

UNIVERSITY OF SOUTH AUSTRALIA

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MOVING FORWARD TOGETHER: AN INTERNATIONAL  
COMPARISON OF SUCCESSFUL STRATEGIES TO IMPROVE  
ACCESS AND EQUITY FOR PEOPLE FROM ETHNIC  
MINORITIES

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improve access and equity for people from ethnic minorities**

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## Foreword

Since the 1970s all levels of government in Australia have stated that programs and initiatives delivered or funded by government must meet the needs of people from ethnic minorities. This results from their acknowledgement that people from ethnic minorities have not had access to those programs and initiatives at a rate comparable to their numbers in the community. Over the past 20 years all levels of government have responded through various initiatives, programs and strategies aiming to redress these inequities.

At the beginning of the new millennium and after 30 years of multicultural policies and programs, the access rate to disability services for people from a non-English speaking background in NSW is still at least 4 times lower than their numbers in the community. While the causes are manifold, the responses over the past decade have been piecemeal at best and had a negative impact at worst.

It is our perception that the beginning of the new millennium has heralded a phase of rhetoric and public relations management where Governments spend money and are quick to point to their initiatives, but where little is known or asked about the effectiveness of any of these initiatives, programs and strategies.

The Multicultural Disability Advocacy Association of NSW (MDAA) commissioned this research by Associate Professor Nicholas Procter from the University of South Australia to examine public sector programs and initiatives that have yielded increased service utilisation rates for people from ethnic minorities. The impetus for this project was MDAA's increasing frustration with endless one-off, uncoordinated initiatives and programs, which are not based on sound research and evaluation and which appear to make the same mistakes and have the same shortfalls program after program. Even more concerning for minorities with a disability are recent trends suggesting that additional monies spent in disability services are actually increasing the service utilisation gap between Anglo-Australians and people from culturally and linguistically diverse backgrounds.

It is clear from the work produced by Professor Procter and his team that there is now evidence, based on international research, to suggest that "improving services to ethnic minority communities within the disability sector requires a constellation of strategic community, policy and service delivery activity".

MDAA commends this report to policy makers and politicians as a guide for how best to address the current racial inequities in the Australian (disability) services system.

Barbel Winter  
Executive Director, MDAA

## **Executive Summary**

This review of the international literature about improving services to ethnic minorities highlights the need for a comprehensive approach, which involves a clear legislative framework; clear policies and directives developed from that framework; and clear strategies for service delivery. One essential element is community participation at each of these different levels. Without the participation of ethnic minority communities in the development of legislation, policies and service delivery, publicly funded services face very difficult challenges in trying to deliver services and conversely, community members face insurmountable difficulties in getting access to those services.

The review also highlights that ten years ago Sweden, Canada and Australia were cited as leading countries for developing responses to improving the health of their migrant communities. Since then the United Kingdom (UK) appears to have taken over the lead in developing the most proactive, comprehensive approach to service delivery. The review also indicates that the United States of America (US) and Canada appear to rely more on protecting the rights of the individual from discriminatory treatment, essentially a more passive, reactive approach requiring individuals to complain when they believe they are being discriminated against.

The review highlights common areas and differences in approach in the UK, Canada and the US. Common areas include the establishment of legislative frameworks setting out the rights of citizens and residents and the service obligations for public and publicly funded services. Differences include government approaches to the development of policies and policy directives flowing from the legislative frameworks established: governments in the UK are more active than their counterparts in Canada and the US. There are also different responses in the different health sectors, with mental health more proactive than others.

The UK experience, as the example of the most integrated legislative and policy development framework, illustrates some of the challenges to improving service access for people from ethnic minorities, as well as ways to succeed. Overcoming institutionalised racism and indirect discrimination in the provision of services is part of this path to success.

The review concludes by extrapolating the principles and strategies required to succeed in providing culturally accessible services. They include strong leadership to change the 'culture' of an organisation; training all staff to become culturally competent; and managing resources to deliver services to the whole community, regardless of the cultural background of the individuals concerned.

The review indicates how using these principles and strategies in the disability services sector would redress the current inequitable service provision in NSW.

## **Introduction**

The aim of this literature review is to examine the successful provision of public services to people within ethnic minority populations experiencing disability. In particular, the review centres on the experiences of various western democratic nations in providing services to migrant populations in the health and disability context. This includes exploration of how ethnic minority communities have been able to access the range of health and disability services offered by governments and also, noting successful programs which ensure equity in the distribution of disability related programs and funding across populations.

In commenting on the area of utilisation of services and programs, the review summarises research showing that ethnic minority communities tend to experience differential access to services compared to majority populations in the UK, Canada, and the United States. In many instances, research depicts patterns of access and use which suggests that ethnic minority communities may not be receiving formal assistance for health and disability concerns as the prevalence of these issues in communities would warrant.

The review also discusses a range of explanations regarding differential health status and service access by distinct ethnic communities, utilising information from professional journals, government commissioned research and government reports. Reasoning and analysis on this area derive from a number of different paradigms, both of and within public health, health services management and sociological theory. These understandings are presented as to how these shape recommended interventions and programs for improving community access to government programs in specific disability and health arenas, and enhance the participation of ethnic minority communities within spheres of social life, including education, training and employment.

## **Methodology and general observations**

The review has been written in the context of identifying journals and reports from three nations which have immigration programs and a multicultural policy context similar to that of Australia.

The first strategy in identifying information about utilisation rates of disability programs by migrant communities was to look for relevant studies and meta reviews in the professional journals. In this regard, searches were conducted within various health and disability related journal databases and publishers including: Medline, Academic Search Elite, Sociological Abstracts, Ingenta, Blackwell Synergy, Cinalh, Psych Info, PubMed, CSA Social Services Abstracts, EBSCO professional development collection, Health Source Nursing/ Academic Edition, Oxford University Press Online Journals, Rehab Data, Swetwise Online, SpringerLink and Wiley Interscience. The descriptors for these searches were the terms:

- Ethnicity
- Disability
- Health status
- Service use
- Service utilisation
- Access
- Immigrant
- Discrimination
- Migrant
- Culturally diverse
- Cultural competence
- Service development
- Minority groups
- Health disparities
- Health inequalities

The second major source of information on the review was to search for various government reports and commissioned studies on disability, disability services and

migrant communities, within government web sites. Searches were made to health departments and social service departments within countries such as Canada, the UK and USA. A final strategy in searching for relevant articles and important studies was to check the bibliographies and references of papers found via the above methods. As many studies and reports were published locally and not necessarily internationally available and distributed, many of these reports are secondary citations in this review.

The various reports and papers available to the study were examined to identify the range of interventions and initiatives seen as effective for improving the quality and uptake of services for ethnic minority communities. One of the early observations in searching for this literature was that there tended to be little attention within disability related journals on this issue of access to services, or inequalities in service distribution across population groups. Searches yielded little in the way of investigations covering the spectrum of disabilities, i.e. sensory and physical, health related and psychiatric disability and use of services.

There was generally much more attention being placed on the use of health services by ethnic minority communities and attention to the prevalence of illness and disease among community groups rather than disability, the former being a considerable literature on inequities in health from a public health perspective. This might be a reflection on the situation that migrant related health receives generally much more attention than disability (Ahmad 2000).

The reviewers were surprised to find little information on access to services and utilisation rates in the disability sector by ethnic minority communities. It was interesting to observe that within large mainstream reports on disability within nations such as Canada and the UK, reports which surveyed and documented the level and spread of disabilities across the nation, there was little mention of experiences of disability within specific ethnic groups. It follows from this, that if national governments are not measuring ethnic status and differences or disparities on prevalence then there may be no

attention on service use, as the two areas are closely linked. Prevalence issues need to be considered along with population levels in evaluating the use of services.

With general health care, however, there appears to be more of a historical focus on examining the health and illness relating to ethnic minority populations. Certainly, there is a larger range of information to draw on from Canada the UK, and the US. Reports from Scandinavian countries such as Sweden and Norway had also documented the health and illness rates of migrant populations in relation to the general population. These studies in health care, public health and primary health care have often also included a focus on service utilisation and various interventions and policy recommendations for improving health provisions.

This review, while focusing on disability issues, will include reference to this context of health and illness and make the suggestion that trends in this literature may have a strong connection to the areas of ethnicity, disability and access to public services. This is especially in the context where information about disability services has not been identified<sup>1</sup>.

A further issue to note in producing this review is that there are a range of problematic issues highlighted in the literature regarding definitions of ethnicity, access, service use, and disability and the way these concepts are operationalised within the relevant research. There is generally a significant diversity across many of the studies referred to according to how utilisation is measured and understood and also how ethnicity is identified and defined, both by researchers and by community members involved in studies.

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<sup>1</sup> A point to make about disability services compared to health services can be made with respect to available information. An observation about health services in these countries is that public health services are very large centralised organisations and in many instances operate on national levels, as evidenced in the UK. The history of these large organizations and the depth of their research base may mean that more resources are provided to conduct large scale epidemiological studies. In contrast the diversity of disability issues and service responses may mean that information about disability remains on the individual level of specific disabilities and related services, rather than collected at the broader macro level. In Australia for instance, the context of services is considerably fragmented with many organizations usually delivering services to one category area of disability.

This issue is related to the language used in this review. The language used across professional and national contexts to describe ethnicity and use of services, disability and chronic health issues, is highly variable. In the UK, 'ethnic minority communities' appears to be the term used within Government research and also professional writing. In Canada, the term 'immigrant community' is popular. Elsewhere within the United States terminology such as 'racial and ethnic minorities' is most commonly used. In Australia, the term 'culturally and linguistically diverse communities' has emerged within government descriptions in recent years, replacing the descriptor, 'non-English speaking background'. In this report, the term 'ethnic minority community' has been preferred, mainly because much of the literature emanates from the UK and the US.

### **Organisation of this report**

The organisation of this review occurs as follows. The literature on service utilisation strategies will be discussed in three national contexts, these being the United States, the UK and Canada. Research on each nation's efforts in the area is summarised in a chapter or section on each nation, allowing specific information to be considered in national policy environments. Within each section, the review will note prevalence and service utilisation studies and will move to focus on how nations have developed programs to respond to increasing quality and utilisation. Included here is a general description of the range of interventions commonly seen as required to improve effectiveness in this area. Each section also summarises the aspects of planning, human resource management and service delivery which have been seen as successful by authors and commentators. Towards the end of the review, these summaries are compiled to establish a list of service principles. This range of approaches and strategies demonstrates that improving access to services requires committed and collaborative efforts from those involved in sector (policy) development, service management and delivery and community associations. The discussion begins in the United States.

### **Study One: Service utilisation in the US: issues and program responses**

Given the wide range of disability issues, health /disease contexts and service areas across this topic area, the reviewers decided to focus on two areas of service delivery and reform in the United States. These areas included vocational rehabilitation services for people with disabilities as well as the mental health care systems within the country. This decision was made also due to there being an evident history of research about service utilisation within these service sectors. Narrowing the focus would allow the review to discuss service reforms and strategies for improving service quality and access within a historical and contextual view of each area.

### **Prevalence and Service utilisation**

Any discussion of ethnicity and disability and rates of service utilisation needs to take place in the context of disability prevalence within communities and also other factors such as income, employment, gender and education. In relation to prevalence of disability in the US, Bradsher's (1995) analysis of disability and ethnicity statistics suggests that African Americans and American Indians experience higher levels of disability as groups than other groups. He also suggests that gender is a factor across ethnic groups, with higher rates of women than men experiencing disability within the 15 to 64 age range<sup>2</sup> (Bradsher 1996; see also National Center for the Dissemination of Disability Research 1999).

Smart and Smart (1997), in discussing the disproportionately higher disability rates of ethnic minorities, suggests that these are intimately linked with five areas of structural disadvantage. These areas include low income and poverty, employment in workforces or jobs with high levels of injury risk, low levels of education, low levels of insurance coverage and inaccuracy in disability assessments and tests. As higher numbers of people of ethnic minority status occupy positions of low socio-economic status and lack health insurance or other financial means of improving their health or situation, they

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<sup>2</sup> In Australia people with disability are usually people aged between 0-65 years.

experience higher risk of poor health, or disability related injury. Socio-economic status remains a major consideration in discussing disability and ethnicity.

*“Persons with low income are at a disadvantage in preventing the onset of disability and in ameliorating its effects after acquiring the disability...They have less wealth at their disposal and are less able to secure either health care or job retraining. Persons with disabilities thus enter a cycle of low income, lack of financial resources for further education, poor health and unemployment. This cycle is more pernicious for persons of racial/ethnic minority status” (Smart and Smart 1997 p.10).*

Given the higher levels of need among communities for assistance and help in living with various disabilities and gaining independence, employment and education opportunities, there has been a disturbing under-utilisation of specialist services along with general public services by communities in the US. This occurs in the context where numbers of ethnic minority community members are growing as a percentage of the national population (Flowers, Edwards et al. 1996) and are highly concentrated in many urban centres (Wilson, Harley et al. 2001) .

According to a 1999 report by the National Council of Disability (NCD), ethnic minority communities have experienced extensive levels of discrimination and barriers to disability services and broader public services. The report presents a range of hearings in the context of the policy developments over the last decade regarding legislation and specific provisions relating to anti-discrimination legislation and rehabilitation services (National Council on Disability 1999).

The Council notes that while the Anti Discrimination Act may have had significant impacts on the majority population with disability in facilitating access to disability and rehabilitation programs, services for people from diverse cultural minorities had not sufficiently improved over that time. The report cites personal testimony and utilisation statistics to suggest that people from ethnic minority backgrounds experience disability related discrimination in access to services such as employment and additional ethnicity related discrimination within the disability services sector.

*“NCD found in 1993 that “persons from minority backgrounds with disabilities...do not have appropriate training and career development opportunities.” NCD believes this finding is still applicable today. On the basis of the low employment numbers for minorities with disabilities and the testimony presented at the 1998 NCD hearing in San Francisco, it is apparent that minority individuals with disabilities still have tremendous difficulty gaining access to culturally appropriate job training and career development opportunities. Although all people with disabilities confront these barriers, the barriers are more persistent and more pronounced for people with disabilities from diverse cultural backgrounds... While the labor force participation rate for people 18 to 64 years old who do not have disabilities is nearly 83 percent, it is only about 52 percent for those with disabilities, and only about 38.6 percent for non-Whites with disabilities. For people with severe disabilities, the labor force participation rate is about 30 percent for Whites, 21.2 percent for Hispanics, and 17.8 percent for Blacks... Moreover, minority individuals with disabilities often have tremendous difficulty obtaining employment with minority-owned businesses because of the stigma attached to disability within many minority communities. In some racial and ethnic communities, as in some White communities, people with disabilities are still perceived as bad for business, as not worth investing in as employees or courting as customers, and in some cases as bearers of bad luck” (National Council on Disability 1999 p. N/A)<sup>3</sup>...*

In respect to the disability services and rehabilitation services arena, the report mentions that many rehabilitation organisations in states and regions of considerable cultural diversity, have not embraced the service development reforms required under the national ‘Rehabilitation Cultural Diversity Initiative’ program, started in 1992<sup>4</sup>. The report discusses the connections between the experiences of simultaneous disadvantage. Vocational rehabilitation services, seen as a key access for people to employment training as well as being an employer of people with disabilities, are still seen to be under-performing in providing equitable services to diverse community members, in job

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<sup>3</sup> N/A refers to page numbers being unavailable due the published report being a web based document.

<sup>4</sup> This program of service development for rehabilitation services was formulated from Amendments to the 1973 Rehabilitation Act, a document which set plans for achieving equity in service provision to all communities. The Amendments considered that:

*“Patterns of inequitable treatment of minorities have been documented in all major junctures of the vocational process. As compared to White-Americans, a larger percentage of African-American applicants to the vocational rehabilitation system are denied acceptance. Of the applicants accepted for service, a larger percentage of African-American cases are closed without being rehabilitated. Minorities are provided less training than their white counterparts. Consistently, less money is spent on minorities than on their white counterparts” (cited in Flowers, Edwards et al. 1996 p. 22).*

placements and numbers of clients accepted to the service<sup>5</sup> (see also Dziekan and Okocha 1993; National Council on Disability 1999).

A long line of research in this area, focusing on the acceptance of African Americans to vocational recreational services<sup>6</sup>, considers that decision making within these services serves to systematically disadvantage these community members in gaining assistance (Wilson, Harley et al. 2001). Historically, reasons given in the research for this disparate treatment include the lack of cultural competence on the part of service staff, ethnocentric views by staff members on the work potential of African Americans, cultural mistrust of services by community members themselves leading to a self-fulfilling rejection and also the incongruence of the individualistic culture of vocational counselling services and more collective orientations of community members (Thompson 1997; Wilson, Harley et al. 2001; Hasnain, Sotnik et al. 2003). Thompson argues that the dominant cultural themes of individualism, independence and control pervade disability services in the US, leading to conflicts between the perceptions of both service professionals and ethnic minority community members on rehabilitative outcomes and means of working toward them (Thompson 1997).

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<sup>5</sup> “One area where the lack of minority representation is particularly apparent is disability-related counselling services. Several respondents at the hearing stressed the tremendous need for cultural identification between clients and counselors in the provision of culturally appropriate counselling services. In a recent national study funded by the National Institute on Disability and Rehabilitation Research (NIDRR), 82 state rehabilitation agencies (general and blind) were surveyed about the racial and ethnic composition of their workforces. Within the 56 agencies responding, the aggregate breakdowns of their staffs were 87.4 percent Caucasian American, 7.7 percent African American, 1.9 percent Hispanic American, 2.9 percent Asian American and Pacific Islander, and 0.1 percent other. Within district offices, which tended to have lower salaries across the board, the staffs were reported as 79.5 percent Caucasian American, 13.3 percent African American, 4.8 percent Hispanic American, 1.7 percent Asian American and Pacific Islander, and 0.5 percent Native American. The same study found that professionals of minority backgrounds are significantly underrepresented nationally” (National Council on Disability 1999).

<sup>6</sup> See the following definition of these programs: “**Vocational Rehabilitation:** This term refers to programs conducted by state Vocational Rehabilitation agencies operating under the Rehabilitation Act of 1973. Vocational Rehabilitation programs provide or arrange for a wide array of training, educational, medical, and other services individualized to the needs of persons with disabilities. The services are intended to help these persons acquire, re-acquire, or maintain gainful employment. Most of the funding is provided by the federal government” (National Institute on Disability and Rehabilitation Research 1998).

The nexus between notions of individualism and independence and the role of family, friends and community networks gives rise to several interrelated questions:

- Could it be that in order to meet the challenges of individual need, a single organisational structure is needed within each service system – perhaps in partnership with other community advocacy and support groups?
- Could individualism, independence and control (broadly defined) operate, for example, as some kind of coherent system or set of structures? Or will its development be situational and lacking in enduring patterns?
- If individualism, independence and control are regarded as systemic in form, what is the rationale in support of an enlargement of focus involving the wider social system? Or are there several underlying types of rationales rather than a singular master process?
- And within these various scenarios, what scope, if any, remains for (1) clients to advance individual rights and individualism? And, (2) a family, kinship and social network to maintain its supportive interests?

Thompson's (1997) discussion of congruence and incongruence with individualism implies that once some activities have been initiated in a personal local context, there is potential for many cross-currents – family and community – of social connections without losing the professional identity of local services.

While cultural factors have been highlighted in explanations regarding poor use of services by African Americans and other ethnic minority groups, language barriers and the limited availability of interpreters, information in community languages, and bilingual services have also been considered as important reasons for under-utilisation (Leal-Idrogo 1995). Furthermore, interpreting and translation services within the field of disability require additional reorientation to individual needs and capacities. Disabilities relating to hearing, speech and vision require interpreting and translation services, where these are provided, to take these into account (National Council on Disability 1999). While there have been recent developments in the requirement that Federal agencies work towards providing interpreters and translated materials for community members

accessing their programs <sup>7</sup>, it appears that many disability services provided by local governments and private organisations do not have this requirement (National Council on Disability 1999).

Researchers have noted that low utilisation rates reflect other issues concerning the representation of decision makers within disability services. A survey study by Flower et al. (1996) of 32 Independent Living Centers in the mid-west of the country, highlighted problems with the level of service offered to people from ethnic minority communities and extensive problems in collecting data on ethnicity. 58% of the centres reported having no planning in respect to servicing the specific needs of these communities. The study also suggested that the workforce of the centres was under-representative of the major communities in the local populations and that these community members were more under-represented in the decision making, executive staff/ board members of the organisations (Flowers, Edwards et al. 1996).

Staff recruitment and decision making processes have been seen as central by reports as factors perpetuating poor rates of service to diverse groups. The NCD report notes that low staff recruitment of people from diverse minority groups in disability or rehabilitation programs helps continue the situation where services are unable to be offered in languages other than English. Given the poor availability of interpreters across certain sectors and regions, bilingual staff, especially those with a disability or who thoroughly understand disability issues are seen as an important means of improving access. In a related theme, the access of minority groups to decision making structures is a key movement for ensuring that decision making reflects the inclusion of ethnic minority groups and that managers and executives possess knowledge and experience of cultural issues.

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<sup>7</sup> Recently the US Administration issued Executive Order 13166: Improving Access to Services for Persons with Limited English Proficiency. This provision requires Federal agencies to effectively provide services to people of limited English proficiency, suggests that departments will become more obliged to provide interpreting and multilingual information and communication (National Council on Disability 2000).

Another area of disability which documents the under-utilisation of health-disability services is that of mental health and mental health services. The US Surgeon General's report illustrates a variety of dynamics of service availability and utilisation by ethnic minority communities in comparison with Anglo-Americans. The report's summary reviews of recent knowledge about service use and ethnicity noted that different rates of access exist for all major ethnic groupings compared to Anglo-Americans (US Department of Health and Human Services 2001a).

Despite overall prevalence issues for mental illness and related disability being similar, African Americans, due to socio-economic and social cultural factors had a very different level of access to formal mental health services. Lower income earners can fall between private and public health insurance coverage which facilitates access to assistance. Where community members do access formal services, African Americans have been reported as over-diagnosed with Schizophrenia and less for affective disorders compared to other groups. Overall, members of this group are less likely to receive treatment (US Department of Health and Human Services 2001a).

In relation to Asian Americans, the report notes that there is little knowledge on the many specific ethnic groups in this area, making it difficult for service planners and professions to develop appropriate interventions. Members of these communities had the least utilisation of formal services, and as with other groups found it difficult at times to receive services from clinicians from their own ethnicity group. The report noted the cultural factors of stigma and shame which may impact on health seeking behaviour and also the range of informal supports and help members of these communities may be able to access. Asian Americans' access to financial resources and the different cultural traditions and understandings of mental and emotional health were also connected to low levels of access (see also Zhang, Snowden et al. 1998; US Department of Health and Human Services 2001a).

Many of these above issues, those concerning access to health insurance, bilingual mental health programs, and understanding mental health programs were discussed as highly relevant in discussing the mental health services needs of Hispanic Americans. Members

of these communities face major socio-economic disadvantage and major disparities in their access to mental health services (US Department of Health and Human Services 2001a). In concluding on the issue of service access, the Surgeon General reported:

*“Racial and ethnic minorities do not use mental health services at rates comparable to those of whites or in proportion to the prevalence of mental illness in either minority populations or the general population. The reasons for lower rates of utilization are complex. Research suggests that cost and lack of health insurance, fragmentation of services, culturally mediated stigma or patterns of help-seeking, mistrust of specialty mental health services, and the insensitivity of many mental health care systems, all discourage racial and ethnic minorities’ use of mental health care.”(US Department of Health and Human Services 2001a p. 164).*

### **Responses to improving utilisation and quality service**

In identifying successful programs which increase rates of utilisation by ethnic minorities in services<sup>8</sup>, clarification needs to be made regarding the areas of servicing under reform and the focus of developmental strategies. All publicly funded programs and services in employment, education and training, housing, and child care services, have been the target of interventions and recommendations sought by groups such as the National Council on Disability. In this context, health, disability and rehabilitation services are discussed as part of this equation for change. Other reports, which may be concerned

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<sup>8</sup> In discussing successful programs, the review mainly focuses on literature making recommendations towards improvements that need to occur. While there are some actual examples of where services have raised utilisation levels, it is important to emphasise that the area of organisational development and improvement in health status and service use for migrant communities is under-researched. Dreachslin, Weech-Maldonadob et al. (2004) have made the following observations in regard to existing American research:

*“The relationship between racial and ethnic diversity, diversity management practices, and organizational outcomes is at a nascent stage of development but some evidence exists that racial and ethnic diversity can be leveraged by leadership to produce an organizational advantage as evidenced by financial performance, organizational productivity, and employee satisfaction.....Most importantly, the potential impact of organizational behavior on racial and ethnic disparities in health access, treatment, or outcome has not been directly studied. This paucity of research applies also to the clinical practice literature where the available research does not establish a link between the cultural competence of clinicians and the reduction of racial and ethnic disparities”(Dreachslin, Weech-Maldonadob et al. 2004 p. 968).*

about utilisation and access to specific sectors of treatment and rehabilitation, for instance mental health care, tend to focus on policy and organisational change within this area.

However, one of the strongest aspects of exploring government responses to improving service utilisation rates is the position that reforms are necessarily multifaceted and regularly aimed across many levels of intervention. These include the need for strong policy responses towards financing and supporting cultural diversity in service provision, decision making and in the recruitment of ethnic minority community members in relevant organisations, competence education and training for all staff and additionally, interventions on the community level, via outreach, information and education (see e.g. Flowers, Edwards et al. 1996; Hasnain, Sotnik et al. 2003).

Such a focus is evident in relatively recent reports from different areas of disability. For example, the recommendations made by the US National Council on Disability for improving access to services, reflect a policy development as well as community education approach. In an initial recommendation, the Council calls for a major community education initiative around community rights under American Federal laws on discrimination:

*“NCD has learned from grassroots witnesses that the best way to empower minorities with disabilities and their families to take full advantage of federal laws, programs, and services is to provide them with easy-to-understand, culturally appropriate information about what their rights are under various federal laws (e.g., ADA, the Rehabilitation Act, IDEA, the Fair Housing Act) and how best to exercise those rights when a violation occurs. NCD recommends that an interagency team composed of representatives from the departments of Education, Labor, Health and Human Services, Justice, and Housing and Urban Development, along with the Equal Employment Opportunity Commission, Small Business Administration, and Federal Communications Commission, develop and implement a large-scale outreach and training program targeted to people with disabilities from diverse cultural backgrounds and their families that will provide such information directly to the target audiences through a series of forums, workshops, and seminars across the country. These trainings should be repeated on a regular basis so that new people are trained each year and materials routinely updated” (National Council on Disability 1999).*

The Council however, also listed a range of recommendations aimed at improving the operation of employment and rehabilitation related services.

- *“The Department of Labor (DOL), the Small Business Administration (SBA), and the Department of Education should expand funding for culturally appropriate job training and career development opportunities and should require all federally funded programs to demonstrate their ability to meet the language, culture, and disability needs of the whole population in their service areas.*
- *The Rehabilitation Services Administration (RSA) should address the racial disparities apparent in the vocational rehabilitation system, particularly in the areas of job training and placement services.*
- *RSA should strengthen and increase the number of interventions outlined in Section 21 of the Rehabilitation Act, which requires vocational rehabilitation agencies to take action to better address the needs of underserved groups within their service areas.*
- *RSA should conduct compliance reviews of all state departments of rehabilitation to determine the extent to which their efforts to comply with Section 21 of the Rehabilitation Act have produced better outcomes for minorities with disabilities in their state.*
- *The SBA, working with the Presidential Task Force on Employment of Adults with Disabilities, should provide more entrepreneurial opportunities for minority individuals with disabilities to promote economic independence.*
- *Federal, state, and local policy makers should incorporate the unique needs of family members of minority individuals with disabilities into the larger disability policy agenda, particularly in the area of employment”.*

Many recommendations were also made towards improving the capacity of services to provide bilingual services and make appropriate use of interpreter and translation services.

- *“The Office of Special Education and Rehabilitative Services should issue a policy memorandum mandating targeted recruitment and hiring of bilingual special education staff at all levels.*
- *Federally funded disability programs should conduct targeted recruitment and hiring of minority individuals who are bilingual and bicultural.*
- *RSA should include language interpreter information and referral as a core service at all centers for independent living servicing significant populations of non-English-speaking people within their service area.*

- *RSA should require all Centers for Independent Living (CIL) with significant non-English speaking populations in their service area to develop language/communication action plans that include:*
  - *Establishing contacts within minority community agencies who can assist in facilitating communication with ethnically diverse populations.*
  - *Developing a language interpreter referral database that is available in multiple languages and alternative formats, including the World Wide Web.*
  - *Sending all existing or new translated materials to the SCLC for widespread distribution to other Centers for Independent Living and related agencies/organizations in the state.*
  - *Establishing sign language and other language and other interpreter/translator training programs that provide instruction on translation of cultural concepts, behaviors and body language, expectations about relationships, and other technical disability-related terms (e.g., medical terms and educational and legal acronyms).*
  - *Providing language-dedicated telephone lines in Spanish and other languages with information in bilingual formats on Web pages.*
- *The Departments of Education, Health and Human Services, Housing and Urban Development, Labor, and Transportation and the Small Business Administration should make available adequate funding to all field offices and grantees for translation and interpretation services.*
- *Congress should ask GAO (General Accounting Office) to investigate the quality of service delivery for diverse individuals with disabilities and their families in terms of language and cultural competence (National Council on Disability 1999).*

In outlining further recommendations the Council highlights that funding Departments such as those across education, health and human services, housing and transport need to hold public services accountable for effectively providing services to cultural minorities, including special outreach services which understand and target the specific needs of local communities.

In promoting specific disability/ rehabilitative programs or outreach, the NCD, in a recent report explored the research regarding effective outreach programs for ethnic minority

community members with disability. The council concluded that “*Outreach, as an intervention, is a frequently recommended strategy designed to improve services to underserved groups, but about which little is known empirically. Proponents claim various outreach models show promise, but the lack of consistency across studies makes it difficult to generalize about the effectiveness of any given approach*” (National Council on Disability 2003 p. N/A).

In a review of literature, the Council explored the various notions of community outreach and noted a variety of approaches which are popular in developing services with under served populations.

*“The models of outreach found in the literature were categorized as: the community-based model, wherein focus is placed on building the capacity of current community organizations; the grassroots model, often using indigenous, native-speakers in venues not typically used by service organizations; the train-the-trainer model, in which trusted community members are trained so that the community maintains the needed knowledge after outreach workers have departed; the peer-to-peer model, which emphasizes the mutual understanding of contemporaries; the partnership model which builds on the partner's expertise and community trust, and the support socialization model which couples outreach with popular events to attract the community”*(National Council on Disability 2003 p. N/A).

In terms of the range of these activities, the Council pointed out that various common themes or strategies have been seen as very effective in engaging under-served communities and improving rates of service. These include

- The need to design culturally appropriate services, activities and practices which are acceptable to members of specific groups.
- The need to engage local leaders and workers who can advise and participate in the development of services, practices or their modification.
- The need to develop needs assessments in participation with community leaders and community members. Needs assessments encourage services to get to know local communities on disability issues, via forming working links and displaying interest. The organisation needs to place value on targeted communities and negotiate chosen areas of activity with community members.

- The need to work through communication barriers and across languages, via the provision of interpreters, use of bilingual staff and developing written materials in alternative languages.
- Longer term recruitment of people from ethnic minorities into disability service professions.
- The role of advocacy by services in the sense of highlighting issues specific to communities in broader forums and helping to inform communities about rights, available services and how to access these.
- Helping communities in building or transforming attitudes of mistrust towards formal services. Developing outreach services which value relationships, culture and connection helps community members to gain trust in rehabilitation/ service workers.
- The provision of information which is relevant and communicable to community members. Effective outreach programs utilise various media, networks and agency relationships to develop and disseminate culturally relevant and accurate information and messages regarding available services, rights etc.
- A community focus in strengthening communities is seen as successful in outreach programs. Utilising various strategies such as education, peer education, promoting leadership, adequately resourcing community members and organisations with access to venues, computers, assistance aids etc, work to build skills, knowledge and relationships among community members with disability (National Council on Disability 2003)<sup>9</sup>.

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<sup>9</sup> These themes of community outreach, engagement and participation have also been summarised in the broader health literature on interventions which reduce health disparities. Numerous reviews point out a similar core group of strategies for increasing utilisation and reducing negative health status. A number of these reviews also highlight the role of ethnic minority health workers or health liaison workers as a central role in assisting health services to engage with local communities (Cooper, Hill et al. 2002; see also Lam, McPhee et al. 2003; Nemcek and Sabatier 2003; National Center for Cultural Competence 2004a). These roles have been described whereby:

*“CHWs (community health workers) are trusted community members who establish vital links between health providers and the community. They possess indigenous qualities of the subculture such as verbal and nonverbal language skills; racial/ethnic qualities of the subculture; social/environmental familiarity; and an understanding of the community’s health beliefs, health behaviors, and barriers to health services ..... CHWs are known by various names, such as*

In describing these activities, the Council aims to promote the value of outreach and specialist education programs to the broader government programs assisting Americans with disability. Such programs can successfully be developed within large state and regional public services (National Council on Disability 2003).

The US Surgeon General's response to minority mental health issues provides another interesting example of a sector wide response to improving utilisation. This report outlines a broad range of interventions aimed at areas of government policy, service development among mental health services and programs, research funding and arrangements, and in community education<sup>10</sup>. In listing a summary of desired areas of change, it becomes apparent that improving access to services requires activities on many levels, especially in strengthening the policy and funding environment to target resources in both multicultural and ethno-specific areas of knowledge and service. The desired interventions also describe a need to connect with communities on local levels, and ensure that large scale organisations, which may be federal, state, or local government programs, are able to recognise and respond to the unique mix of ethnicities in the community. The report concludes that action is required in the following areas<sup>11</sup>:

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*indigenous health workers, outreach workers, lay health workers, and health advisers. The "insider" orientation of CHWs provides a cost-effective way to deliver culturally appropriate health care" (Nemcek and Sabatier 2003 p. 261).*

<sup>10</sup> Some other US documents describing multiple levels of organisational development and service design include 'Planning for Cultural and Linguistic Competence in Systems of Care' (National Center for Cultural Competence 2004b) and the 'National Standards for Culturally and Linguistically Appropriate Services in Health Care' (US Department of Health and Human Services 2001b).

<sup>11</sup> See the following summary rationale for this development:

*"The Nation has far to go to eliminate racial and ethnic disparities in mental health. While working toward this goal, the public health system must support the strength and resilience of America's families. The demo-graphic changes anticipated over the next decades magnify the importance of eliminating differences in mental health burden and access to services. Ethnic minority groups are expected to grow as a proportion of the total U.S. population. Therefore, the future mental health of America as a whole will be enhanced substantially by improving the health of racial and ethnic minorities..... It is necessary to expand and improve programs to deliver culturally, linguistically, and geographically accessible mental health services. Financial barriers, including discriminatory health insurance coverage of treatment for mental illness, need to be surmounted. Programs to increase public awareness of mental illness and effective treatments must be developed for racial and ethnic minority communities, as must efforts to overcome shame, stigma, discrimination, and distrust. The time is right for a commitment to expand or redirect resources to support evidence-based, affordable, and culturally appropriate mental health services for racial and ethnic minorities, particularly in settings where those with*

- The development of research areas in culturally competent mental health practices, including treatment approaches and service designs<sup>12</sup>. These include more inclusive research into epidemiological and evidence based practice, psychopharmacology, diagnostic accuracy and formulation.
- The development of mental health promotion activities which increase community resilience, coping and stress reduction among ethnic communities.
- Improving levels of access to treatment in geographical terms and integrating mental health knowledge and treatment with primary care. A focus in federal level reforms should be on primary care patterns among ethnic minority communities.
- Ensuring language assistance /access via provision of interpreting services and production of translated information.
- Coordinating services to high need populations e.g. refugee, homeless, prison based populations.

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*the highest need are not being adequately served, such as jails, prisons, homeless shelters, and foster care“(US Department of Health and Human Services 2001a p. 168).*

<sup>12</sup> ‘Cultural competence’ is a term used on different levels within the literature. It is often used in the context of individual practitioner knowledge and skills in successfully meeting the needs of ethnic minority clients. However, some authors also use the term to discuss the capacity of the health services or organisation to provide competent care to various groups. Giger and Davidhizar define the term:

*“Cultural competence is a dynamic, fluid, continuous process whereby an individual, system, or health care agency, finds meaningful and useful care-delivery strategies based on knowledge of the cultural heritage, beliefs, attitudes and behaviours of those to whom they render care..... Cultural competence connotes a higher, more sophisticated level of refinement of cognitive skills and psychomotor skills, attitudes and personal beliefs” (Giger and Davidhizar 2002 p. 81).*

See also the following articles in describing cultural competence in areas such as medicine and nursing (Canales and Bowers 2001; Kim-Godwin, Clarke et al. 2001; Giger and Davidhizar 2002 p. 81; Xakellis, Brangman et al. 2004).

- Reducing barriers to treatment such as securing parity in health insurance to cover mental health services adequately, expanding public health insurance to uninsured population.
- Examining cost benefits for culturally appropriate services and providing funding for bilingual community health worker positions to bridge cultural, information and language differences.
- Developing community education programs to discuss and reduce discrimination of mental health and related disability and build trust in services.
- Engaging consumers, families and communities in developing services, maintain active relationships with community leaders and organisations “*One way to ensure that mental health services meet the needs of racial and ethnic minority populations is to involve representatives from the community being served in the design, planning, and implementation of services. Modeled on primary health care programs that successfully target recent immigrants and refugees, some minority-oriented mental health programs appear to succeed by maintaining active relationships with community institutions and leaders. These programs do ... outreach, furnish a familiar and welcoming atmosphere, and identify and encourage styles of practice tailored to racial and ethnic minority groups*” (US Department of Health and Human Services 2001a p. 166).
- Support community capacity via the longer term recruitment and training of minority community members in mental health professions and ensure that educational organisations educate all providers in culturally competent care.
- Encourage consumer and family leadership and support minority consumers to connect with the broader consumer movement in mental health.

- Address various social factors impacting on mental health such as violence, racism, discrimination.
- Strengthen natural resources and work effectively on family levels to build capacities, knowledge and skills (US Department of Health and Human Services 2001a p. 160-8).

One of the discussions present in this report as well as in the mental health literature is the planning issue of encouraging ethno-specific programs as compared to the multicultural transformation of mainstream programs. The report, as well as individual studies, for instance studies such as by Lau and Zane (2000), emphasises that establishing ethno-specific services are successful and cost effective planning methods for increasing access to services. These authors, in studying five Asian based services in the Los Angeles area, found that ethno-specific programs showed higher utilisation rates among these services than mainstream programs, and that consumers attending the specific service had lower levels of need for crisis based and emergency interventions, compared to those consumers in the mainstream mental health services. The study also concluded that improved treatment outcomes were noted with specific services, attributable to the fact that services are provided in the language and cultural context of consumers. This was connected to the observation that increased service use led to better treatment outcomes. These patterns and the resulting cost benefit analysis were not observed with controlled comparison with Asian Americans in mainstream services in the area (Lau and Zane 2000).

In the situation where mainstream programs neglect to specifically understand the needs of consumers from ethnic minority groups and to provide targeted, specifically designed programs and human resources, ethno-specific programs have been seen to provide effective and accessible service environments. Given that many larger communities may quickly be able to gain access to specific programs, these remain important options. On a planning level, however, it is important to recognise that separate services would be difficult to establish across all linguistic groups, and that many smaller communities

would not have the trained staff and bilingual workers available to establish a service. Nor may they have the critical mass of population to support the operation of specific services as clients. Additionally, many community members may choose to go to a mainstream service and would still expect the service to deliver culturally appropriate services. To avoid a return to a mainstreaming or ethno-specific services debate which has been held in countries such as Australia, it is important to suggest that the success of ethno-specific services carries messages about how accessible services can be developed and that these areas of success can be developed in larger, mainstream organisations, given political will and management of outreach/specific teams, bilingual and multi-lingual human resources and connections with local communities.

### **Discussion and Summary**

One of the important considerations in the US context is that much of the research in this area has focused on understanding differential utilisation patterns to services and developing explanations, rather than on evaluating successful programs. The information provided by existing research on utilisation patterns, whether gained from hearings with service consumers and families or from quantitative studies on utilisation figures, produces a diverse range of explanations and ideas for change. These interpretations call for a multifaceted approach to interventions which perhaps relies on political decision making (e.g. decisions on funding services, or holding those accountable for not meeting cultural competence standards) just as much as technical knowledge. In terms of research efforts towards evaluating and understanding the successful components of ‘access programs or projects’ or the efficacy of ethno-specific programs, the funding for such research is subject to the same decision making/ political context as is the funding for these services. The other dimension to this discussion is that the policy framework for cultural competence in the area of rehabilitation services is still emerging and organisations are still trying to manage the transition of a peripheral area of planning, i.e. ‘cultural diversity’, into the core business of planning and decision making.

In respect to the knowledge of how to improve access to services, the literature tends to emphasise a range of knowledge and intervention approaches from the disciplines of social work, psychology and counselling, as well as public health and health promotion. This literature provides theoretical approaches as well as emerging experience from health promotion and community health programs, and emphasises that the certainty of strategies tend to be gained upon consultation with local communities. This literature depicts that improving access requires a commitment by agencies towards improving contacts with local community members and gaining a more intimate understanding of cultural, background and contemporary issues and needs. This commitment also entails a preparedness to work across language and cultural understandings and to modify services upon the wishes and needs of community members. In doing this, services need to be able to work out ways of providing services in multiple languages and this requires a combination of the employment of interpreters, bilingual workers and community consultants. The ability of staff members to understand cultural diversity issues and work in new contexts and across languages requires a significant degree of education, awareness knowledge and skills, with all organisational staff needing to participate in diversity planning and service delivery issues. From the literature on the American experience, it appears that a combination of strategies is needed so that increase in service access can be measured in terms of stronger (increasing) referral networks and improved contact with services, improved satisfaction of service quality from consumer perspectives and better service outcomes in health and living with disability.

## **Study Two: Service utilisation in the UK: issues and program responses**

The discussion of health and disability services utilisation for ethnic minority communities in the UK services system reflects many of the needs, issues and preferred responses raised above. Within the UK there are established literatures commenting on the disparities of health status and health service utilisation. There is a strong focus across general health and a considerable amount of research in mental health. There is also a smaller literature on ethnicity and disability in academic and professional publications. As Ahmad states:

*“Analyses of health and health care of minority ethnic groups constitute a major industry. However, interest in disability and chronic illness among minority ethnic communities is relatively new. Much of this research is small scale; often it lacks theoretical sophistication. The more voluminous and more sophisticated mainstream literature on disability, chronic illness and caring rarely includes minority groups” (Ahmad 2000 p. 1).*

### **Prevalence and Service Utilisation**

The considerable literature that Ahmad refers to in the distribution of health status across ethnicity in the UK portrays that many ethnic minority communities have disparate rates of illness compared to the ethnic majority population. Studies have shown that various ethnic minority groups experience higher levels of poor health and disease, a situation that is associated with the low socioeconomic status of many communities, including Indians, Pakistanis and Bangladeshis (Chandola 2001; Cooper 2002; Saxena, Eliahoo et al. 2002). Gender differences have also been apparent in health disparities, with higher rates of morbidity among women as compared to men within the same ethnic groupings, a situation suggesting multiple disadvantages for ethnic minority women (Cooper 2002). Studies have also shown that migration status, experiences of racism and patterns in the use of health services may all have some contribution to lower rates of health among these populations (Davey Smith, Chaturvedi et al. 2000). Explorations have also been made about the health status of refugee groups, depicting a range of additional factors

including isolation, lack of social support, and experiences of anxiety and uncertainty regarding the future and past events (Burnett and Peel 2001).

In the face of less available national data of prevalence of disabilities among British ethnic minority communities, the trends of poor health and low socio-economic status suggest that disability levels among these communities could also be disproportionately higher. Studies noting the low socio-economic status and material disadvantage of ethnic minority families with a member with disability suggest this possibility (Mir, Nocon et al. 2001; Fazil, Bywaters et al. 2002).

The situation from the health related literature on access to health care services and rates of utilisation also presents some concerning trends. Studies in the utilisation of health services have suggested differential patterns, mainly in lower levels of access to secondary and tertiary health services, such as outpatient services. This includes studies focusing on adults (Smaje and Le Grand 1997) and children (Cooper, Smaje et al. 1998; Saxena, Eliahoo et al. 2002). In terms of access to primary care services, such as general practitioners, ethnic minority groups tend to have equitable access, with variations where some community groups, such as Pakistani males and African-Caribbean females seem to have higher use of primary care services - such as General Practitioners - than the majority ethnic population. This situation perhaps reflects higher levels of need among these communities (Smaje and Le Grand 1997; Livingston, Leavey et al. 2002). Chinese speaking communities in Britain are seen to have significantly lower levels of service in primary care (Sprotson, Pitson et al. 2001) and across other levels of service (Smaje and Le Grand 1997). As an evident trend in the use of health services, the lower levels of access to the specialised health sector reveal possible institutional barriers in referral processes between General Practitioners and the specialised services and raise concerns about the standards of care and service being offered to minority groups (Smaje and Le Grand 1997; Cooper, Smaje et al. 1998; Gerrish 1999).

The subject of access to mental health services is a highly interesting study in utilisation rates and reasons for differences among ethnic minority communities compared to the

majority population. Disturbing trends in systematic disadvantageous treatment towards ethnic minorities, particularly African-Caribbean community members, have been very well documented and publicised by statistical studies for a considerable period (Davies, Thornicroft et al. 1996; Mclean, Campbell et al. 2003). In a critical review of published research on the area, Bhui and Stansfield et al. (2003) concluded that African Caribbeans were over represented among inpatients and Asian community members utilised inpatient services less often than the ethnic majority. However their summary of a range of published literature depicted many diverse trends regarding service access. These included higher rates of compulsory (detained) admission among African Caribbeans, with this particular group being less likely to be referred to specialist services, more likelihood of experiencing police involvement in admissions to hospital, and more likely to present in crisis. A further study within their review found that ethnic minority communities maintained less treatment contact with specialist services (Bhui, Stansfield et al. 2003).

Qualitative studies, which are important in understanding services users' experiences of mental health services (Morgan, Mallett et al. 2004), depict various factors which contribute to unequal patterns in the use of these services. These include mistrust of the likely treatment by mental health professionals, language difficulties and barriers to the ability to participate, express feelings and meanings (Grewal and Lloyd 2002). Reports also raise issues where cultural understandings of mental distress can prevent community members from seeing conditions as treatable (Sheikh and Furnham 2000; Grewal and Lloyd 2002).

In a further summary of recent research into pathways to care, and in forming the context to a range of policy and service responses, the Mental Health Branch of the Department of Health reported that the situation “*is clearly unacceptable and unsustainable*”. The report depicted systematic problems within the mental health services whereby, “*Black and minority ethnic people are more likely to experience:*

- *problems in accessing services;*
- *lower satisfaction with services;*
- *cultural and language barriers in assessments;*

- *lower GP involvement in care;*
- *inadequate community-based crisis care;*
- *lower involvement of service users, family and carers;*
- *inadequate support for Black community initiatives;*
- *an aversive pathway into mental health services:*
  - *higher compulsory admission rates to hospital;*
  - *higher involvement in legal system and forensic settings;*
  - *higher rates of transfer to medium and high secure facilities;*
- *higher voluntary admission rates to hospital;*
- *lower satisfaction with hospital care;*
- *lower effectiveness of hospital treatment;*
- *longer stays in hospital;*
- *higher rates of readmission to hospital;*
- *less likelihood of having social care/psychological needs addressed within care planning/ treatments processes;*
- *more severe and coercive treatments;*
- *lower access to talking treatments” (Department of Health 2003 p. 7-8).*

The Department interpreted this situation as representing ‘circles of fear’, where:

- “• *many people, particularly in the Black African and Caribbean communities, do not believe that mainstream mental health services can offer positive help, so they delay seeking help;*
- *they therefore are not engaging with services at an early point in the cycle when they could receive less coercive and more appropriate services, coming instead to services in crisis when they face a range of risks including over and misdiagnosis, police intervention and use of the Mental Health Act;*
- *these aversive care pathways further influence both the nature and outcome of treatment and the willingness of communities to engage with mainstream services”*  
(Department of Health 2003 p. 7-8).

Some of these issues are represented in research into disability service use by ethnic minority families, particularly in the areas of sensory and physical disability and also learning disability. A recent report into the needs of ethnic minority community members with learning disabilities summarised the key access issues as being:

- *“the higher incidence of impairment in a number of areas*
- *low levels of knowledge of services available for the disabled person or carers*
- *poor standards of communication*
- *delays in diagnosis and treatment*
- *isolation, lack of support and high levels of carer stress*
- *low take-up and poor access to services*
- *high levels of unmet need*

- *lower levels of access to benefits and/or receipt of lower amounts of benefits compared to White claimants with similar needs” (Mir, Nocon et al. 2001 p. 9).*

The authors, in developing their summary, noted that these problematic issues of utilisation and prevalence take place in a context of inequities and discrimination in employment, education, health and social services.

*“The higher prevalence of learning difficulties in South Asian communities has been linked to high levels of material and social deprivation. These may combine with other factors such as poor access to maternal health care, misclassification and higher rates of environmental or genetic risk factors.... People with learning difficulties from minority ethnic communities experience simultaneous disadvantage in relation to race, impairment and, for women, gender. Negative stereotypes and attitudes held by service professionals contribute to the disadvantage they face” (Mir, Nocon et al. 2001 p. 12).*

In researching various reports for the Social Services Inspectorate<sup>13</sup>, it is clear that similar patterns of poor access exist for support and social services across physical and sensory disabilities. A report by the Inspectorate on the way local government authorities fund disability programs and services utilised much of its own service inspection data to confirm broader research about the service needs of ethnic minority communities in Britain. The report summarised many service trends relating to the experience of services by ethnic minority communities and the deficiencies within service planning and delivery:

*“These inspections confirmed the findings of other research into the barriers to accessing services by people from black and minority ethnic communities. These include:*

- *lack of appropriate service information and/or its effective distribution*
- *limited awareness of public services in black and minority ethnic communities*
- *fear of dealing with statutory authorities*
- *inhibition reinforced by experience of racist attitudes*

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<sup>13</sup> The Social Services Inspectorate within the Department of Health conducts audits into the performance of social services according to national frameworks and standards of service. Social services appear to be funded by local government authorities. These authorities in turn, fund volunteer and non-government services to provide services to members of the community with disabilities. Some of the inspection reports of local authorities present interesting displays of how the British system monitors the planning and delivery of social services across local population groups. See the following reports for examples (Department of Health 2000a; Department of Health 2002b; Department of Health 2002c).

- *negative past experiences of services*
- *range of language, literacy and communication difficulties*
- *dearth of black and minority ethnic staff in statutory care services, especially trained bilingual support workers*
- *little confidence in the capacity of authorities to understand and meet their needs*
- *poorly developed care pathways offering co-ordinated and holistic health and social care*
- *non-availability of culturally appropriate services*
- *delay in developing advocacy support.*

*These difficulties are all the greater for black and minority ethnic people with limited or no sight and/or hearing and/or constraints on their mobility and/or the lack of a common language. In that sense, they are disadvantaged minorities within a minority” (Department of Health 2001c p. 7-8).*

### **Responses to improving utilisation and quality service**

Such reports indicate the depth of reorientation required by social services and health services within the UK to improve levels of access and outcomes for community members. It is clear from these reports and other qualitative research on the views of community members, that poor use of services is related to the quality of services offered to families and their experience of these services, rather than related to less need for services, given strong family or informal social supports (Ali, Fazil et al. 2001; Bywaters, Ali et al. 2003). In this view, the obligation is on service planners and professions to redevelop the provision of services.

Bywaters et al (2003) in reviewing the findings of their qualitative interviews with family members, suggested that low use of services in many families is due to a range of barriers experienced in seeking formal assistance<sup>14</sup>.

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<sup>14</sup> This is exemplified by the following quote:

*”There is a good deal of evidence in the experience of these parents that their primary problems in caring for severely disabled children resulted from institutional and structural racism, resulting in poor material circumstances and low access to appropriate services. These were sometimes compounded by disablist and sexist attitudes within the Bangladeshi and Pakistani communities which meant that the stigma of having a disabled child and the primary responsibility of caring for them more commonly fell on the mother than the father... These findings offer no comfort to any professionals or service providers who seek to argue that the fatalistic attitude of ethnic minority parents to disability is a key reason for low uptake of services. Although it was not the focus of the present analysis, there was telling evidence that parents were poorly informed about the medical understanding of their children’s impairments, but little evidence that they rejected*

There is generally a large amount of policy and service related information describing the various interventions the Department of Health has undertaken in recent years to generate equalities in service delivery. There is also a range of professional literature on discussing various aspects of service planning and community organisation (see e.g. Priestly 1995; Bhakta, Katbamna et al. 2000; Jones, Atkin et al. 2001). Another area of professional literature centres on the education of professionals in areas such as nursing and community health (see for example: Menon, McKinlay et al. 2001; Chevannes 2002; Hart and Hall 2003).

Within the national health policy development, many planning reports and commissioned studies point to the legislative context, urging the appropriate monitoring and development of services along the lines of ethnicity and service access. Generally over the past 15 years various British Acts have been amended to highlight the needs of communities around and equality in access to services. These Acts, as referred to in reports, include the Race Relations Act 1976, the Children's Act 1999 (Department of Health 2000a), the Health and Social Care Act 2001, the Human Rights Act 1985, the Disability Discrimination Act 1995 and the Race Relations (Amendment) Act 2000 (Department of Health 2003).

An interesting aspect of the Race Relations (Amendment) Act 2000 for this study is that the Act obliges public departments and services to undertake actions to promote equality in policy development, service delivery and employment<sup>15</sup>. In this sense, public services are obliged by law to strive towards creating service planning, delivery and evaluation

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*medical explanations. Equally, the low uptake of service provision was more likely to be the results of socially created barriers to access than parental attitudes" (Bywaters, Ali et al. 2003 p. 508).*

<sup>15</sup> This requirement is known as the general duty as stated within the Act: "All public authorities listed in schedule 1A to the amended Race Relations Act must carry out their functions with 'due regard' to the need to:

- *eliminate unlawful racial discrimination;*
- *promote equality of opportunity; and*
- *promote good relations, between persons of different racial groups" (Commission for Racial Equality 2002 p. 6).*

processes which achieve equality in ethnic representation in service outcomes and employment numbers. The Commission for Racial Equality is the statutory organisation established under the Act to enforce and ensure compliance of these legal provisions towards promoting equality. Part of the work of the Commission has been to publish guidelines for public authorities/ services and inspection agencies regarding the need to publicly account for the performance of services in terms of the above outcomes. All services under the power of the Act, including all health and social services, must publish a Race Equality Scheme. The Scheme details an organisation's planning and monitoring and the review of existing services in terms of how these contribute or hinder achieving equality in service outcomes and employment ratios. In a framework developed to assist inspection/ accreditation organisations such as the Social Services Inspectorate, the Commission states that public services need to demonstrate a considerable array of equality measures. Plans to achieve these, including data collection, monitoring and evaluation and statements of achievement are part of each organisation's accreditation under the Act's legal provisions, which are built in to broader accreditation standards for health and disability services. The framework document informs inspectors that "*Public authorities that meet the duties consistently, as a regular part of their functions, should expect to be achieving the following outcomes, in the medium to long term:*

- *A workforce that represents at all levels the different communities it serves*
- *No significant differences between ethnic groups in staff perceptions of equal treatment*
- *No significant differences between ethnic groups in the profile of service users*
- *No significant differences between ethnic groups in satisfaction rates among service users*
- *No significant differences between ethnic groups in levels of public confidence*
- *Services meet the needs of the communities the authority serves*
- *No significant differences between ethnic groups in complaints from service users*
- *No significant differences between ethnic groups in service outcomes*
- *No complaints of unlawful racial discrimination or harassment" (Commission for Racial Equality 2002 p. 4-5).*

In responding to the legal provisions of this Act and others in a complex policy context, the Department of Health has developed a number of policy frameworks covering the evolution of other policy, service planning and workforce development in this area.

These policy initiatives span the breadth of activities of the Department and include frameworks of action for social services. These include service development plans which focus on planning process, data collection, review and evaluation and consultation processes with community members.

Other initiatives are focused on the human resources and staff development processes within the Department. Together these documents reflect a very significant example of national policy development to improve services to the culturally diverse community. Some of these can be described briefly.

*'The Vital Connection: An Equalities Framework for the NHS'* is an equal opportunity policy/ strategy which aims to improve and support the diversity of the workforce of the National Health Service, as well as impact on employment opportunities and services available for local communities. This policy is based on diversity principles and encourages measures for the recruitment and employment of people from ethnic minority communities and people with disability<sup>16</sup> (Department of Health 2000c).

*'Improving Working Lives'* is a policy framework concerning human resources within the NHS and improving the working conditions of employees. The framework establishes standards of material for workplace conditions, desired mechanisms for the support and development of staff knowledge and skills and also management and communication standards (Department of Health 2000b). Within this framework, the NHS has

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<sup>16</sup> See the following summary from this document:

“To deliver the Government’s modernisation program and to respond to these equality challenges, all parts of the NHS must work together towards three strategic equality aims: (1) **a workforce for equality and diversity**: To recruit, develop and retain a workforce that is able to deliver high quality services that are accessible, responsive and appropriate to meet the diverse needs of different groups, and individuals: (2) **a better place to work**: To ensure that the NHS is a fair employer achieving equality of opportunity and outcomes in the workplace and (3): **a service using its leverage to make a difference**: To ensure the NHS uses its influence and resources as an employer to make a difference to the life opportunities and the health of its local community especially those who are shut out or disadvantaged. ...These three aims are crucially linked and interdependent - they form a vital connection in maintaining the pace of modernisation. In the following example, we see how great the gains can be when we clearly link action on all three aims in pursuit of a wider strategy to improve health and services, and to promote fair employment and neighbourhood renewal” (Department of Health 2000c p. 8).

established support networks for staff of ethnic minority background on national, regional and local levels. These networks have multiple purposes whereby staff members can focus interest and knowledge on activities which benefit themselves, other workers and also their employing organisations via organised participation in planning and education (Department of Health 2001b)<sup>17</sup>.

*'Positively Diverse'* is an organisational development program, which aims to help individual services and organisations to develop a new culture of service planning, communication and evaluation which reflects the general goals of achieving equality and equity in employment conditions and diversity in the workplace. The program has devised a range of guidebooks<sup>18</sup>, planning and evaluation models for services and also highlights the achievements of new projects and initiatives across the country. The program assists managers to re-orientate their organisations in accordance with those policies above such as *'Improving Working Lives'* (Department of Health 2001b).

It is apparent from many of these documents that the British Department of Health has made a substantial commitment towards building and supporting a culturally diverse

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<sup>17</sup> The document details the purpose of ethnic minority worker networks, where these have a role to:

- *"Be a source of information and guidance to trust boards, organisational leadership and staff in general, including their staff side representatives*
- *Offer a safe and learning environment*
- *Offer individual or peer group support and counselling*
- *Provide access to career advice*
- *Provide role models and advocates for progress in making diversity happen and work*
- *Provide access to BME (Black and minority ethnic) role models to build confidence and inspire individuals*
- *Celebrate and promote success*
- *Provide support to organisations to interpret local, regional and national initiatives and discuss the impact on BME groups*
- *Increase staff awareness of organisational goals and philosophy*
- *Empower staff by improving their knowledge of local, regional and national issues in health care*
- *Demonstrate the organisation's commitment to equality and diversity through positive investment in people*
- *Promote the NHS in the wider community as a good employer and positive career choice*
- *Contribute to awareness training of staff in the special needs of BME patients/clients"*  
(Department of Health 2001a p. 4).

<sup>18</sup> See for instance the Department's guidebook for social services to older people from ethnic minority communities: *'Developing Services for Minority Ethnic Older People: The Audit Tool. Practice Guidance for Councils with Social Services Responsibilities'* (Department of Health 2002a).

workforce and that this development reflects a response to concerns about poor service provision to ethnic minority communities as well a response to its responsibility to these communities as a large employer. The policy context is favorable toward the recruitment of ethnic minority workers as an important means to improve the flexibility of local services in terms of the cultural and linguistic knowledge and skills of teams within services.

On a service delivery level, it is noted, especially from Social Service Inspectorate reports, that various disability related services are employing a large range of practices for providing services to different groups in the community and that there is a rich range of planning experience emerging. One of the central themes in planning services such as rehabilitation groups, support groups, information and counselling services for parents and special education for children etc., is how local government authorities are achieving equity in providing services for many distinct communities. This additionally occurs where local authorities are both providers of social services as well as funding agencies for smaller voluntary programs or local associations (Department of Health 2001c).

For instance, the Social Services Inspectorate notes that some local authorities have struggled over decisions to fund separate disability support programs for specific communities or direct resources into 'mainstreaming', that is, devoting resources within larger services. It is apparent from their report that many services are achieving a balance between these two areas of development. The Inspectorate praised local authorities that worked to develop their own organisations, in terms of improved planning and data collection and analysis, the development of staff education in cultural diversity etc., as well as fund local associations to strengthen community resources, knowledge and connections. The Inspectorate also praised authorities which made these decisions in ongoing consultation with local community members, and which strived to have representation of these communities on decision making bodies. There were examples given where local authorities had developed specific teams within mainstream services, and where they have funded community support groups within local ethnic minority

associations (Department of Health 2001c). In terms of promoting a stronger focus on specific programs and groups, the Inspectorate has advised social services that:

*“In order to overcome institutional racism, Social Services Departments should re-think the approach of providing a common service for everyone and treating both black and white older people the same. This requires greater confidence in developing targeted and specific services rather than being over concerned that this means special treatment...(for ethnic minority community members)”(Department of Health 1999 p. 5).*

A key message is that specific targeting of the needs of various communities and the development of service responses is an aspect of service planning which needs to become systemic or fully integrated. In producing a summary of service development priorities to improve access to disability support programs, the Inspectorate recommended that local authorities needed:

- *”to improve their analysis and understanding of the diverse needs and requirements of people from the many different black and minority ethnic communities, so as to achieve equity of access to services;*
- *to review their workforce planning and development strategies to ensure that sufficient staff with the necessary combination of skills are trained and deployed to best effect;*
- *to promote the development of independent agencies able to empower and to advocate on behalf of black and minority ethnic adults with disabilities;*
- *to define their service development priorities in association with relevant local black and minority ethnic interests, so as to achieve equity of choice and quality of service;*
- *to ensure the appropriate allocation of their resources on the basis of need across all sections of the population;*
- *to set challenging and measurable goals and to be active in monitoring their achievement” (Department of Health 2001c p. 6).*

Mir, Nocon et al’s (2001) commissioned study into the service needs of ethnic minority community members with learning disability, has presented a range of ‘service

principles' for increasing the quality of services<sup>19</sup>. These principles were developed from reviewing successful programs and initiatives across the country in the area of learning disability and cover educational and social services. The authors' principles include the need for strong, continuing partnership with local communities which demonstrate commitment and joint decision making and which can support community members to participate in these planning and decision making processes. The report also calls for the role of advocacy to be strengthened in some community groups, with resources needed to assist communities to organise a voice on disability issues within mainstream service provision. Advocacy services also need to be always available for individuals and families. Mir et al also note that services need to recognise the collective cultural values present in many communities and how these values may run counter to the independence movement of disability services. Family members in many situations need to be involved in individual care plans, assessment and decision making (Mir, Nocon et al. 2001).

A further comment in the report reminds services that discriminatory attitudes within communities do exist regarding disability and that such attitudes need to be discussed with families in terms of their negative impact on life choices and opportunities. Community members need to be empowered in their experience of disability and caring for a person with disability (Mir, Nocon et al. 2001).

The report also recognises that support groups are seen as valuable ways to help community members become informed and aware of their rights. These groups require stable funding and connection to broader planning processes to increase participation. For this to happen, mainstream services still require modification and to improve cultural competence in planning and partnership. With this connection, support groups are gateways to the community and can help as referral networks and ways of generating information and discussion (Mir, Nocon et al. 2001).

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<sup>19</sup> In developing service principles, the study presents a number of case studies from various local communities across England. The case studies either present examples of good practice around certain roles eg advocacy or education, or they present dilemmas and issues common to the field. The report references these case projects and programs. However most of these have been published locally or within local government reports.

The report recommends the improved availability of interpreters and bilingual workers within services for people with learning disability, and that these workers should receive support and education. At the same time, all staff require competency training to prevent ethnic minority needs remaining a peripheral issue on the margins of service planning. Mir, Nocon et al. (2001) suggest that organisational levels of competence are required to help community members feel there is some interest across the experience of organisations, i.e. a good level of continuity in the experience of being valued and having cultural identity and language valued.

The authors' summation regarding organisational competence in this area requires that services need ongoing links and information about the specific communities in their catchment area. Information and community relationships are required to identify patterns of need, the outcomes of referrals and service provision and other areas of performance. As in the Inspectorate's report above, Mir, Nocon et al. (2001) argue that ethno-specific programs do have positive outcomes for many ethnic minority groups and that these need strengthening and secure funding as a means to develop a group identity around specific disability issues and ethnicity. This identity helps promote positive esteem among members and maintains a voice on a community and planning level. The promotion of specific community groups and resources needs to be combined with the cultural development of mainstream services, so that there is a level of integration between the government level and community association level services (Mir, Nocon et al. 2001).

The strategy to strengthen local support groups concerning specific disabilities, for example, groups for South Asian people with visual impairment or Black Caribbean groups with hearing Impairment has been noted by numerous other authors. Priestley (1995) in studying an association for blind Asian people, argued that ethnic minority groups should be supported separately, at least on group and organisational levels. He points out that many members of these groups may experience distance from the general (white) disability rights movement and they do not feel represented by, or able to be accommodated by, many mainstream disability programs. One important aspect of

promoting the separate development of specific support organisations is that members gain confidence and skills. Over time such knowledge and skills will allow community members to access other services and experience more options in the broader disability movement, providing that these services also develop their cultural accessibility (Priestly 1995).

The unique place of ethnic minority community members and their experience of specific disabilities as different from the dominant disability cultures have been highlighted by Jones, Atkin et al. (2001). Their research with young Asian deaf people details various experiences where services influenced by deaf culture are not able to accommodate the religious and cultural aspects of the young people's identity. Their study highlighted how minority parents were worried about education for their children and the thought that their children would be socialised into deaf culture and away from their ethnic identity. Such concerns limited parents' trust in educational and disability support services, and hence their access. The authors argue for the development of specific projects within mainstream programs for young Asian deaf people and that advocates of deaf culture need to be able to recognise diversity of ethnicity, culture and gender (see also Ahmad, Darr et al. 2000; Jones, Atkin et al. 2001).

In a framework designed to improve access to mental health services, the Department of Health highlighted three key areas of development from which to undertake strategic action. The document '*Delivering Race Equality: A Framework for Action*' prioritises the areas of data/ information collection and analysis, appropriate and responsive services and community engagement as pivotal and interlocking factors in service reform. Highlighting examples of best practice in each area, the report describes a range of detailed actions <sup>20</sup>.

Under information collection and analysis, the report obliges services to:

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<sup>20</sup> Similar to other British reports, this document provides examples of notable projects which explain and detail the strategies and actions within the framework. Additionally, the report's appendices present a highly detailed range of actions for increasing access to services. The examples of good practice do not appear to be systemically evaluated, but are described in terms of improving outcomes and how such strategies in community engagement and culturally appropriate service can be realised.

- *“Identify and record patients’ ethnicity (and gender and other relevant data)*
- *Ensure staff, patients and their relatives/carers understand the importance of ethnicity data for improving services*
- *Map ethnic information throughout care pathways to inform decisions about appropriate treatment/services*
- *Trust Boards monitor and review collection and use of ethnic information as part of the Clinical Governance process*
- *Gather local demographic data and conduct with communities needs assessments, including understanding how different cultures within the area regard mental ill health*
- *Use ethnic data strategically to map representation and plan services designed around these different needs/understandings*
- *Monitor collection and use of ethnic data*
- *Monitor local services for impact on different racial groups using outcome and performance indicator data. Mechanisms might include monitoring of local delivery plans,...annual user surveys and development of local benchmarking”(Department of Health 2003 p. 12-13).*

In terms of developing appropriate and responsive services, mental health services will be required to

- *“Assess individual (staff) and organizational learning/development needs*
- *Promote and enable staff to undertake training on RR(A)A 2000 (Race Relations Amendment Act) general duty.*
- *Make workforce representative of the community it serves.*
- *Develop benchmarks and monitor progress on appropriateness and responsiveness of services. Look for outliers and take action as appropriate”(Department of Health 2003 p. 15).*

Lastly, the framework priorities include a number of plans for improved engagement with community members. These activities include the need to:

- *“Support the community engagement process of recruiting and developing Black and minority ethnic Community Development Workers..*
- *Integrate consultation with and representation of Black and minority ethnic VCS specialist services,*
- *Include community and faith groups into the strategic planning process and key joint planning groups*
- *Put in place robust mechanisms to ensure this representation is underpinned by consultation and engagement with the wider local Black and minority ethnic community*
- *Develop benchmarks of and monitor progress on community engagement, referring to relevant local government targets/activity. Account should be taken of*

*local councils' responsibility to maximize the impact of initiatives and synergy across activities" (Department of Health 2003 p. 18).*

In commenting on these actions, it appears that the rationale for this development is clearly related to an analysis of the current barriers to mental health services experienced by ethnic minority community members. Within the information collection actions, there is a move to learn about any differential outcomes for community members according to ethnicity and also develop analysis of the types of pathway to assistance which results in positive outcomes for community members. In respect to developing more responsive services, there is, like so much of the literature on this area, an emphasis on the education of staff in relation to service standards and obligations and the recruitment of bilingual and representative staff in clinical areas. Under the community engagement category, there is also recognition of the need for community development activities and mental health promotion and education. This is combined with improving mechanisms for community participation in planning and decision making.

### **Discussion and Summary**

The various descriptions of policy and service development in this particular study demonstrate a very substantial effort by British authorities to understand and respond to problematic service utilisation issues. The presence and depth of reports, across many areas of health and disability services, suggest that policy makers are making a concerted effort to operationalise notions of inclusion, access and equality in the provision of public service across community groups and interests.

A number of themes stand out in looking at the organisation of these efforts. First, compared to other nations such as the US, there is a strong structural analysis openly present within many of the reports, and the commonly used explanatory analysis, institutional racism, is usually the theoretical basis for development. It is interesting that legislative provisions such as the Race Relations Act and inquiries, such as the Stephen Lawrence Inquiry and the subsequent Macpherson Report, have given recognition to institutional racism as discriminatory service practices which need systematic removal

from the operation of public services in the UK, including law enforcement authorities, educational services, the employment sector and health care/social services (Department of Health 1999; see also Esmail 2004). This awareness of the need for a strong policy driven process, and also the nation's centralised health and social services system, has enabled the development of a more coordinated framework of standards, accountability and enforcement provisions. The amount of activity apparent in the reports also demonstrates that the nation is developing a unique range of knowledge about this area on local and regional levels.

A further interesting aspect of the documents from the UK is that there is an approach to developing both mainstream and specific community programs. The Inspectorate reports suggest that local authorities take the view that there cannot be an 'either/or' approach to the issue of funding service development initiatives, e.g. multicultural teams, staff training and community outreach programs, or local community associations. A more comprehensive program for raising service utilisation, or providing services which meet community needs, includes both areas of development and resourcing.

Another theme present in the reports and articles in this study was the recognition of community advocacy as a central role for improving service quality and accessibility. Many reports referred to the important nature of advocacy programs and that community organisations are often pivotal in helping community members to have a voice in expressing their needs and interests, and also meeting others with similar experiences and interests. Advocacy and support programs are seen as helping community members to form a collective identity and expression. Many reports noted that advocacy and support organisations required improvements in ongoing funding and recognition and that these are key organisations in advising and sharing knowledge with mainstream educational and rehabilitative services. Advocacy programs also help improve referral links and successful access to mainstream programs.

In general, the documents illustrating service development in the UK describe many of the areas of planning and organisational change which were documented in the earlier

study on the United States. Individual areas of planning in British documents included workforce development in terms of staff education in cultural competence and the recruitment and employment of minority professionals and health service workers. Also included was a range of strategies for building relationships with communities and improving participation practices. Such strategies included those associated with health promotion, community education and community development approaches. Building connections with community members is a central area of activity for enabling new services and practices which are culturally informed and responsive to community members' needs, social circumstance, background and identity. A strongly apparent area of planning was the focus on information and analysis, and the need for services to improve their collection and analysis of information which could depict utilisation patterns and outcomes for individuals and all ethnic minority groups, in comparison with the majority population. Importantly, all of these planning areas are supported by a policy context expressing the desire for equal opportunity and equality across the workforce population and in services available to the community. The UK provides a very significant example of policy makers integrating understandings of cultural diversity, inclusive of diversity in ethnicity, ability, sexuality, age, etc, into plans of action within large and complex health and social services.

### **Study Three: Service utilisation in Canada: issues and program responses**

A great number of the themes present in the first two studies are again prevalent in examining the health and disability service situation in Canada. Finding published data on levels of disability among ethnic minority communities was difficult compared to the US and Britain. Major reports such as *'In Unison 2000: Persons with Disability in Canada'* and *'Advancing the Inclusion of Persons with Disabilities'* do not appear to comment on this experience of disability within various ethnic minority groups, although the later report has a focus on disability within Canada's Aboriginal communities (Health Canada 2000b; Government of Canada 2002). There is certainly a broader academic literature discussing the experiential effects and difficulties of people living with disability and ethnic minority status, and commenting on the sociological intersections of ethnicity and disability (see for example, Health Canada 2000a; Ontario Human Rights Commission 2001; Stienstra 2002; Khanlou 2003). There is also professional literature detailing the education of professionals in the rehabilitative workforce in terms of cultural competence skills and knowledge (Dyck and Forwell 1997; Forwell, Whiteford et al. 2001; Majumdar, Browne et al. 2004). However, the review's search of journal publications did not locate many evaluative studies of strategies for improving access to disability services. In a similar situation to the other two nations, there appeared to be a larger research focus on disparities in health care and access to health care services.

#### **Prevalence and Service utilisation**

Within this literature, trends on the health of Canadian ethnic minority communities suggest that there are not large disparities in health status between immigrant communities and non-immigrant communities (Globerman 1998; Health Canada 1999; Health Canada 2001a). In reviews by Health Canada, some ethnic minority communities appeared to experience fewer long term activity limitations (indicative of disability) than the majority population<sup>21</sup>. There are also research trends suggesting that many newer

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<sup>21</sup> However, an important consideration in relation to this Canadian research is that specific refugee communities are not seen to share this positive health status of other immigrant communities (Health Canada 1999).

established communities on the whole, are healthier than non-immigrant communities and that their health deteriorates the longer they live in Canada (Chen, Ng and Wilkins cited in Health Canada, 1999 p. 22-23).

*“National data reveal that immigrants (especially recent immigrants) are less likely than the Canadian-born population to have chronic conditions or disabilities. Generally, this is attributed to two factors: (1) those in good health are more likely to emigrate; and (2) the Canadian immigration screening process disqualifies people with serious medical conditions” (Health Canada 1999 p. 23-4).*

*“Findings indicate that most immigrant women arrive in Canada in good health but experience an increased risk of poor health status over time owing to financial hardship, work- and resettlement-related stress, inadequate social support, changing health behaviors, and cultural, economic, and systemic barriers to appropriate health services. Contrary to popular belief, there is no evidence that immigrants over utilize health-care services as a whole; however, underutilization is prevalent in the use of preventive and mental health services. Findings further suggest that the health of immigrant and visible minority women is largely determined by environmental and living conditions, and often changes in response to pressures associated with poverty, marginalization, and class inequity” (Hyman 2002 p. 338) <sup>22</sup>.*

In terms of health service utilisation, studies have found that immigrant communities, as a whole, tend to utilise health services at similar rates to non-immigrant groups, with some exceptions in certain areas<sup>23</sup> (Blais and Maiga 1999; Health Canada 1999).

Laroche's study revealed that immigrant communities have lower rates of G.P. usage compared to non-immigrant communities (Laroche 2000), while others have found that higher rates of G.P. use exist for some immigrant communities (Health Canada 1999). In a study in Quebec by Blais and Maiga (1999) G.P usage was found to be similar across

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<sup>22</sup> A study of the prevalence of chronic disease and disability amongst Canadians suggests health and disability status is associated with gender, with women having higher rates of chronic disease and disability compared to men, a finding consistent across all ethnic groups classified in the study (DesMeules, Turner et al. 2003).

<sup>23</sup> A review by Globerman, which was focused on exploring claims that immigrant communities over use health services, concluded that “*over the complete life cycle, there may be little difference in health care utilization patterns both across immigrant groups, as well as between immigrants and native-born Canadians*” (Globerman 1998 p. 22).

all groups, but with ethnic minority groups having higher rates of usage of private specialists<sup>24</sup>.

In terms of mental health services, numerous studies point to consistent under utilisation of formal services<sup>25</sup> (Kirmayer, Galbaud du Fort et al. 1996; Health Canada 1999; Pyke, Morris et al. 2001). Similar trends of underutilisation have been found with respect to using preventative health services, such as screening services in Women's health (Hyman 2002).

### **Barriers to service use**

In reviewing the literature of service use and the accessibility of services, a report from Health Canada notes that more research is needed<sup>26</sup>, especially given that smaller studies

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<sup>24</sup> An interesting aspect to service use by ethnic minority communities and various utilisation studies is that many community members may use different services in different ways, and that their patterns of use may change over time, according to their acculturation status and familiarity with the host society (Leduc and Proulx 2004). On a broader level, there is a need to contextualise what utilisation studies actually can reveal. There are many interpretations on the possible meanings concerning utilisation disparities and how these are problematic. Health Canada provides an interesting range of explanations:

*“Much published research that attempts to measure, rather than describe, access of underserved populations has used utilization as a measure of access. There are serious limitations in equating access with utilization as differences in utilization may or may not indicate problems with access. For example if a certain group (e.g. immigrants, or Aboriginal people) is found to have similar levels of utilization as the overall Canadian population, this could mean that the population: is of equivalent health status as the general population and uses health services similarly; is healthier than the general population but uses services more than are needed; is sicker than the population but due to access barriers uses services less; has different patterns of service utilization (e.g. uses fewer preventive, but more acute, services); is of lower health status than the general population but relies on resources outside of the health system” (Health Canada 2000a p. N/A).*

<sup>25</sup> Kirmayer, Galbaud du Fort et al. explored service utilisation across medical services and specialised mental health services. Similar rates of use were observed across non-immigrant and immigrant groups for the use of medical services while use of mental health services and other health services for psychological distress was significantly lower for the immigrant communities involved in the study. Lower use of services was more apparent in the Vietnamese and Philippine groups:

*“Taken together, these analyses suggest substantial under-utilization of mental health services by immigrant groups that cannot be attributed to differences in gender, level of education, employment status, level of distress, or alternative sources of care. The most important factors appear to be the understanding and interpretation of psychological symptoms, the desire to deal with personal problems on one's own or within the family and the perception that health care professionals who understand the immigrants' cultural background are not available” (Kirmayer, Galbaud du Fort et al. 1996 p. 126-7).*

<sup>26</sup> *“Much less research was found than expected in the area of health system support and*

have raised knowledge about the barriers to service for immigrant women, refugee community members, and torture survivors. In these studies, there is generally a strong awareness of the common difficulties experienced by service users and those in need. Such issues include language difficulties, cultural misunderstandings, staff discrimination and devaluing of cultural identity, etc. A combination of these factors is commonly attributed as the reasons why services may be under-utilised (Health Canada 1999; see also Simms 1999; Women's Health in Women's Hands Community Health Centre 2003)<sup>27</sup>.

In examining the range of barriers and practices which may limit community member uptake of services, a recent Canadian report suggested that meeting language needs is perhaps the most critical factor needing systematic development across the health sector. After a review of national studies,

*“There is compelling evidence that language barriers have an adverse effect on initial access to health services. These barriers are not limited to encounters with physician and hospital care. Patients face significant barriers to health*

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*renewal, given the prominence of the topic and the potential effects on some immigrants of regionalization, spending reductions or slowdowns and changes in focus from institutions to the community. Existing research focuses on conventional health care utilization data (hospital and physician care), costs of services for immigrants, accessibility of services related to cultural appropriateness, provider sensitivity and knowledge, and other barriers” (Health Canada 1999 p. 53).*

<sup>27</sup> From Simms' report of the conference of the National Organization of Immigrant and Visible Minority Women of Canada.

*“The main issues raised at this conference were: isolation from mainstream society created by differing cultural values; cultural belief systems and practices that create serious barriers for women in their understanding, accessing and interaction with the health care system; lack of access to culturally-sensitive health care services; problems of professional accreditation which prevent highly-qualified professionals from this population from participating in the health care professions; the inability of large numbers of immigrant and refugee women to speak English or French. (This language problem is seen as the major obstacle to accessing social services.); the under-representation of immigrant and racial minority women in the health care professions, on the boards of directors of hospitals, universities, and other major institutions that not only train personnel but also set policies that determine the level and type of health care in the country; compromised mental health due to the stigmatization of their immigration and socio-economic status, racism, and general marginalization. This situation leads to alienation, frustration, isolation and, ultimately, to stress, which results in poor mental health” (Simms 1999 p. N/A).*

*promotion/prevention programs: there is also evidence that they face significant barriers to first contact with a variety of providers.... Recent research that includes the variables of both ethnicity and official language proficiency suggests that in many cases, language, rather than cultural beliefs and practices of patients, may be the most significant barrier to initial contact with health services” ... (Health Canada 2001b p. vi).*

This particular report also detailed the impact of communication difficulties between professionals and clients/ patients and how quality of care can be compromised in various ways, including patient satisfaction.

*“Quality of care for those who are not fluent in an official language is affected through interaction with health professionals who may, because of language barriers, fail to meet ethical standards in providing health care. Language barriers may result in failure to protect patient confidentiality, or to obtain informed consent.... A number of studies have examined different aspects of patient satisfaction with care. Patients who do not speak the same language as their health care providers consistently report lower satisfaction than those who share the same language as their providers” (Health Canada 2001b p. vi).*

Beyond the explanations of issues on the service level, there is also a range of commentary about the way in which services operate and the representation of staff and decision making within health services. Simms’ (1999) report on the conference of the 1995 National Organization of Immigrant and Visible Minority Women of Canada noted that under-representation of minority women in the health care professions is a major issue, one that contributes to the ‘invisibility’ of their needs in service planning, delivery and research.

In their commentary on the accessibility of health services and immigrant health Galabuzi and Labonte, raise the importance of connecting service level issues, such as the provision of interpreter services, to the macro level of structural factors such as education, employment and urban housing. In their analysis, the health and health care access of immigrant communities is directly related to community member marginalisation from safe and well paying jobs within the workforce and education opportunities which help members to gain higher socio-economic status.

*The 'racialization of poverty' compounds inequalities in living conditions and health status. Labour market segregation, high unemployment, low occupation status, living in substandard housing and in dangerous or distressed neighborhoods, homelessness, working at dangerous work sites, working extended hours and/or multiple jobs, and experience with everyday forms of racism, lead to unequal health service utilization and differential health status (Health Canada 2003 p. 3).*

These authors point out that any analysis of health care service access needs to take into account the nature of systemic exclusion or institutional racism. Health services also perpetuate practices of institutional racism and may help to contribute to the lower health status of immigrant communities via the unreflective maintenance of barriers and disincentives to effective use (see also Women's Health in Women's Hands Community Health Centre 2003). Their analysis is common to various structural explanations found within the fields of public health and health promotion. Such explanations call for reform of health service practices both within the operations of service themselves, i.e. in the management of human resources and in the services offered to communities, and also in the broader roles of the health sector in raising attention to other areas of disadvantage and marginalisation (e.g. in the workforce).

### **Responses to improving utilisation and quality service**

As highlighted above, a number of broad ranging reviews have commented on the lack of research into program strategies which increase access to services and quality for ethnic minority communities. The general situation in Canada regarding this situation is very similar to the previous national studies: the low availability of comprehensive research on proven, effective strategies for improving services to communities is contrasted with a vast range of proposals for improving access and quality. Many of these proposals cover levels of policy, service development and community oriented interventions. In light of the previous parts of this review, it is interesting to see some consistency emerging when the Canadian proposals for action are considered.

An extensive review entitled '*Certain Circumstances: Issues in Equity and Responsiveness in Access to Health Care in Canada*' has summarised areas of change across many areas including:

- the proactive recruitment of health service providers from under-served communities
- improving cultural diversity education for providers in their pre-service (university education) preparation
- the development of alternative service/ practitioner roles, for instance the development of bilingual health liaison workers, or bilingual community educators/ outreach workers
- the role of specialist academic health research centres and the need for such centres to continually trial and research strategies and service models which improve access to services
- the improvement of service programs in terms of flexibility and creatively in funding scenarios/ schemes
- improvement to the provision of interpreters within services and the need for an overarching policy for the provision of interpreters across service sectors
- the development of community outreach/ education initiatives which provide information to community members and provide accessible avenues to learning and assistance. These programs also to produce new sources of information or improve community literature on key health and disability issues
- the need to improve policy and funding structures in the ways services are funded between larger institutions and community organisations, in which the latter may be more able to reach underserved communities
- the need to develop diversity policy frameworks which establish standards of accessibility and quality of care across cultural and linguistic difference. These policy frameworks should contain clear statements of action within the above areas and also contain mechanisms for data collection, monitoring, reporting and enforcement
- the establishment of better practices in the areas of participation and decision making. This area includes improving representation on decision making committees within programs and organisations, within research initiatives and planning forums (Health Canada 2000a)<sup>28</sup>.

The report provides substantial detail in developing action in each of these above areas and includes cautions that such directives need to be undertaken as central planning priorities within service sectors. There are many examples where discontinuities in the funding of effective programs or research projects work to disadvantage progress in the multicultural development or capacity of the larger health arena. The marginalisation of various smaller programs and ethno-specific community projects in certain areas of health and disability helps continue the situation where services and their availability are fragmented across geographic areas, and in linguistic and cultural terms. The '*Certain*

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<sup>28</sup> These strategies are summarized from the section of the report entitled Responses/Solutions.

*Circumstances'* report discusses this planning difficulty in terms of advantages and disadvantages of population specific programs:

*“One approach to addressing barriers is to develop services focused on specific populations. These services may be operated by hospitals, community health centres, public health departments, or community based not-for-profit organizations. There are a number of potential advantages to population-specific initiatives in addressing access needs. These include:*

- *centralization of resources*
- *development of a "Centre of Expertise"*
- *an environment which facilitates confidence and participation of clients*
- *clear accountability for provision of access services*
- *greater potential for community direction and control, responsiveness to needs, and flexibility*
- *potential to build in bridging/advocacy functions to other parts of the health system.*

*However, they also have a number of potential disadvantages, which suggest that they should not be the only response to access needs. In addition to requiring a "critical mass" of clients (which means that they will not meet the needs of smaller populations or those in smaller centres), such responses risk "ghettoizing" clients. Provision of a population specific service may result in restricted choice for clients if other alternatives are not provided” (Health Canada 2000a p.n/a).*

Within this discussion, the report draws out a central theme of the success of ethno-specific programs and suggests that large organisations can also mirror the advantages of programs which are driven by consumer preferences.

*‘Most innovative programs combine several initiatives into their response. What these programs seem to have in common is that they are developed in response to health needs and access barriers as experienced by users. They also focus on organizational change and community partnerships’ (Health Canada 2000a p. n/a).*

The themes of inclusion within the proposals of the above report are mirrored within an article published by Health Canada and written from contributions by Galabuzi and Labonte. In responding to their analysis of the structural factors of discrimination, racism and socio-economic inequality, they call for a framework for promoting social inclusion and the establishment of social rights. In advocating the development of stronger policy

frameworks in this area, they suggest that the focus should not only be on marginalised groups, but also on the social conditions and inequities which continue to disadvantage minority groups in socio-economic, health care and educational terms. Within the health care sector, they recommend that a policy focus on social inclusion should be expressed via changes to the organisation of health services and on broader social conditions which limit people's health care opportunities. Their requisites for organisational change in health care organisations include

- *“increasing access to appropriate health services for immigrants and racialized groups that incorporate culturally sensitive and language specific services for all health needs, including mental health services*
- *confronting racism in policy and practice and putting legal restrictions on racism in place*
- *training health workers to be culturally sensitive, and other activities designed to help reverse the process and impact of social exclusion*
- *hiring health workers from visible minority groups*
- *helping minority communities build support networks*
- *protecting racialized workers and new immigrants from unsafe and discriminatory working environments*
- *undertaking research into the impacts of the multiple dimensions of social exclusion on the health status of the target group*
- *empowering racialized groups to participate in developing policy and program responses to the multiple dimensions of social exclusion” (Health Canada 2003 p. 4)<sup>29</sup>.*

Additionally, the authors suggest that health planners and policy makers can also influence other policy areas: *“As partners with other policy-makers, the health sector can also act as a knowledge broker and advocate in areas such as housing, transportation and urban planning” (Health Canada 2003 p. 4).*

Assessing the existing policy response to service utilisation issues, beyond the above recommendations, is difficult in the Canadian context due to the relative absence of available or published departmental policy directives<sup>30</sup>. There are some examples of

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<sup>29</sup> See also the report by the Women's Health in Women's Hands Community Health Centre (2003) in advocating a range of recommendations for service policy based on an anti-racist approach. This report concerns services available to young women from ethnic minorities.

<sup>30</sup> This information may be available, but does not appear to be readily published on government websites in a manner comparable to the UK.

documents which promote policy frameworks for equity and diversity. One of these relates to the area of mental health care as a reform plan driving the development of mental health services within a regional area of Ontario.

Reports from this development depict that regional authorities have responded to the area's considerable cultural diversity by employing a framework of diversity (Central East (Whitby) Mental Health Implementation Task Force 2002; Champlain District Mental Health Implementation Taskforce 2002). The authors state that

*“In order for Central East (name of planning region) to effectively reform its mental health system, it must, on a systemic level, embrace diversity. It must become a system in which cultural competence and inclusivity are the norm” (Central East (Whitby) Mental Health Implementation Task Force 2002 p. 49).*

The proposed framework nominates three arms for assisting the regional and local service to embrace diversity. These include a system inclusiveness strategy, which focuses on

*“operational policy, practices and composition that acknowledge, support and encourage diversity. (The) management structure will make a commitment and plan to align program policies and practices in a way that emphasizes cultural competence in the following areas:*

- *declaration of the importance of diversity;*
- *policies, procedures and practices;*
- *personnel practices; and,*
- *organization composition” (ibid. p. 50).*

The second part of the framework is an outreach and linkages strategy which demonstrates methods for specifically engaging under-served communities.

*“This strategy is based on the assumption that although organizations may become ‘diversity friendly’ with the implementation of the ‘system inclusiveness strategy, it does not mean that traditionally marginalized populations will begin using their services. There will need to be an effort to ensure that diverse population groups are informed of the available services, and that services are marketed in a way that invites participation. The Outreach and Linkages Strategy proposes a continuous and well-developed strategy<sup>31</sup> for communication and linkages with diverse population groups” (ibid. p. 50).*

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<sup>31</sup> This strategy is described as containing actions such as the:

The third arm of the policy is described as the diverse treatments strategy, which focuses on

*“approaches, services, programs and structures that are founded on evidence-based practice and regular community consultation. It includes policies, procedures, training and education that enable services to be provided in a culturally and linguistically appropriate manner. Agencies may be “diversity friendly” and well linked with diverse population groups, but they will also need to adapt services or create new programs to address special needs and values” (ibid. p. 51).*

In terms of human resource policy, the search also found some evidence of documents within the health and disability sector promoting the employment of a culturally diverse workforce. The Ontario provincial government has encouraged employers within long term residential services to consider strategies for recruiting and employing immigrant workers. Pointing out the need for health employers to follow equal opportunity legislation, the document also provides the following justification for employing workers from new and established immigrant communities:

*“Recent and established immigrants offer a tremendous recruitment opportunity for long-term care facilities. There are two key reasons for targeting recent and established immigrant groups. First, there is a general shortage of Canadian-born workers, particularly those in health professions such as nursing. Many people born outside of Canada have been trained and are looking for ways to gain qualifications in Canada. By offering them an initial opportunity in your facility, when their qualifications come*

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- *“Involvement of diverse communities in the system management structure.*
  - *Development of promotional and educational materials appropriate and accessible to identified communities.*
  - *Promotion of services through various communication channels.*
  - *Development of specific alternative strategies for publicity within identified diverse communities” (Central East (Whitby) Mental Health Implementation Task Force 2002 p.6).*

This policy arm also promotes “active ‘outreach’ and ‘inreach’ with organizations that traditionally support diverse populations, such as ethno-specific agencies, immigrant aid agencies, settlement agencies, shelters, hostels and other community-based organizations. For example, this strategy would include:

- *Involvement of diverse communities in the planning, delivery and management of services.*
- *Inviting diverse communities to provide education/information sessions to staff.*
- *Ensuring that meetings and conferences are structured so as to facilitate the involvement of diverse communities.*
- *Using a range of mainstream and non-mainstream media to promote programs and services.*
- *Using culturally appropriate vehicles for communication with diverse communities.*
- *Developing and maintaining ongoing communication with leaders of relevant communities.*
- *Mechanisms and resources are allocated to foster and develop networks and linkages” (ibid. p. e6).*

*through, they will most likely want to stay with your facility. Secondly, your facility may require workers with knowledge or skills pertaining to certain cultural groups. While this may not preclude hiring Canadian born citizens from a specific cultural background, you can expand the potential pool of qualified applicants by considering new and established immigrants” (Ministry of Health and Long-Term Care 2004 p.14).*

Apart from a small number of documents, the search did not find a solid policy context within health detailing provisions for diversity and equity in the health workforce. This is in contrast with the British context which had a broad array of statements, mechanisms and funded programs. This appears to be the same case in other policy areas. Beyond the health and disability service arenas, it is important to point out however that the Canadian context does have equal opportunity and anti-discrimination legislation<sup>32</sup> which affords citizens protection from discrimination based on racial grounds and which would implicate the activities of health and disability services (Ontario Human Rights Commission 2001). In addition, there are information and promotion agencies supporting equal opportunity and helping employers to understand the policy context and how it benefits employers and communities (see for example, Government of Ontario 2001). Canada also has legislation in the form of the Canadian Multiculturalism Act (1985) which promotes recognition of cultural diversity and cultural identity, equal participation and access to services (Government of Canada 2003a). Another interesting agency is the legislatively established Race Relations Foundation which is an organisation committed to assisting cultural diversity and anti-racist practice across spheres such as education, employment and other areas (Government of Canada 2003b).

In assessing this situation it appears that Canadian health and disability authorities may be relying on promoting this broader range of legislative provisions to its service planners and policy makers rather than on reinterpreting these into its own policy documents. However, the lack of a strong policy context, where policy makers have directly reinterpreted national legislation into a set of coherent frameworks which document service and employment standards, and hold agencies accountable for action and monitoring change, is noticeable on the information reviewed to date.

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<sup>32</sup> The ‘*Canadian Human Rights Act*’. See Ontario Human Rights Commission (2001) for more detailed discussion on discrimination on multiples grounds, an issue very relevant for ethnic minority community members with disability.

## Examples of service and community level initiatives

In exploring some examples of action on a service development level, there are a number of Canadian articles which depict how programs have become successful in lifting the utilisation rates of services with specific communities. It is useful to include these in the review as they also illustrate how certain organisations have implemented the types of policy components listed above.

The first of these is a paper by Ramaliu and Thurston (2003) who report on the development of a community based program for assisting refugees who had experienced torture and trauma prior to living in Canada. Their article describes various ‘best practice’ service strategies and inter-agency collaborations undertaken by the program to address the specific needs of various community members who were experiencing torture and trauma related disabilities, including Post Traumatic Stress Disorder and various other impairments. In developing the treatment program over many years, the organisation undertook a number of steps to increase the capacity of its own organisation as well as the larger service provider sector which could provide required services to this client group. Briefly, these activities included:

- Significant formal and informal participation practices with clients<sup>33</sup>, ethno-specific community members, workers and leaders, the volunteers of the service, representatives from government services, medical and counselling professionals and workers from other non-government programs.
- The connection of this program with a larger volunteer program of the parent organisation. This link allowed the treatment program to connect to the various ethnic minority community members forming the background constituency of the service and allowed for more meaningful information sharing, participation and community knowledge.

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<sup>33</sup> The authors provided the background to these consultations:

*“Efforts were also made to seek the input of survivors of torture. Because of ethical considerations related to stigmatization, labelling, and fear of retraumatization, these efforts were less systematic and more individualized. These consisted of home visits, casual meetings, and information sharing mostly with survivors who had successfully overcome the sequel of trauma after several years in Canada” (Ramaliu and Thurston 2003 p. 167).*

- The recruitment of professionals from various ethnic minority communities to build up the representation of the program and increase its bilingual/ bicultural knowledge and skills and community links.
- Providing various educational activities for workers from various public and private organisations, medical and counselling services on the needs of the client group.
- Developing networks of treating professionals from these organisations that could provide services to the client group across organisational and sector boundaries. The treatment program secured brokerage funds to pay these professionals for their services but also allowed for 'in kind' provision. The networks were also maintained via participation and educational activities for members and formal agreements between organisations. Referral to these 'networked' providers, for services such as counselling, specialist medical conditions and various therapies, became a central role for the treatment program.

One of the interesting aspects of the program's work in establishing this type of collaborative service was that the program achieved good relationships with local communities as well as impacted on the mainstream service sector and helped these services become more accessible:

*“One of the apparent successes in the development of the (treatment) program was the development of a common vision among immigrant-serving organizations and mainstream service providers. The building of working relationships helped to break the assumption that mainstream organizations were more professional than immigrant-serving agencies. On the other hand, the collaboration increased refugee access to services provided by mainstream organizations. As their services became inclusive of a culturally diverse population, the need to build cultural competency and “to practice difference” was enhanced. Exposure to training and awareness offered by the program served this purpose. Developing cross-cultural communication skills to facilitate medical, psychological, and crisis management of survivors of torture, along with political and advocacy education, survivors’ social and legal issues, self-care, and coping strategies, have been some of the topics discussed among service providers. By virtue of ethical responsibilities and a sense of ownership about the program, service providers have been in the forefront of the social action to denounce the effects of torture (e.g., court testimonies), advocate for the needs of survivors, and help build professional knowledge (e.g., research and publications, college and university teaching). Addressing the complex health needs of survivors of torture and building community capacity to continually address their needs are indicators of the program success” (Ramaliu and Thurston 2003 p .171).*

The program perhaps illustrates the need for flexible programming for meeting the service needs of minority groups within a context of limited resources:

*“(the) service to survivors of torture is provided in a collaborative service model - a multiparty collaboration wherein working relationships have been built and refined among various professionals and organizations. The ... Program is unique in the city in providing this multidisciplinary and multidimensional response to the refugees it serves. Lacking a collaborative model, singular programs are at risk of limits in program design, capacity, and sustainability” (Ramaliu and Thurston 2003 p. 168).*

A further service level discussion on accessibility is provided by Pyke, Morris et al. (2001) in regard to mental health services. The authors describe a range of organisational changes undertaken by a community mental health agency in Toronto, a city with great cultural and ethnic diversity, in order to help ethnic minority clients gain access to treatment, information and rehabilitation services. The organisation’s directions for change were instigated at board and staff levels with the development of anti-discrimination and employment equities policies and the establishment of an anti-racism subcommittee. Various plans of action were developed from this subgroup including the need for a proactive recruitment and support plans for improving ethnic minority representation on both staff and board levels and achieving equity in the use of the organisation’s range of mental health programs (Pyke, Morris et al. 2001).

On the service level, the organisation targeted the various ethnic minority communities in its service area and also began to work more closely with other providers who had established programs with these communities. The article describes one relationship stemming from inter-agency collaborations whereby a Somali community worker was employed part-time within two provider organisations, and played a pivotal role in connecting the staff of the mental health program with local members of the Somali community. This work role assisted information sharing and networking between the mental health service and a range of ethno-specific programs of the community. Eventually educational programs were developed to assist local Somali workers to better understand the mental health of community members and also assist staff and other

mainstream providers in understanding some of the background issues facing the community.

The authors report that such collaborative arrangements and educational processes have greatly improved the program's links with the local Somali population, resulting in improved access and quality of service. The experience has also helped the program to learn significant approaches which it will take in connecting with other groups on a community, capacity building basis. The program reported that it had already employed a number of bilingual case managers from other local groups (Pyke, Morris et al. 2001).

## **Discussion and Summary**

Reflection upon the material presented in the preceding pages suggests that Canada has a considerable understanding of the needs of migrant groups in terms of health care and health status. Many of the understandings about health service use have a public health flavour to them, with many commentators discussing ethnic minority community access to services in terms of a population health approach.

The review found numerous documents advocating an array of required responses for improving the range of services available to community members. Similar to the previous nations, the range of initiatives included those on levels of policy development, organisational change and planning, and operating on the community level.

In terms of policy development, it was noted that Canada has a substantial legislative base calling for the recognition of cultural identity and participation rights across all community groups, and that services should be afforded to minority communities on equitable terms. The review suggested that, compared to the UK, Canada did not present a substantial interpretation of these provisions within policies in the health and disability<sup>34</sup> sectors. This meant it was difficult to see how services would be obliged to

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<sup>34</sup> The review found it difficult to comment on specific disability services and those in the area of rehabilitation. The range of services in the disability sector in Canada is highly diverse and fragmented, with many local community agencies involved. The review found reports commenting on the highly varied context of service provision, and the mix of national, provincial and local services within the disability

develop effective services for minority community members where there is a lack of explicit service requirements and accountability processes<sup>35</sup>. This situation may be the result of the various literature and research reviews by *Health Canada*, which purport that health status and health service utilisation does not appear to be significantly lower for immigrant communities. It is interesting to consider that where there has been a well known history of under-utilisation, as seen in mental health for example, there has been a committed policy response on diversity issues and improving service quality.

In respect to exploring the service and community levels of activity, there was a range of discussions detailing areas of service change and the development of human resources. These papers raised the need for an improved approach to the provision of interpreter services, an increased recruitment of staff from minority backgrounds<sup>36</sup> and further cultural competence education and training for all staff members, including at the pre-employment level. One paper also discussed the need for services to consider specialist worker/ service roles, such as liaison, information and education to improve referral and information links between communities and organisations.

The review found some studies which illustrated interesting examples of collaboration and organisational change in relevant areas. Studies showed the value of organisational

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arenas. Website searches revealed that there are a number of multicultural advocacy and information organisations focused on disability within Canadian provinces. In exploring all of this information on the sector, it was difficult to find an explicit focus on service use by ethnic minority communities. Reports surveyed included: (Blackford, Fougere et al. 1999; Human Resources Development Canada 1999; Health Canada 2000b; Government of Canada 2002; Office for Disability Issues 2002).

<sup>35</sup> Common understandings within the literature on accessible services indicate that the needs of minority community members tend to remain invisible to large state bureaucracies, unless there is a substantial effort to reach out to communities and review the actual use of services by community members.

<sup>36</sup> A number of Canadian commentators were critical of simplistic approaches of recruiting ethnic minority workers as a means of being able 'match' the ethnic/ gender background of clients with an available staff member of the same cultural / gender background. Authors were wary that often the recruitment of minority workers for this reason is seen as the sole answer for the under utilisation issue. Improving access and utilisation, they argue, requires a range of strategies and work force development options, including education to raise the cultural competence of all staff and the development of different roles, e.g. health liaison workers. Recruitment of minority workers is still required to improve the cultural representativeness of the workforce and for reasons of equal opportunity and inclusion (Health Canada 2000a; Le Centre d'excellence pour la santé des femmes 2000; Women's Health in Women's Hands Community Health Centre 2003).

networks and agreements in planning joint services for specific client groups, and that networks can provide a basis for change to mainstream services as well as support and inform local community groups. In these examples, organisations used strategies such as community participation, community education and staff education in integrated ways, so that each area of activity supported the other strategies, and fostered a sense of shared purpose and interest across community participants, professional staff and participating organisations.

## **Successful approaches to increasing access, utilisation and equity in the provision of services: Implications of the literature**

In this section, the review summarises and discusses many of the common themes present in the literature on utilisation from the three preceding national studies. In particular, the discussion focuses on approaches to policy and service development which have been seen as successful in creating more accessible services. The discussion also highlights that successful efforts to improve the services offered to ethnic minority communities are based on integrating change across multiple levels of policy and service planning. These efforts are also based on developing significant and participatory relationships with local community networks and agencies from other service sectors. The discussion also makes mention of the international context of health inequalities and the efforts of other nations.

### **Successful aspects of Policy and Service Development**

There are a number of major observations that can be made about the policy development process in the various countries studied. Starting at the broad level of the legislative basis of policy, it is important to note that rights and entitlements to service for members of ethnic minorities, and the subsequent expectations of equity are enabled via legislative provisions in the areas of anti-discrimination, equal opportunity and other specific national and state Acts. This legislative platform, common in all three nations, provides rights to residents and citizens and establishes 'service obligations' for public and publicly funded services.

There appears to be various emphasis on how national and regional governments have responded to laws about rights and obligations, with some governments taking a more proactive response of developing policy to achieve more concrete levels of equity in the provision of services and in employment of ethnic minority community members – for example in the UK, and others acknowledging that the law protects citizens' interests, and that citizens, with an awareness of their rights and entitlements, will eventually help influence how services will respond to their needs (see Bollini and Siem 1995).

There was an interesting aspect of the legal provision / organisational policy connection in the UK, whereby policy and service development was driven by legal provisions which highlighted desired equity targets and also requested compliance by various public services. The emphasis which governments place on policy development in this area may relate to the history of research which shows long term disparities in service access or treatment afforded to ethnic minorities. It may also be related to the acknowledgement of differential treatment in legal proceedings, and where courts and legal bodies have subsequently made judgments and recommendations for removing discriminatory and racist behaviour from public services.

In connection to the above two points, some service sectors have developed sector wide plans for increasing the quality and accessibility of services, e.g. as evidenced by the examples from mental health. In this situation, policies have been developed which target the activities of many areas of a service sector, for example in the UK there is an integrated policy context including specific approaches to diversity and equality within recruitment and employment, human resources support and management, organisational change and planning and services to the community. There were also examples where policies within a sector also targeted the education of professionals and included educational and training organisations as collaborators in achieving equity.

Many commentators regard the need for an overt policy process as a central step in beginning to address health inequalities and poor service provision. The acknowledgment of the issues of equality and equity and the need to attempt to operationalise these concepts in terms of the accessibility and use of services to the local communities is pivotal. An important assumption of this policy development is that the problematic nature of poor access to services can remain invisible, along with the negative outcomes this may have for community members experiencing poor health or disability, unless there is a proactive stance taken by policy makers. For instance, unless there is a set of service standards and requirements for achieving equity in the provision and distribution of services, and an accompanying process of collecting and generating

data on community use and preferences, service managers and policy personnel will not be able to acknowledge the extent of equity being achieved. They will neither be able to explain nor comment on how services are meeting the diversity of needs of community members.

The UK example, in appearing to offer the foremost illustration of a centralised policy approach to improving services and building a representative and equitable workforce, shows just how challenging this area of change can be. The experiences of a number of research and service projects point to these challenges as well as successful ways of implementing change. The reports by Inspectorates depicted a significant variation in the amount of development undertaken by different health authorities, with some health and social service authorities undertaking innovative planning and service designs and other services producing very little acknowledgment of cultural diversity issues. A similar situation was evident in the US concerning access to vocational services. While the sector here was directed by an access and equity type framework, there was a mixed uptake of recommendations by different services. In this respect, Culley (2001) suggests that while very important, policy frameworks of equal opportunity and increasing minority employment have often failed to be acted upon by services. She provides a number of reasons why frameworks commonly fail to achieve improved representation and equity. These reasons include a failure of many policy initiatives to establish and fund concrete, realistic activities based on clear objectives, and the non-acknowledgement of various disincentives for service managers to follow up on new policy. These disincentives may be the extra cost of implementing policy, and also the challenges to existing employment arrangements and traditional practice structures (Culley 2001). A further challenge is that funding new programs and staff to target ethnic minority communities raises the possibilities of cuts to existing areas of service. Such moves can be unpopular with existing clientele and raise various political dynamics among clients, staff and service management.

Culley also raises the shallow understanding of racism and its correction, via improved representation, contained in many policy documents in the UK. She argues that most

policies are essentialist in the themes of ethnicity, racism and representation in unrealistic ways. When imposed on service staff as new policy, these notions can be embraced superficially and managed on paper, yet without significant 'cultural' change to the attitudes, understandings and practices of staff. Diversity policy is something that is managed expediently according to competing organisational and professional interests (Culley 2001). Her analysis perhaps points to the basis of commitment required by local services to develop services in this area. While political and higher departmental commitments are important to establishing change, there needs to be considerable thought to how local services understand, commit to and implement new policy guidelines. The variation between services which have acted and those who have not suggests that successful organisations in this area are those committed to cultural diversity issues. Leadership on the sector level and within individual organisations is a prerequisite to success (Health Canada 2000a; Culley 2001).

Many of commentaries on policy development in the review noted the challenge of conceptualising service responses for increasing access and quality. There was evidence from all three nations that there were struggles and conflicts in planning for the development of mainstream programs or the funding of ethno or population specific programs. The policy literature generally details a range of arguments and careful analysis in discussing how governments need to proceed in this area. Often there are tensions between directives to meet community needs and to support local support groups and advocacy associations and other directives regarding integrated services and avoiding separatist or parallel services. The review noted that there is an emerging understanding that sectors need to support both areas of development if possible, and that mainstream services need programs which strengthen specific local groups and identity, but which also aim at improving the cultural competence of staff knowledge, skills and organisational responses. Documents from Canada and the UK raised the need for funding bodies to understand that the diversity of needs can be successfully met by flexibility and diversity in service design – that is, there can be a proactive approach to supporting separate groups in the context of acknowledging and discussing fears of

separatism and flawed notions of the 'same treatment for everyone' (Health Canada 2000a; Department of Health 2001c; Johns 2004).

In a discussion of the UK experience, Johns (2004) argues that policy platforms need to be very clear about the way in which diversity is conceptualised and how the idea of employment initiatives in recruiting ethnic minority workers is tied to expectations of improvements in service. He suggests that the simplistic notion of improving representation and the numbers of minority workers will lead to improved services is pervasive in many examples of policy, yet flawed when the experiences of organisations and employees are considered. There are many dangers of expecting minority workers to represent their communities in professional duties. These workers become 'ethnicised' in all parts of their working identity. His concerns include the marginalisation of minority interests as being the responsibility of minority workers and the situation where these workers identify with professional culture and perpetuate ethnocentric practices of their profession rather than be advocates of their representative community. Other concerns relate to rejection of diversity policies and minority workers by other staff and misunderstandings of the nature of diversity, culture and positive discrimination (Johns 2004).

Many of the descriptions of organisational planning and service change referred to in the review reveal an awareness of some of the challenges to be worked through in planning decisions. This is perhaps why approaches to cultural competence prioritise competence as the key concept of development rather than ethnic matching or representation. Approaches which emphasise staff education and the development of knowledge and skills have tended to point out that establishing quality services is an organisation wide responsibility. Staff with a commitment to diversity and who possess the knowledge and skills to work across cultural and linguistic boundaries are central to improving links with local community members and can be effective advocates. The competency approach does not necessarily preclude the need to employ minority workers, but argues that diversity issues are everyone's concern. Examples of programs found in the review highlighted the success of outreach programs where staff from all backgrounds worked

with specific communities, and workers from these communities were present as advisors and cultural brokers, not as the sole professional work force. In these programs, staff had the experience of working and building professional relationships across cultures and also worked with other organisations with similar interests in connecting to particular community groups.

A feature of the services which have made successful efforts to engage local communities is a combination of leadership among staff and management. Examples of successful programs developed individual service policies on accessibility and equity and were able to translate policy targets into feasible activities. Such activities included increasing the diversity of board and staff membership and extensive education strategies for staff. The successful programs also placed a high value of strategies which established relationships with community members and invited their knowledge and expertise into the organisation. These programs also understood that building participation took significant amounts of time and resources and required that services deliver on expectations established with community members. A further approach was that successful programs made a substantial effort to work across barriers of language and understanding, where resources for interpreters, translation and the development of community education, information materials were made available on a consistent level.

The review also found that community level interventions were seen as very important by numerous reports. Reports from the disability areas in the UK noted that community networks of carers and consumers and local workers need to be recognised and strengthened by the work of larger organisations and disability services. Programs which were effective in supporting networks were those which offered information, education and also, in some cases a participatory model of learning and exchange focused on a particular health or disability issue. Community networks play important roles in community and individual advocacy, communication, social support and as advisors to organisations. These networks also help in building referral links and a working knowledge of reputable professionals and support workers. In contributing to the development of community resources and networks, programs worked outside traditional

organisational boundaries, connecting successfully with other programs and thinking outside organisational interests. Such programs also worked successfully with local community members, establishing new worker roles in terms of liaison and peer educators. The challenge for large organisations is to engage effectively with a core constituency of community members who are experiencing disability related issues which are also the interest of the organisation. The implication of this is that large programs in a diverse community will need multiple series of relations according to the number of different groups in their catchment area. Successful bureaucracies will have strategic plans and participatory relationships with numerous community groups, with a mix of population specific strategies within an overall multicultural program.

### **Improving accessibility and utilisation in the international context**

The review initially attempted to research attempts to improve service utilisation from many countries with known immigration programs and multicultural policy. Searches were made for publications from countries within Scandinavia, Europe and Africa. Information from New Zealand was also considered. In these searches it became clear that a great deal of the available documentation in the English language is derived from the UK, US and Canada, with this observation helping to guide the eventual focus of the review.

The searches of articles and publications within Scandinavian and other European countries revealed literature in the area of health inequalities and service utilisation by immigrant communities. There was again a strong focus on general health and mental health in countries such as Sweden, Denmark and the Netherlands, where numerous studies have been undertaken on whether negative patterns of health status and service use exist for the ethnic minority groups in these nations (Sundquist 1995; Uniken Venema, Garretsen et al. 1995; Knipscheer, de Jong et al. 2000; Helsedepartment/Ministry of Social Affairs 2002; Krasnik, Norredam et al. 2002; Samarasinghe and Arvidsson 2002; Uitenbroek and Verhoeff 2002; Iverson and Morken 2003; Ghazinour, Richter et al. 2004; National Institute of Public Health 2004). Within literature on

disability rates and service use, many articles found remained at the general level and did not detail usage rates by ethnicity (e.g. Krokstad and Westin 2004).

With respect to articles discussing methods or interventions for improving access, the review found only scant material from these nations. Nearly all of the available materials reported only utilisation issues and rarely moved towards discussing the level of policy and service development required to improve rates of use. The most detail gained for any one country concerned articles discussing cultural competence education in Swedish health care centres and in medical education (Ekblad, Marttila et al. 2000; Wachtler and Troein 2003).

A discussion of health inequalities on the international level, written a decade ago, made some interesting comments about the responses of governments to issues of poor health status and under-utilisation of services. This perhaps helps to understand why some nations seem to produce large amounts of knowledge on development while others do not:

*“It is very difficult to make generalizations on the patterns of migrant health policies in the various receiving countries because of the many historical, political and cultural elements which have shaped interaction between the host societies and their migrant and ethnic groups.... However, two broad categories may be identified: (a) Countries in the first category display a 'passive' attitude, in which migrants are expected to make use of the existing health system without any major modification. Of course, cultural differences and linguistic barriers are understood by individual professionals and organizations (usually non-governmental organizations, NGOs) within the country, but the provision of special programmes and services and organizational modifications are not deemed necessary. Information on the health of migrants is usually very scanty as well as the monitoring of health care delivery. (b) Countries in the second category show an 'active' attitude, in which the special health needs of immigrant communities are acknowledged and steps are taken by the health authorities to ensure that linguistic and cultural barriers are minimized. This is usually accomplished by organizing specific services for different ethnic groups, especially in large cities, by organizational changes within mainstream health services to accommodate the requests of a multiethnic clientele, or by a mixture of these two elements. Usually, information on the health of migrant communities for planning and evaluation purposes is fairly well developed in countries showing an 'active' attitude” (Bollini and Siem 1995 p. 826- 7).*

This article cites Sweden, Canada and Australia as leading countries for developing responses to improving the health status of their migrant communities. It would be promising to consider the Scandinavian nations in more depth regarding specialist policy and programs. It is likely, however, that this effort would require additional resources to work across languages in reading local reports and journals. The active and passive attitudes raised by the above comments are evident throughout the documentation recorded within the review. Overall it appears that the UK is the best example of an active response to minority services and planning, with the great range of material generated by the National Health Service and various authorities published and openly available to the public. The extent of thinking and discussion is indicative of a nation quite serious about improving the health of ethnic minority communities.

The United States perhaps reflects a more individualised approach to services within the area, and more of a reliance on protecting the rights of the individual against discriminatory treatment. Canada, judging by the information uncovered by the study, appears to be in a similar position to the US, where there is a strong legal context of protection and rights, but less of a presence on policy directives within health and disability sectors.

## **Integrated Policy, Service and Community Capacity Building**

The review has documented and described many areas of policy and organisational development seen as successful in promoting movement towards more accessible and useful services. Improving services to ethnic minority communities within the disability sector requires a constellation of strategic community, policy and service delivery activity. Without synergies being created between these three domains, progress will be stifled and human and structural resources will continue to be used in singular governance structures without involving community participation. Below is a list of strategies and principles described within the reports and articles reviewed that support this conclusion:

### **Principles**

- Decisive leadership from policy makers and planners in the sector. This should take the form of setting the context for the development of integrated diversity policies across the lifespan in areas such as human resources management and service planning. This leadership should also include setting realistic policy targets, schedules for organisational change and clear models of funding.
- Management of individual services should include appropriate resource allocation to support organisational change that is effectively in line with broader policy initiatives.
- Management of individual services to support organisational change, demonstrate leadership and allocate resources effectively in line with broader policy initiatives.
- A willingness to promote and embrace organisational structures that ensure community members can meaningfully participate and contribute to the development of services for themselves and members of their communities.

- Working collaboratively, to build alliances and partnerships within and beyond the disability sector whereby larger services may develop a range of concurrent ethno-specific and multicultural programs in response to the diversity of the local populations inclusive of flexible and creative programming.
- Policy makers to integrate notions of cultural diversity policy within the overall policy context of a sector or jurisdiction. Assessment of this principle could begin with the questions: To what extent are the cultural diversity policies integral across all the operations of a department? To what extent has our department regarded cultural diversity policies as an ‘add on’?

## **Strategies**

- Policies supporting the development of services need to take into account service strategies targeting the activities of other public services. That is, a focus on improving the accessibility of other services as well as within the specific sector.
- Policy makers to establish standards of access and equity, plans for the improvement of data collection methods and analysis and forms of reporting, accountability, and evaluation by individual services and programs. Data should include quantitative and qualitative sources of information and measures of equity need to be designed in relation to population statistics and prevalence estimates.
- Planners to consult with various committed staff members across the sector and consider how staff can establish networks of interest and activity across individual service boundaries. Creative and flexible approaches to the administration of staff activities can free workers to consult and share expertise across organisational boundaries, and catchment areas.

- Policy makers to action flexible and innovative ways of providing interpreter and translation services to clients of the services within the sector, including those non government services and programs the sector funds.
- Policy makers and service management to develop action and evaluate plans to increase the diversity of staff members to reflect the general diversity of the community. This strategy should be seen as contributing to the diversity of staff's cultural knowledge and connections to local community, rather than as a major service strategy of 'ethnic matching'.
- Policy makers and service management to develop plans for the ongoing development and education of staff members in various diversity issues associated with the accessibility of services, cultural factors influencing understanding of disability and health related conditions and also communication. Staff education strategies need to adopt principles of lifelong learning and include the topics of flexible service design, networking, outreach strategies and community education.
- Service sector collaboration with educational institutions to increase the cultural competency (awareness, knowledge and skills) of professionals and workers during their initial education.
- The development of strategies for engaging local communities and community networks so as to include community members and representatives in the development of useful services for specific communities. Services should be designed and delivered in respect to common preferences communicated by community members. Strategies for engaging community members include outreach community education and development, using the local media, developing new information resources and creating specialist liaison and peer education positions for local community members and workers.

- Strategies for strengthening existing support, advocacy, referral and education networks and associations within and across specific communities. Community networks, usually comprised of key individuals and representative organisations, can provide considerable information and knowledge to mainstream programs and help increase referral rates and improve service outcomes.
- Strategies for working legitimately across organisational boundaries, where numerous services can share projects and workers where these have common outcomes for individual programs.

## **Conclusion**

Broadly speaking, poor access to services is seen as resulting from an array of various factors, including issues on structural, service, and community levels. The literature examined in this report points to interactions between these levels of social activity as being influential on successful access to services. For example structural factors such as institutional racism and indirect discrimination in educational and employment areas affect the socio-economic status of many ethnic community members, which in turn limits their access to primary and secondary services in health care. Within public health and disability services, the invisibility of migrant needs, service utilisation patterns and low levels of staff cultural competence, is likely to lead to services being less accessible to community members who cannot afford alternative services in the private sector. Within many ethnic minority communities, disablist and stigmatising attitudes and fears of culturally inappropriate services may lead members not to seek help from formal services.

In researching the literature on successful strategies for promoting utilisation, many commentators and governments have noted that improving access to services requires a multifaceted and multilevel range of interventions. These include establishing a strong policy context covering reform of health service practices and human resource practices in regard to cultural diversity and representation. Policy reform also includes promoting

diversity programs across areas such as income support, education and training and labour market programs. On the service level, supported by this policy context, services have been noted as needing development across areas of data collection, planning and evaluation, staff education, community promotion/ information and professional practices and services. Within a community context, a range of interventions have been highlighted which aim to increase the knowledge, literacy and information regarding specific disabilities and appropriate services for community members. Advocacy programs, community education and community development (strengthening community associations and structures) are seen as important community level interventions.

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