

SERVICES FOR PEOPLE WITH INTELLECTUAL DISABILITY OF CULTURALLY AND LINGUISTICALLY DIVERSE BACKGROUNDS

by

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Abstract

This study focuses on services for people with intellectual disability and high support needs from culturally and linguistically diverse backgrounds living in a suburban region of south-east Queensland. Previous Australian research about people with intellectual disability from diverse cultural backgrounds has largely occurred in Victoria and has focused on children only. Data in this study were collated through group interviews and individual interviews. Participants in the group interviews were 18 disability workers or ethnic community workers with current or previous experience working with people with intellectual disability and high support needs of culturally and linguistically diverse backgrounds. Supplementary data was obtained through two individual interviews with family carers of culturally and linguistically diverse backgrounds. Interview questions were open-ended and prompted participants to discuss relevant experiences issues and strategies. Five issues emerged from the data. These were classified as isolation, cultural differences, linguistic differences, inter-sectoral links and access. Participants identified a range of personal and organisational strategies that they had successfully utilised in relation to each of these issues. The creation of linkages between the disability and ethnic community services sectors would enable further strategies to be identified and implemented to address this significant service development need and to achieve access and equity for this group of people with disability. The impact on services of small scale exploratory research in a localised area is discussed.

Introduction

It is noted that within Australia, people with intellectual disability and their family carers may experience a range of difficulties in achieving and maintaining access to appropriate support services. These difficulties can include waiting lists for services, negative attitudes towards people with intellectual disability, inaccurate advice, limited service choices, inappropriate service emphases, insufficient practical support and conflicting values between service providers and service recipients (Bruggemann, 1995; Neumayer & Bleasdale, 1996; Parmenter, 1999; Stainton & Besser, 1998). Maligeorgos (1992), Moss (1992), Pane (1993) and Schofield (1990) suggested that, in Australia, having a disability and being from culturally or linguistically diverse backgrounds can be a double disadvantage, as it can exacerbate difficulties accessing appropriate support services. Similar observations are made

in the international disability literature (e.g., Kinebanian & Stomph from the Netherlands, 1992; Lynch, 1992, from the U.S.A.). This current study focuses on people from culturally or linguistically diverse backgrounds with intellectual disability and high support needs.

Fitzgerald, Mullavey-O'Byrne and Clemson (1997, p. 3) define culture as "the learned, shared beliefs, values, attitudes and behaviours that are characteristic of a society or population". They define ethnicity as based on the sharing of a common characteristic that could be physical, linguistic, behavioural, cultural or environmental. In Australia, linguistic diversity refers to languages other than English. A person is from a non-English speaking background if they were born in a country where the principal language is not English (hereon referred to as a non-English speaking country), or if one or both of their parents were born in a non-English speaking country (Fitch, Papanicolaou & Maligeorgos, 1992, p.6).

This study was carried out in the Brisbane South region, which includes the southern suburbs of the city of Brisbane, and the outer suburban local government areas of Redlands and Logan City. This comprises approximately half of the Brisbane Metropolitan area. Brisbane is one of six state capital cities in Australia and has a population of approximately 2 million people. The Brisbane South region includes the highest proportion of people of culturally and linguistically diverse backgrounds in the state of Queensland (Australian Bureau of Statistics, 1997). The aim of the study was to investigate whether services for people with intellectual disability and high support needs in this region are addressing the needs of people of culturally and linguistically backgrounds.

Background

At the 1996 Australian census, 29% of the Australian population (approximately 18 million people) was recorded as being born overseas in a non-English speaking country, or had at least one parent who was born overseas in a non-English speaking country (Australian Bureau of Statistics, 1997, p.41). Accurate statistics on the number of people in Australia of culturally and linguistically diverse background who have intellectual disability do not appear to exist. Reasons for this include lower response rates to population surveys by people of culturally and linguistically diverse backgrounds,

and health and disability screening requirements for prospective immigrants which exclude people with long term illness or disability (Department of Families Youth and Community Care, 1997). For these reasons, the accuracy of the following statistic should be viewed with some caution. The Australian Bureau of Statistics (1993) reported that approximately 14,700 people with a disability living in Queensland do not use English as the main language spoken at home. The proportion of this group who have intellectual disability and high support needs is not known. Through personal and professional experiences, the researchers in the current project were aware that people with intellectual disability from culturally and linguistically diverse backgrounds lived in institutions, group homes and with their families in the Brisbane South region. However no statistics were available in Queensland to identify how many people were living in each of these situations.

Both the Commonwealth Disability Services Act (1986), and the various Australian state disability services acts and anti-discrimination acts, recognise that support services and funding programs should be designed and implemented to meet the needs of people who may experience disadvantages because of their Indigenous or other cultural background, gender or geographic location. However, the Australian Law Reform Commission (1996, p. 136) in its review of Commonwealth disability services, concluded that “strategies to improve access for people of non-English speaking background were inadequate” and that “submissions stated that people of non-English speaking background with disability continued to experience discrimination based on their ethnicity, their religion and their disability”.

One factor contributing to the above concerns may be that the principles of disability service delivery may not be congruent with the values of some cultural groups. For example, the emphasis on independence is a focus of most contemporary disability services in Australia, North America and Europe. However, Kinebanian and Stomph (1992) point out:

In most non-Western societies, such values as being part of the family, accepting other people's decisions, and honouring the family are more important than independence. In many non-Western cultures, dependence is a respectable choice. (p. 752)

Research in an Australian Context

Although Australia has a multicultural society, the “cultural mix” varies from state to state and location to location (Australian Bureau of Statistics, 1997). Articles by workers from state based ethnic disability organisations (Maligeorgos, 1992; Politis, 1992) and some research reports (Pane, 1993; Schofield, 1990; Vellotti, 1997; Westbrook, Legge & Pennay, 1993) have discussed the experiences of people with a range of disabilities of culturally and linguistically diverse backgrounds in southern states of Australia. These indicated that issues of access to culturally appropriate services are relevant

to people with a range of disabilities in Australia, but did not focus on experiences of people with intellectual disability. However, three Australian research reports focusing on people with intellectual disability of culturally and linguistically diverse backgrounds were located (Action on Disabilities within Ethnic Communities, 1995; Fitch, 1989 & 1991). All three only investigated children and all were undertaken and self-published by one Victorian multicultural disability advocacy organisation. Agency workers and family members participated in these projects. Consistent findings included that some children with intellectual disability of non-English speaking background and their families: often lacked information about services available to them, and under-utilised these services; often perceived services as unresponsive to their needs and cultural differences; sometimes had different understandings of the terms “disability”, “delayed” and “intellectual disability”; and sometimes perceived disability issues as low priority compared with, for example, housing and employment. In addition, intellectual disability is often identified later in children of non-English speaking background. The “stigma” of having a family member with an intellectual disability sometimes prevented family members from seeking advice and help. Although there are commonalities (e.g., lack of responsiveness to personal needs and values), these issues vary from those identified for people with intellectual disability from Anglo-Australian backgrounds which are identified at the beginning of this paper (Bruggemann, 1995; Neumayer & Bleasdale, 1996; Parmenter, 1999; Stainton & Besser, 1998).

From the service provider point of view, Fitch (1991) found that many of the intellectual disability workers considered working with children of non-English speaking background as expensive, and felt that providing other services were higher priorities. Other workers stated that their service was there for all to use, but were unaware how difficult access to their service was for people of diverse cultural and linguistic backgrounds. Velotti (1997) noted that disability workers sometimes made the inaccurate assumption that people with disabilities from “ethnic communities” had extended families for support. In addition, Westbrook et al. (1993), found that intellectual disability was one of four “least accepted disabilities” among health practitioners from a range of cultural backgrounds (including Chinese, Italian, German, Greek, Arabic and Anglo Australians). Therefore strategies for providing culturally appropriate services may need to focus on both people with intellectual disability and their families, and disability workers. More research using this consultative and action based approach, (such as those used by Action on Disabilities within Ethnic Communities, 1995, and Fitch, 1989 & 1991), in other locations and across the age span, is needed.

Strategies for addressing cultural issues

A range of strategies for addressing cultural and linguistic issues within disability services are identified in the literature.

Germanos-Koutsounadis (1990) and Fitch et al. (1992) suggested that disability services need to consult with ethnic communities in relation to developing policies and organisation-wide strategies to facilitate service delivery for people of non-English speaking background. The importance of health and disability workers developing cross-cultural skills, including an understanding of their own values and beliefs is frequently recommended in the literature (e.g., Kinnebanian & Stomph, 1992; Lynch, 1992; Morse, 1987; Phipps, 1995). Schofield (1990) suggested the employment of bilingual or bicultural staff and the provision of multilingual information. Fitch et al. (1992) included all of the above strategies in an access model which included objectives about: service location; needs assessment; access to information; internal information systems; culturally appropriate services; staff training and recruitment practices; and service development processes. Papanicolaou (1994) found variations in the willingness and ability of disability organisations to implement this access model. This was the only research found which addressed the implementation of strategies.

Taking into consideration the limited scope of Australian research into people with intellectual disability from culturally and linguistically diverse backgrounds, the questions asked in this research were:

- are the above issues and strategies relating to service provision relevant for people with intellectual disability and high support needs of culturally and linguistically diverse backgrounds across the age span and in another geographical location?
- are there other issues and strategies that are specific to this group of people?

Method

An advisory group, comprising four representatives of community based ethnic disability and health services and one representative from a disability service, guided the research project. People with intellectual disability and high support needs often have very limited communication and independence skills and are therefore at particular risk of experiencing difficulties in accessing services, which is why they are the focus of this study. Communication limitations result in them relying on family members and service providers to make substitute decisions about accessing support services. In relation to research about quality of life for people with disability, Timmons and Brown (1997) suggested that although not ideal as a data source, the perceptions of professional and family members are relevant, particularly when the people with disability are “language disabled” (p. 186). Similarly in this study, due to communication barriers, it was not possible to involve people with intellectual disability and high support needs directly as participants, however their experiences were explored through service providers and family members. Group interviews were the primary data collection method. These interviews were similar to focus groups, but were more flexible in relation to numbers of participants, and participants

knowing each other (Krueger, 1994). However they shared the advantages of focus groups in that they “encourage discussion and a greater variety of communication than is often found in other forms of data collection” (Phan & Fitzgerald, 1996, p.13).

Group interviews

As workers’ experiences often involve contact with a number of people with disability and a range of services, and because workers are often in a position to assist people with disabilities and their families, the primary source of data for this research was disability and ethnic community workers. All disability and ethnic community services in the region covered by the study (N=28), were identified. Letters were sent to each which explained the project and invited a representative from each service to a group interview. The participant selection criterion for these representatives was workers who had current or previous experience working with people with intellectual disability and high support needs of culturally and linguistically diverse backgrounds. This participant recruitment procedure combined purposeful, opportunistic and self-selection sampling (Patton, 1990). It was decided that disability workers and ethnic community workers would have different but complementary experiences and that it was important to involve both groups as participants. Due to differences in funding arrangements and organisational processes (for example the non-government services are funded by the government services), government and non-government disability workers were interviewed separately. Three group interviews were undertaken. The first was with three workers from non-government disability services. A further 3 workers had arranged to attend, but were detained at short notice. They were sent a copy of the group interview summary for comment and all agreed that the content reflected their own experiences. The second group interview was with 10 workers from community based ethnic services. The third group interview was with five disability workers from government disability agencies. In total, 12 women and 6 men participated in group interviews. Nine of the 18 participants were from culturally diverse backgrounds. Interview questions were open-ended and prompted participants to discuss relevant experiences, issues and strategies (see Appendix for group interview question schedule). Towards the end of each group interview participants were given a summary of Fitch et al.’s (1992) access model and were asked questions about its relevance to the local context.

Individual interviews

To gain data about family experiences, all group interview participants were asked to identify family carers willing to be approached for an individual interview. This participant recruitment procedure combined purposeful and opportunistic sampling (Patton, 1990). Group interview participants from either sector had difficulty identifying families who were not experiencing stress or crisis and who would therefore be willing to participate. Therefore, only two individual interviews

undertaken with family carers of a person with intellectual disability of culturally and linguistically diverse background. These interviews were regarded as supplementary data. They were not intended to represent the range of family experiences, but to gain some understanding of whether their individual experiences were consistent with the perspectives of the ethnic community and disability workers. One carer came from a Middle Eastern country and the other came from a European country. One interview involved a professional interpreter, the other did not. The interview questions (see Appendix) were adapted from a manual on community health needs assessments with culturally diverse communities (Larson, van Kooten-Prasad, Frkovic & Manderson, 1998).

Data analysis

The data sources (whiteboard summaries and transcripts of the three group interviews and two individual interviews) were initially categorised according to participants' experiences, issues, and strategies. Thematic analysis of these categories involved the identification of key points, and converging and diverging statements, which enabled patterns within the data to be identified (Patton, 1990). Five issues were identified, which incorporated the range of experiences, opinions, and strategies that participants had described and suggested. Each issue was summarised and sample quotes were collated from transcripts. Consensus was achieved between the two researchers at each step in the analysis process. Although the number of participants was relatively small, there was a high degree of consistency in the issues raised and strategies suggested. This consistency was later confirmed through the checks outlined below.

Rigour

One of the researchers, who is from a culturally diverse background, and who has extensive group facilitation and interview experience, facilitated all of the group interviews and undertook both of the individual interviews. A white-board was used at each group interview to record in summary the experiences, issues and strategies being discussed. A column format was used to classify comments into experiences, issues and strategies (e.g., see Table 1). Apparent links within and between columns were identified. This information was checked and clarified with participants for accuracy and consensus during each group interview. In addition, interviews were audiotaped and detailed notes were made during the interviews by the co-facilitator (the other researcher). Summaries of each group interview and the analysed discussion of the data from across the group and individual interviews, were sent to 10 participants for review and verification for further accuracy checks and comments. These participants volunteered at the group interviews to undertake this task. Eight responses were received. All respondents confirmed that the summaries and discussion of issues and strategies accurately reflected the group interviews in which they participated. Three changes, relating to anonymity and emphasis were

requested and made. Colleague checks involving the five Advisory Group members affirmed the issues and strategies identified. A forum was organised as an opportunity for feedback on a draft report of the study, networking and forward planning. Invitations were sent to all participants and all of the disability and ethnic services identified at the beginning of the study. Thirty-five participants and other interested people attended this forum, many of whom were from a culturally diverse backgrounds. All forum participants in attendance concurred with the issues and strategies identified in the study and three additional strategies were identified by forum participants.

Results and Discussion

This section will summarise, compare and contrast data from the group interviews, individual interviews and literature. Examples and participant quotations are included to increase the depth of the summaries (Patton, 1990). Five issues were identified and participants' experiences and strategies are presented in relation to each. These five issues were consistently identified in the group and individual interviews. Participants identified a range of personal and organisational strategies which they had successfully utilised in relation to each of these issues. Through the participant checking processes outlined above, consensus about the appropriateness of these strategies was indicated.

Isolation

All group interview participants agreed that many people with intellectual disability of non-English speaking background and their family carers are isolated from their wider (Anglo-Australian) community in the region of the study. Some disability workers queried whether families who are not receiving mainstream disability services are receiving support through their extended family or ethnic community. However, similarly to Velotti (1997), other disability workers and the ethnic workers suggested that this type of support was rare. Ethnic workers reported that individuals with intellectual disability are sometimes 'identified' when families come to the attention of ethnic workers for other reasons. For example, one ethnic service worker outlined a situation in which a 35 year old woman with physical and intellectual disability had lived in a room in her family home for many years. This woman's situation had come to the attention of an ethnic support service when her mother became a client of the support service for health related reasons.

Neither of the carers who were interviewed had an extended family to rely upon for additional support and assistance and both appeared to be isolated from their local community, but for different reasons. One carer, a widow, spoke about the difficulty of always having to be available to support her son and not having the opportunity to have an extended break. The other carer expressed great concerns about the local community, which was perceived to have a high crime rate. Social contact for this family only took place in the context of their ethnic/religious community.

**Table 1. Example of information recorded on white board at group interview
(with workers from non-government disability services).**

Experiences	Underlying Issues	Possible Strategies
Difficulty matching workers of the same cultural background, if there are a number of clients from diverse backgrounds.	<ul style="list-style-type: none"> • Management and funding 	<ul style="list-style-type: none"> • Match where possible • Family given funds to hire own worker
Some NESB families are unaware of disability services	<ul style="list-style-type: none"> • Lack of communication about services eg. via medical services and schools (this is a general problem, not just for NESB families) • Cross referral between disability and NESB organisations not happening 	<ul style="list-style-type: none"> • Find out about NESB organisations • There are pockets of “good practice” – we need to share this
NESB families may not understand or accept communications	<ul style="list-style-type: none"> • Lack of trust or service credibility 	<ul style="list-style-type: none"> • Requires long term work
NESB families don’t speak English	<ul style="list-style-type: none"> • Communication 	<ul style="list-style-type: none"> • Use interpreters (but it is expensive) • Hiring bilingual workers • Family hires worker from own community network • Translate paperwork eg. service agreement (but it is expensive)
NESB family attitude to people with intellectual disabilities	<ul style="list-style-type: none"> • Shame, stigma 	<ul style="list-style-type: none"> • Long term process – needs future planning and case management • Find out info about cultural attitudes to reduce guessing
NESB family expectations and dreams are very different	<ul style="list-style-type: none"> • Cultural differences in values – eg. independence is not valued in all cultures 	<ul style="list-style-type: none"> • Activities sampling • Gradual introduction • Broker to another organisation ie. fund an ethno-specific service
Untrained bilingual disability workers	<ul style="list-style-type: none"> • Need for training • Poor communication between managers and bilingual workers – lack of trust between them 	<ul style="list-style-type: none"> • Finding bilingual workers with welfare or community work training • Conduct training
NESB clients “appear” when older carers experience a crisis	<ul style="list-style-type: none"> • Isolation – lack of early access to services and lack of forward planning 	
Anglo workers have a lack of knowledge of other cultures (eg. What is culture specific and what is family specific)	<ul style="list-style-type: none"> • Lack of cultural knowledge 	<ul style="list-style-type: none"> • Cultural awareness training eg. HACC does this kind of training

A number of inter-related reasons were identified by participants as contributing to the isolation of people with intellectual disability of non-English speaking background and their families. These reasons were also identified in the literature. Ethnic workers reported that carers in some ethnic communities perceive their care-giving as a family responsibility rather than a professional or support service role. As one carer stated: “*We do not receive assistance from anyone and we do not wish to receive assistance from them. ... The family is the most important thing... They are not paid to be there but they love you and care for you.*”

The ethnic workers agreed that this strong sense of family responsibility has prevented some families from seeking assistance, either from ethnic community welfare services or from mainstream disability services. “*In my community, when I work with such families, I have to go to them. They do not come to me. That is the way we have to work.*” The ethnic workers had also observed that carers often perceive their son or daughter with an intellectual disability as a ‘perpetual child’ and had very protective attitudes towards their son or daughter. These attitudes appeared to contribute to the isolation of these families. However, it is acknowledged that this perception and response are similar to those of some Anglo-Australian carers, and may not be culturally based.

The government disability workers queried whether members of ethnic communities are “missing out” on community education about people with disabilities in recent decades. This information has contributed to the development of more knowledge about abilities to learn and potential lifestyle options for people with intellectual disability among Anglo-Australian carers.

Strategies suggested by participants for reducing isolation were:

- increase disability workers’ awareness of the isolation of many families of non-English speaking background, to counter assumptions that these families may have other supports and to encourage services to be proactive in facilitating access for these families;
- foster community based supports through community based organisations that are in addition to disability services (e.g., family to family linking);
- disseminate disability information through ethnic electronic media organisations, newspapers and newsletters;
- use community education strategies about people with disability of culturally and linguistically diverse background similar to those currently used for health education (such as cancer screening public education campaigns specifically for people of diverse of cultural and linguistic backgrounds).

Cultural beliefs and cultural differences

One disability worker said: “*Her English was fine, but I found that it was more her traditions and expectations of life. These can be very different. We are not talking about communication barriers but cultural thinking.*” Cultural beliefs about the cause and nature of intellectual disability were raised by participants in all of the group interviews. The ethnic workers said families from some cultural groups perceive intellectual disability as the result of the person’s past life actions. These workers stated that within some ethnic communities, being known to have a person with a disability in the family would jeopardise their siblings’ chances of marrying.

The two ethnic workers with prior experience in intellectual disability services recognised that some service principles may not be congruent with cultural beliefs and attitudes. For example, “social role valorisation” strategies (such as assisting people to access public facilities) could be challenging for some cultural groups who preferred to maintain privacy about their family member with a disability. In addition, the non-government disability workers indicated that the concept of maximising individual ‘independence’ embraced by most services for people with intellectual disability does not appear to be important to some families of non-English speaking background who accept high levels of interdependence within families. This is similar to the observations of Kinebanian and Stomph (1992) outlined earlier in this paper.

None of the disability worker participants had received formal cultural awareness training. Several discussed being unsure whether particular characteristics were typical of the cultural background of a family or were specific to that family. For example: “*who knows what belongs to cultures and what belongs to families, particularly since I only have a sample of one family [from this culture] to work with*”. Some workers also commented on the difficulty of developing cross-cultural understanding when so many different cultural and linguistic groups are represented in their service area.

Two government disability workers reported experiencing difficulty in accessing support and resources from a particular ethnic community for their client. They suggested that this was because they, the support workers, were not from this particular community and were males undertaking what was perceived to be a female carer role.

The government disability workers discussed the challenges of understanding and supporting cultural beliefs and preferences with people with intellectual disability who do not have verbal communication skills. For example, difficulties determining a person’s perceptions of their cultural identity, especially in supported accommodation settings and if family members visit rarely, can lead to difficulties ascertaining the person’s preferences in décor, food, activities and social contacts.

Both of the carers highlighted the importance of feeling that their cultural and religious traditions and beliefs were understood and respected. Both carers explained the role of their religion in their caring role for their son or daughter, for example: *“I believe that if I do the right thing and look after him, then God will provide for him when I’ve gone”*.

Strategies suggested by participants for increasing cross-cultural understanding were:

- provide support services which reflect the family’s cultural values and beliefs;
- foster trust building processes (e.g., visit the family at their home, accept meals if offered);
- provide cross cultural training that increases workers’ awareness of their own culture as well as other cultures;
- seek information from ethnic community workers.

The ethnic workers emphasised that each family of non-English speaking background is unique and that disability workers would need to be aware that there are large variations in attitudes, beliefs and practices within as well as between ethnic groups. Disability workers are familiar with individualised service provision and so the concept that each family within an ethnic group is different should not be difficult to accept, if accompanied by cross cultural awareness training.

The two ethnic workers who had previously worked within mainstream intellectual disability services suggested that disability services’ philosophies and practices could be implemented whilst concurrently respecting the cultural and spiritual beliefs of people of non-English background.

Language difficulties

All of the disability workers had experienced language related difficulties in communicating with people of linguistically diverse background and their families. One government disability worker mentioned particular difficulties in communicating with families over the telephone. Only two disability workers had used interpreter services, and access to interpreters was limited in both of these situations because of costs. Due to resource limitations, all of the disability workers had used informal interpreters such as the relatives or friends of a person of linguistically diverse background, even though this is not a recommended practice.

Two government workers reported that there were bilingual workers at their workplace, but these workers’ linguistic skills were not utilised with families from their linguistic background. One government worker recounted an experience in which he had sought to recruit a bilingual worker from a particular cultural group for one of his clients, only to be advised that this was a potentially discriminatory employee recruitment practice. In contrast, whilst having the funding flexibility to recruit bilingual workers, the non-government disability

workers had encountered difficulties finding and training workers from some ethnic communities.

Strategies suggested by participants for decreasing language difficulties were:

- liaise with ethnic community workers;
- use interpreter services (despite costs);
- employ and utilise the skills of bilingual workers;
- implement brokerage in service delivery (e.g., enable families to employ a support worker from own culture with whom they feel comfortable in terms of privacy issues);
- use face to face, rather than telephone contact;
- provide printed information in the family’s preferred language;
- increase disability workers’ awareness and understanding of accents;
- increase disability workers’ awareness of their own speech patterns.

Inter-sectoral links

“It is an irony that the people who have the resources [disability workers] aren’t seeing the clients, but the people who don’t have the resources [ethnic workers] are! This is why you need a lot more liaison going on.” All participants agreed that there are very limited links between the intellectual disability services sector and the ethnic community services sector in the region where this study was undertaken. The links which do exist are informal and were established when specific needs arose. The ethnic community workers requested information about people with intellectual disability, the range of disability services and funding programs. One worker stated that complex financial accountability and quality assurance requirements may prevent small ethnic community organisations from applying for disability funds. Conversely, the disability workers requested information about bilingual workers, ethnic services and ethnic groups. The forum which was incorporated into this study was intended to foster inter-sectoral links.

Strategies suggested by participants for increasing inter-sectoral links were for workers to:

- find out more about local ethnic community services and local disability services;
- provide information about local disability services to ethnic community services and vice versa;
- organise joint individual/family support work between disability and ethnic community services (through contacts established through processes such as those above);
- since difficulties were being encountered by disability workers in locating existing resources, centralised information and resources about cultural and language groups represented in the local region were suggested;
- organise further intersectoral forums.

Access

The participants from each of the disability groups indicated that people of non-English speaking background appeared to be under-represented as clients in all except one of their services. Similarly, the ethnic workers reported low rates of disability service access by families of non-English speaking background. In addition, government disability workers indicated that they did not know the actual numbers of people of non-English speaking background receiving their services, as the client database was inaccurate in relation to people's cultural and linguistic background.

The ethnic workers said that mainstream intellectual disability services did not appear to be consistently addressing the access needs of people with disability of non-English speaking background. Several of these workers observed that when families did attempt to use mainstream intellectual disability services, they often encountered difficulties and challenges. One worker described services' inability to cater for different food and cultural practices, for example *"The mainstream services would love to have a Vietnamese day but they won't put on Vietnamese food or a Vietnamese worker. The clients all have to fit in with what is already going on."* Another worker described a disability service refusing to provide services to clients of culturally and linguistically diverse background because workers were "not trained" to work with these families: *"When we contact them, the officer will say because of the language/cultural problem, it is hard for them to work with the client."*

All group interview participants commented that people of culturally and linguistically diverse background with intellectual disability most often were referred to their service when a crisis occurred with their (often ageing) family carer. However this situation also occurs for mature aged Anglo-Australian people with intellectual disability. Such similarities in experience need to be recognised to avoid exaggerating differences. Increased communication between ethnic and disability workers may facilitate this process.

In addition, the issue of access to services was discussed in each of the group interviews by asking for comments on the relevance to their organisation of the access model developed by Fitch et al. (1992), the components of which are summarised earlier in this paper. A common theme in the disability worker comments was that disability services were stretched in providing services to their current clients. In particular the non-government workers indicated that their organisations currently had waiting lists and were not able to provide additional services. As one worker said:

I am confident that the community disability sector is committed to addressing the issues of access to services for all. However, the practical reality is that putting resources (that cannot meet present needs) into areas such as ethnic access are not likely to be seen as high priorities without additional funding.

In addition, some of the disability workers perceived that their services were there for all to use and that non-English speaking background people would receive services if they requested. This inaccurate perception is consistent with Fitch's (1991) finding. Government disability workers indicated Fitch et al's (1992) access model appears to be a good guide for organisations to use. The government disability workers noted, with concern, that few of the access model's strategies had been implemented within their organisation, and that many of the strategies suggested in the access model required additional funding, which could be difficult to obtain. The ethnic workers agreed with Fitch's (1992) proposal that mainstream disability services should take responsibility for implementing organisation wide access strategies, rather than relying only on individual worker initiatives. However they also identified an active role for the ethnic sector in developing services for people with intellectual disability from particular cultural or linguistic groups, to provide choices for families.

Strategies that were suggested to increase access of disability services by people of culturally and linguistically diverse background include, all of the strategies listed for the previous issues, plus;

- disseminate local examples of effective practice throughout disability services;
- provide family brokerage options and some services for people from particular cultural or linguistic groups;
- improve data collection about service users' cultural or linguistic background;
- foster feedback and consultation processes within ethnic communities;
- identify needs of family carers;
- plan ahead with families to facilitate their acceptance of gradual transitions to support options beyond the immediate family;
- use ethnic community venues and involve ethnic community leaders when providing services;
- involve a person of culturally diverse background in the assessment of any disability service funding applications from ethnic community organisations.

Participants from all three group interviews suggested that a centralised, probably government based service was needed to coordinate policy development, dissemination of information to ethnic communities, staff training, resource provision, and funding information. In addition, a separate, community based service to undertake individualised family support and education when accessing mainstream intellectual disability services, was suggested.

Concluding Comments

Despite variations in experiences, the issues and strategies identified by participants from disability services, ethnic community services and families were consistent. It appears that whilst all people with intellectual disability and high support

needs, and their families may experience difficulties with accessing appropriate services, these difficulties can be exacerbated by cultural and linguistic differences. The five themes identified in the region studied: isolation, cultural beliefs and differences, language, inter-sectoral links and access, can be illustrated as in Figure 1. Four of these themes reflect the issues previously identified in the disability and cultural diversity literature based on other geographical locations in Australia. The theme which does not appear to have been identified and discussed previously is that of inter-sectoral links. The development of culturally appropriate services and increased access may be facilitated if both disability services and ethnic community services adopt active roles in this process, rather than each sector relying on the other to be the “prime mover”. This may help to link disability and cultural knowledge and expertise, as each of these areas of expertise are currently focused in one sector only in the region investigated in this study. This would then increase the overlap between sectors and with potential service recipients.

The only issue that appears to vary specifically for people with intellectual disability and high support needs relates to expressing personal cultural identity and preferred cultural practices in daily life. As with other areas of choice making for people with intellectual disability with whom verbal communication is limited, service providers could offer individuals choices relating to their cultural background and learn from their non-verbal responses. These choices could range from contact with other people from their own cultural or linguistic group, to types of food, music, room décor and annual celebrations. Empowering individuals with disability, through supporting them to have choices, is a basic principle of disability service provision (Brown, 1997; O’Brien & O’Brien, 1996).

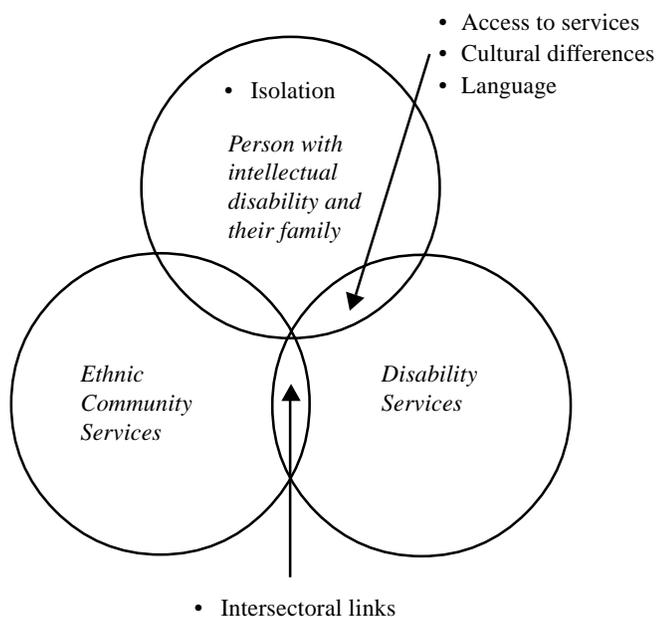


Figure 1: Issues for people with intellectual disability from culturally and linguistically diverse backgrounds

While many of the issues and strategies identified in this study are similar to those identified in the literature, there appears to be benefits from gathering local data. Firstly, specific strategies were identified that could be implemented by an individual within an organisation, without needing to wait for large scale organisational change (e.g., organising joint individual/family support work and using ethnic community venues for services). Secondly, local differences and emphases can be identified (such as the need to develop inter-sectoral links). Thirdly, information about needs and issues may be more likely to be “owned” by local organisations and more likely to provide an impetus for change, than more remotely gathered information. The local interest and impact in this research project is reflected to date in the following: over 200 requests for copies of the research report; five requests to speak with disability services staff groups about the issues and strategies identified; an invitation to discussions with a parent advocacy group; the acknowledgment of access issues for people of culturally and linguistically diverse background in a state government disability services planning document (Disability Services Queensland, 1999); the selection of one of the participants in this study (who is from a culturally diverse background) for a ministerial advisory committee; three funding grants to establish a Queensland wide advocacy and resource service for people with disabilities of diverse cultural backgrounds; and an invitation to develop cultural diversity training for disability service workers. Similar action research processes, requiring modest resources, could be undertaken in other locations, both within Australia or internationally.

Fitch (1991) suggested that, “the impetus from one relatively small pilot study can ultimately influence wider program planning and delivery”. Similarly, Davis (2000) and Dickson (2000) promoted direct links between research and service development or change in the disability and health sectors. To further complete the action research cycle (Argyris & Schon, 1989) it would be appropriate to evaluate any new services or changes to service delivery that occur in relation to the above impetus.

The research process involved an advisory group, participants from different sectors, carer interviews and an inter-sectoral forum. The consistent local acceptance of the findings of the project suggest that this process is appropriate despite the small number of participants involved. However, it would be preferable to involve a larger number of family carers as participants. Secondly, when services to people with a broader range of disabilities were being considered, then the involvement of people with disabilities themselves would be vital (and this is occurring during the establishment of the advocacy and resource service). Thirdly, more emphasis on the development of a concrete action plan at the forum stage of the process would possibly facilitate the impetus for service based changes.

As well as addressing disability services, there is a need to consider community development initiatives. Issues experienced by people with intellectual disability of diverse cultural and linguistic backgrounds and their families cannot be addressed by services alone. Partnerships and links may be fostered outside of services. Advocacy is identified by Fitch et al. (1992) as crucial to the development of culturally appropriate services. Links between local advocacy organisations and ethnic organisations may need to be further developed.

Acknowledgements

This study was funded by The University of Queensland, through its Research Grants Scheme. The study was supported by senior staff of Disability Services Queensland. The study was supported and advised by an Advisory Group which comprised of the following members: Ms Margaret Hess, Director Ethnic Communities Council of Queensland HACC Resource Centre, Ms Evana Matkovic, Cross Cultural Health Worker, Logan Women's Health Centre; Ms Judy Pagan, Disability Program Department of Families, Youth and Community Care; Dr Venkat Pulla, Coordinator Brisbane Migrant Resource Centre; Mr John Wilkinson, Ethnic Communities Disability Network of Queensland. The contributions of all interview and forum participants are acknowledged and appreciated.

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Appendix

Group Interview Questions

What are your **experiences** in working with clients of non-English speaking background with intellectual disabilities?

- Please give examples (without identifying anyone) of your personal experiences
- Please give anecdotes from your organisation
- What made it different to work with non-English speaking background clients, compared with Anglo-Australian clients?

As a group, let's now examine all these experiences and identify the **underlying issues** in these experiences.

Let's examine all the difficulties and challenges we identified earlier, and brain-storm **possible solutions**.

There's an organisation in Victoria, ADEC, which has done a lot of work to assist disability services to become more accessible and culturally appropriate for clients of non-English speaking background. They have developed an *access model* (participants were handed information about this model) for services to use. I'm interested in your feedback on **how feasible and realistic you think this access model is, if you had to use it in your organisation**.

Carer interview questions

1. Before we start, could you tell me what country you came from and how you came to be in Australia?
2. How would you describe _____'s disability, do you consider it an intellectual disability?
3. Could you describe what is involved in caring for _____?
 - *What kind of things does _____ need assistance with?*
 - *How long have you been caring for _____?*
4. Do you receive any assistance from other family members or friends? Could you describe what kind of assistance they give you
5. Do you receive any assistance in relation to _____ from organisations or services? Could you describe what kind of assistance they give you.

If the person being cared for has used disability services, the following questions will be asked of each service. If there's too many, the carer will choose three to focus on.

6. How did you find out about this service?
 - *Who suggested or referred _____ to this service?*

7. What were the reasons _____ went to the service?
8. In your opinion, was/is the service helpful for _____?
9. Who was involved in deciding what treatments/services _____ received/s?
10. Has _____ encountered any problems whilst using this service? What about you, have you encountered any problems?
11. When you personally had contact with this service, did you speak to them in English or in _____?
 - *If in English – How was that, did you have difficulties?*
 - *If in _____ - Who interpreted for you, how was that for you?*
12. What about _____, did/does s/he have any language difficulties with that service?
13. Is _____ still going to this service? In your opinion, is this a good thing?
 - *If not, what were the reasons for stopping?*
 - *If they're seeing another similar service provider ask - In what ways is the new one better than the old service?*
17. Thinking back over the whole period you have been caring for _____, what was the most difficult time for you?
 - *What made it difficult?*
 - *What did you do to cope?*
 - *What things did you find helpful in that period?*
18. Who are the people who are the most helpful to you now? In what ways are they helpful?
19. Can you think of any services which are not available, that you would like to have available to _____ or yourself as his/her carer?
20. Is there anything else you would like to add to our discussion today?

If the person being cared for has not used disability services, the following questions will be asked.

14. In your opinion, do you think _____'s well-being would improve by receiving assistance from a disability service, say for example, day options, supported employment, therapy (whatever is an appropriate example)
 - *If yes, what kind of assistance do you think would improve _____'s well being?*
 - *If no, are there any other things that could make _____'s life better?*
15. What about you - do you think your well being would improve by receiving assistance from a disability or carers service, say for example, respite care, carer's support.
 - *If yes, what kind of assistance do you think would improve your life?*
 - *If no, are there any other things that could make your life easier?*
16. Are there any particular reason why you have not used any disability services for _____? Could you describe these please.
 - Have you had any problems with services in the past?
 - Did you simply not know about services?