their families about their experiences in using services in relation to the rights provision contained within the Disability Service Standards. A total of ten workshops were held in Mirrabooka, Gosnells, Bassendean and Subiaco during 2007 and 2008. Each workshop had a specific topic that enabled the project to interact with various cultural and disability groups such as Cerebral Palsy, Autism, intellectual disabilities, developmental disabilities, accommodation support services, women with disabilities, Muslim and Vietnamese communities.

At these workshops, people with a disability, their families, carers and community leaders from CaLD backgrounds indicated there was a lack of understanding and consideration of their cultural beliefs and practices. Service providers generally were not aware and/or responsive to the cultural or religious needs of people from CaLD background even though all of the standards profess to enable people with a disability their families and carers to be actively included in service provision processes.

Examples of how services need to improve and how they uphold the standards to enable more inclusive CaLD participation and better CaLD services are illustrated below:

Standard 1 Service Access

In Standard 1 of the Disability Services Standards, agencies are required to ensure individuals understand how they can qualify for a service, how long they may need to wait for a service and what other options may be available. It also requires the agency to provide appropriate resources that inform CaLD people with English difficulties about the

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services available to ensure they understand the eligibility criteria for accessing these services. Such resources should include provision of interpreters and materials relevant to the client's language and cultural background.

Some problems identified at the workshops included a lack of awareness of the services available and the processes involved in accessing these services among people from CaLD backgrounds with limited English. For example, a mother of a young child with a disability indicated she had been waiting for seven months for an agency to provide a service and that she was beginning to give up on the belief that anyone was interested in helping her. The individual reported that the agency hadn't provided her with an interpreter when she first applied for the service and was therefore unable to understand that she was placed on the agency's waiting list.

In addition, some cultures are shy to ask for help from agencies, they are grateful for what ever small help they receive and may perceive that asking for help too often may cause people to feel they are being ungrateful. Agencies need to ensure that individuals from a CaLD background understand what service an individual can obtain from the agency and that if they have similar problems in the future that they are welcome to ask for assistance. This was found to be the case for one workshop participant who mentioned they had received the service from their Local Area Coordinator a few years prior and felt they wouldn't be welcomed to ask for assistance for their current concern. A few participants who have temporary residency visas indicated that they were unable to access services even though they were willing to pay. Agencies should aim at assisting the individual find a service that is appropriate to their needs, should they not meet the eligibility criteria for that particular service.

Standard 2 - Individual needs

One of the most disempowering feelings for people from a CaLD background is the feeling of loneliness and isolation from the traditional support of family members and social systems found in their country of origin. This can lead to depression, lack of confidence and feelings of reduced opportunities to interact within the Australian society.

A number of participants indicated a lack of opportunities for individuals with disabilities and their carers to access social support that is appropriate to their cultural or religious belief systems. They were fearful that by accessing social support outside their specific community the individual with a disability may be engaging in actions that are forbidden to their cultural/religious practices; such as eating non permissible food, or being in an environment that is deemed inappropriate for men and women to interact. The absence of a cultural appropriate environment could result in people from an ethnic background with disability being socially isolated and devalued as Australian citizens. When agencies address the individual needs (Standard 2) of their consumers from ethnic backgrounds the agency needs to ensure their services are adequate and flexible enough to include an individual's financial, physical, emotional, cultural, language, religious and social needs.

Standard 3 - Decision making and choice

Frequently, people with a disability from a CaLD background are members of family units where every family member has a specific role. These roles stem from strong religious or

cultural traditions and create a hierarchical system where decisions are made by the head of the family through family consultation. Upholding these family structures in some cultures is seen as the building blocks that support and enable an individual with a disability to lead a productive life.

Within the workshop, it was identified that agencies have difficulties recognising these family structures and involving them in the decision making process. Decisions made without appropriate consultations created tensions within the individual's family such as family members feeling that the person with a disability had relinquished their cultural identity and values and each family member being perceived as an insignificant contributor to upholding the needs of the person with a disability.

Agencies tend to believe they are upholding standard 3 when they provide a range of choices that enable the person with a disability make an independent decision, this is correct in its basic form but become impractical for individuals who are members of close knit families where decisions are made in a collective manner. Agencies need to ensure they are upholding cultural values of families by respecting and supporting the cultural process of consulting family members before decisions are made.

Standard 4 - Privacy, Dignity and Confidentiality

One service provider relayed an incident where an interpreter was provided for a client who had different cultural beliefs from the client and had initiated an argument that criticized these beliefs. The client felt that their cultural beliefs were not valued and doubted the interpreter's ability to maintain confidentiality about the issues that had been discussed. This incident raises the importance for agencies to ensure that people they bring in to assist an individual are adequately trained and informed about the need to reassure the individual that the information obtained will be kept in confidentiality. Agencies should also ensure that their employees and contracting agencies such as interpreters values the idea that all individuals need to feel their cultural beliefs are respected regardless of their personal feelings.

Standard 5 - Participation and Integration

Standard 5 states that *each person with a disability is supported and encouraged to participate and be involved in the life of the community*. This standard recognises that a person regardless of their ethnic background should have opportunities to participate in the activities and everyday events in the community. The community must be one that they identify with whether it is ethnic, religious, mainstream Australian or a combination of these communities.

A number of the participants commented on feeling isolated, lack of confidence and loneliness due to limited opportunities of participating in community events. One of the participants commented on how agency staff assumed that the only community she could identify with was her ethnic community. The staff had no understanding of how her ethnic community would support and value the inclusion of people with a disability. This response by the agency had caused her to feel devalued and that both the Australian society and her ethnic community did not see the importance of providing opportunities for her to be involved in community events and activities.

PROMOTING THE DISABILITY SERVICES STANDARDS

Agencies need to recognise that clients may identify with different communities that may have traditional ways on how they interact, value and involve people with disabilities. It is the responsibility of the agency to work with a person with a disability from a CaLD background to find out what communities they identify with and how that community provides support for a person with a disability. The agency should then begin providing support, encouragement and information on ways to enable that individual to participate in that community.

Standard 6 - Valued Status

Some participants felt ridiculed and disrespected by agency staff because of their cultural practices and the way they dress. This caused them to feel their cultural beliefs were devalued and fearful of obtaining support for their disability and interacting with the general Australian community. People from a CaLD background should not feel forced to obtain approval from agencies regarding the way they dress or their cultural practices in order to feel respected and valued members of the Australian community. Agencies that uphold standard 6, will see that each individual, regardless of their disability, religious or cultural beliefs are a valued member of the Australian society.

Standard 7 - Complaints and Disputes

It was also reported at the workshop that some people were fearful and apprehensive about making complaints to agencies regarding the way they received a service. This can be seen from one of the comments at the workshop where a participant reported her experience with an agency's support worker who wasn't listening to her needs and frequently assumed they knew what was best for her. When the client was informed that she could make a complaint, she became concerned about how she would be treated after the complaint was made. Her concerns included; being subjected to further neglect and becoming a target for abuse by the agency. This reaction can be attributed to the way complaints are received from an individual's country of origin, where an individual would be subjected to undue hardship because they made complaints about the way government and agencies were run. This example raises the importance for agencies to be more sensitive to the needs of people from a CaLD background when upholding Standard 7. Agencies should create a welcoming environment where individuals from a CaLD background feel their complaints or concerns are providing positive feedback for an agency to improve its service.

Standard 8 - Service Management

A number of participants were vocal about how they thought services should be run when upholding these standards, but felt they didn't know how to make suggestions to agencies. It was found that clients were not included in consultative processes or welcomed to provide feedback on the services provided. This was found to be partially due to agencies making assumptions that people from an ethnic background lacked interest in being part of the consultative process. In upholding standard 8, service providers should ensure that they provide measures that include clients from an ethnic background in program development, management, review and those that encourage them to provide their cultural perspectives on services and issues. Such measures may involve providing education and training programs and having clients as board and steering committee members.

Standard 9 - Protection of Human Rights and Freedom of Abuse and Neglect.

One participant felt that she was being subjected to indirect racial abuse as the staff of an agency was making judgments on what she was capable of doing because of her ethnic background, they had excluded her from an activity because they perceived it to contravened her cultural beliefs. Agencies have the responsibility of protecting the human rights of the client including their rights to self expression of cultural values, beliefs and practices; they cannot make assumptions or exclude individuals according to the perceived appropriateness of activities according to an individual's culture as each individual may practice their culture differently. Agencies should also enable the individual to be valued as a contributing member of both ethnic and mainstream communities.

Conclusion

The Disability Services Standards is a framework that assists people with disabilities, their families/carers and service providers to collaborate in the development and maintenance of high quality services. All funded disability service providers are expected to be fully compliant with all the standards. In meeting the individual needs and duty of care issues, service providers should always consult consumers and their families about their needs. Their cultural, language, social and religious needs should also be considered. The responsibility is also placed upon consumers to voice their needs and concerns to enable them to obtain the best quality service and feel that their diverse cultural or religious needs are valued and respected. If you feel you have a concern about a Disability funded agency not upholding the standards you can either inform the DSC's Consumer Liaison Officer on 9426 9224 or call EDAC on 9388 7455 to speak to an Individual Advocate.