Te Poari Tautoko I Nga Rohe Ki Te Raki

Northern DHB Support Agency

Working with District Health Boards towards excellence in health and disability support services

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Culturally Competent Child Disability Services in New Zealand

Literature Review

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Table of Contents

7. Appendices

1. Executive Summary

Disability care requires specialised services. Health and disability systems are complex to navigate (Bronheim et al., 2006). For peoples from culturally and linguistically diverse (CALD) backgrounds the disability system is difficult to understand. The difficulties include what services are provided; how they are provided and how to get access to services. Additionally, culturally diverse groups may have different understandings of disability and of caring for people with a disability. For many, disability services may not have existed in countries of origin. Families from ethnic minority groups are less likely to participate in decision-making about the services that they and their children receive (Bronheim et al., 2006).

There are few studies in New Zealand of the responsiveness of disability services to the culturally and linguistically diverse groups served. The few New Zealand studies that are available are of adult populations with disabilities (Ripple Trust, 2003; Tse et al. 2006). In 2006, the *Auckland Regional Settlement Strategy* identified improving access to disability services for refugees and new migrants as a health action area. In 2007, the *Auckland Regional Settlement Strategy Health Steering Group* comprising representatives of the three Auckland region District Health Boards undertook a needs analysis for children and young people with disabilities from CALD backgrounds. The report found that clients from refugee and new migrant backgrounds comprised between 20 and 25 %[1] of the caseloads of Child Disability Services in the Auckland region. Families from non-English speaking backgrounds and from refugee backgrounds presented with high and complex needs, and had intensive needs for disability services and support. The findings of the needs analysis indicated that from the available information, there appeared to be disparities between CALD and the total population[2] in:

- the uptake of needs assessments
- access to support services after assessments, and
- access to equipment and technology.

The findings suggest that refugee and new migrant children with disabilities may not be receiving the same quality of care as the total population.

Internationally, cultural competence frameworks and cultural models of care are an emerging response to improving the responsiveness of Child Disability Services to the culturally and linguistically diverse populations served. This paper presents the findings of the international literature on providing culturally competent care for children and young people from CALD backgrounds including organisational cultural competence frameworks; cultural brokerage models; cultural competency professional development programmes; and research and evaluation methods.

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[1] The culturally and linguistically diverse groups served are those coded by Statistics New Zealand at Level 2 as *Asian NFD, Southeast Asian, Chinese, Indian, Other Asian, Middle Eastern, Latin American/Hispanic, African (or cultural group of African origin* and *Other* (see Appendix 1)

[2] The Ministry of Health *Pacific Peoples' experience of disability: A paper for the Pacific Health and Disability Action Plan review* (2008) findings show similar disparities and issues of access (see Appendix 2)

2. Defining Cultural Competence in New Zealand

The concept of 'cultural competence' was developed in health care to better meet the needs of increasingly culturally diverse populations, and in response to the growing evidence of disparities in the health of ethnic minority groups (Betancourt et al., 2003; Brach & Fraser, 2002). In New Zealand, interpreting what is meant by cultural competence is complicated by the fact that the Health Practitioner's Competence Assurance Act does not give a clear definition of the term. Professional registration bodies for the health and disability workforce in New Zealand have each defined cultural competence in different ways. Some examples of the definitions that are being used are shown in this section including those of the Medical Council of New Zealand (MCNZ), Nursing Council of New Zealand (NCNZ), the Aotearoa New Zealand Association of Social Workers (ANZASW), the Auckland Region Allied/Public Health/Technical MECA, the Occupational Therapy Board of New Zealand, and the Physiotherapy Board of New Zealand

2.1 The Medical Council of New Zealand

The Medical Council of New Zealand published the following *Statement on Cultural Competence* in August 2006

Purpose of this statement
This statement outlines the attitudes, knowledge and skills expected of doctors in their dealings with all patients:

The Council has developed a complementary *Statement on best practices when providing care to Mäori patients and their whänau* which deals with the standard expected of doctors when dealing with Mäori patients. A resource booklet entitled Best health outcomes for Mäori: Practice implications has also been developed which addresses the disparity between mainstream and Mäori health outcomes, discusses cultural concepts and provides advice for doctors. These resources should be read in conjunction with this statement. The Council also aims to develop additional resources to help doctors when treating patients from other cultural groups

Introduction

1. Medical doctors in New Zealand work with a population that is culturally diverse. This is reflected by the many ethnic groups within our population, and also in other groupings that patients may identify with, such as disability culture, gay culture or a particular religious group. The medical workforce itself includes many international medical graduates and a variety of ethnic groups. Cross cultural doctor-patient interactions are therefore common, and doctors need to be competent in dealing with patients whose cultures differ from their own

2. Patients' cultures affect the ways they understand health and illness, how they access health care services, and how they respond to health care interventions. The purpose of cultural competence is to improve the quality of health care services and outcomes for patients

3. Benefits of appreciating and understanding cultural issues in the doctor-patient

relationship include:

- Developing a trusting relationship
- Gaining increased information from patients
- Improving communication with patients
- Helping negotiate differences
- Increasing compliance with treatment and ensuring better patient outcomes
- Increased patient satisfaction

4. Cultural appreciation or understanding also has the potential to improve the efficiency and cost-effectiveness of health care delivery

Statutory responsibilities

5. In addition to setting standards of clinical competence, the Medical Council has a responsibility under section 118(i) of the Health Practitioners Competence Assurance Act 2003 to ensure the cultural competence of doctors

6. The Code of Health and Disability Services Consumers' Rights (the Code) also imposes a statutory duty upon doctors. The Code states:

Right 1 – Right to be treated with respect
(1) Every consumer has the right to be treated with respect.
(2) Every consumer has the right to have his or her privacy respected.
(3) Every consumer has the right to be provided with services that take into account the needs, values and beliefs of different cultural, religious, social and ethnic groups, including the needs, values and beliefs of Mäori

Right 2 – Right to freedom from discrimination, coercion, harassment and exploitation
Every consumer has the right to be free from discrimination, coercion, harassment, and sexual, financial or other exploitation

Right 3 – Right to dignity and independence
Every consumer has the right to have services provided in a manner that respects the dignity and independence of the individual

Definition of cultural competence

7. The Council has adopted the following definition of cultural competence:

"Cultural competence requires an awareness of cultural diversity and the ability to function effectively, and respectfully, when working with and treating people of different cultural backgrounds. Cultural competence means a doctor has the attitudes, skills and knowledge needed to achieve this. A culturally competent doctor will acknowledge:

- That New Zealand has a culturally diverse population
- That a doctor's culture and belief systems influence his or her interactions with patients and accepts this may impact on the doctor-patient relationship
- That a positive patient outcome is achieved when a doctor and patient have mutual respect and understanding."

8. Cultural mores identified by the Council are not restricted to ethnicity, but also include (and are not limited to) those related to gender, spiritual beliefs, sexual orientation, lifestyle, beliefs, age, social status or perceived economic worth

9. The Council emphasises that doctors need to be able to recognise and respect differing cultural perspectives of patients, for the purpose of effective clinical functioning in order to improve health outcomes for patients

Cultural competence standards

10. To work successfully with patients of different cultural backgrounds, a doctor needs to demonstrate the appropriate attitudes, awareness, knowledge and skills:

11. Attitudes

    - A willingness to understand your own cultural values and the influence these have on your interactions with patients
    - A commitment to the ongoing development of your own cultural awareness and practices and those of your colleagues and staff
    - A preparedness not to impose your own values on patients
    - A willingness to appropriately challenge the cultural bias of individual colleagues or systemic bias within health care services where this will have a negative impact on patients

12. Awareness and knowledge
    - An awareness of the limitations of your knowledge and openness to ongoing learning and development in partnership with patients
    - An awareness that general cultural information may not apply to specific patients and that individual patients should not be thought of as stereotypes
    - An awareness that cultural factors influence health and illness, including disease prevalence and response to treatment
    - A respect for your patients and an understanding of their cultural beliefs, values and practices
    - An understanding that patients’ cultural beliefs, values and practices influence their perceptions of health, illness and disease; their health care practices; their interactions with medical professionals and the health care system; and treatment preferences
    - An understanding that the concept of culture extends beyond ethnicity, and that patients may identify with several cultural groupings
    - An awareness of the general beliefs, values, behaviours and health practices of particular cultural groups most often encountered by the practitioner, and knowledge of how this can be applied in the clinical situation

13. Skills
    - The ability to establish a rapport with patients of other cultures.
    - The ability to elicit a patient’s cultural issues which might impact on the doctor-patient relationship
    - The ability to recognise when your actions might not be acceptable or might be offensive to patients
    - The ability to use cultural information when making a diagnosis

- The ability to work with the patient's cultural beliefs, values and practices in developing a relevant management plan
- The ability to include the patient's family in their health care when appropriate
- The ability to work cooperatively with others in a patient's culture (both professionals and other community resource people) where this is desired by the patient and does not conflict with other clinical or ethical requirements
- The ability to communicate effectively cross culturally and:

    - Recognise that the verbal and nonverbal communication styles of patients may differ from your own and adapt as required.
    - Work effectively with interpreters when required
    - Seek assistance when necessary to better understand the patient's cultural needs

2.2 Auckland Region Allied/Public Health/Technical MECA

Cultural Responsiveness

This practice domain advances the competencies for practitioners regarding cultural competence for Pacific cultures or for people from other cultures that you interact with in your clinical/professional practice. Cultural responsiveness requires and awareness of cultural diversity and the ability to function effectively and respectfully when working with people from different cultural backgrounds. It also requires awareness of the practitioner's own identity and values, as well as an understanding of how these relate to practice. Cultural mores are not restricted to ethnicity but also include (but are not limited to) those related to gender, spiritual beliefs, sexual orientation, abilities, lifestyle, beliefs, age, social status, or received economic worth. The development of objectives based on the themes identified below relies on maintaining key relationships to ensure oversight, direction, leadership and guidance from the appropriate people within local organisations and the community.

Theme	***Example of Activities***
Demonstrates alignment of clinical/professional practice and appropriateness with policies related to other cultural population groups represented in your DHB	- Develops and maintains relationships with groups representing an identified culture - Demonstrates a working relationship with relevant community resources - Demonstrates an understanding and analysis of current issues in specific client groups - Links DHB Strategic plan with clinical practice in key target areas
Develops an in-depth understanding of an identified cultural group within your DHB	- Researches into an identified culture, its wider environmental context, leadership structure and its interplay with clinical practice - Researches DHB vision and values and that culture's population group's principles of health, linking this to own role and responsibilities - Researches disparities in the DHB population and links this to own service
Leads and supports an aspect of cultural responsiveness within own service area	- Demonstrates leadership and role modelling in both clinical and professional practice and service delivery - Challenges culturally inappropriate practices and supports staff to make changes - Is actively involved in developing cultural policies within own service - Develops needs assessment of cultural requirements for staff - Cultural knowledge and appropriateness is applied to clinical and professional practice

	- Demonstrates an understanding of own issues regarding cultural intervention - Demonstrates a working relationship with relevant community groups - Develops understanding and analysis of current issues in specific client groups - Leads the DHB Strategic Plan with clinical practice in key target areas

2.3 Nursing Council of New Zealand

***Guidelines for Cultural Safety, the Treaty of Waitangi, and Maori Health in Nursing and Midwifery Education and Practice* (NCNZ, 2002)**

The cultural safety concept in the 2002 guidelines 'incorporate[s] a broad definition that 'in addition to ethnicity' includes, 'groups that are as diverse as social, religious and gender groups' (NZNC, 2002, p.4). The Nursing Council of New Zealand (2002, p.7) defines cultural safety as:

> *The effective nursing or midwifery practice of a person or family from another culture, and is determined by that person or family. Culture includes, but is not restricted to, age or generation; gender; sexual orientation; occupation and socioeconomic status; ethnic origin or migrant experience; religious or spiritual belief; and disability.*
>
> *The nurse or midwife delivering the nursing or midwifery service will have undertaken a process of reflection on his or her own cultural identity and will recognise the impact that his or her personal culture has on his or her professional practice. Unsafe cultural practice comprises any action which diminishes, demeans or disempowers the cultural identity and wellbeing of an individual.*

In 2007, *Competencies for Registered Nurses* were introduced including the requirement to practice "in a manner that the client determines as being culturally safe" (NCNZ, 2007, p. 9).

Cultural Safety Competencies for Registered Nurses

The Nursing Council of New Zealand, (2002) *Guidelines for cultural safety, the Treaty of Waitangi, and Maori health in nursing and midwifery education and practice* serve as the basis for the indicators of competence related to the practice of cultural safety for all ethnic groups in New Zealand. The 2007 *Competencies for registered nurses* provide the indicators that nurses are expected to demonstrate when practising "in a manner that the client determines as being culturally safe" (NZNC, 2007, p. 9). The competencies include the nurse's ability to (NZNC, 2007, p. 9):

- apply the principles of cultural safety to nursing practice;
- recognise the impact of the culture of nursing on client care and endeavour to protect the client's wellbeing within this culture;

- practise in a way that respects each client's identity and right to hold personal beliefs, values and goals;
- assist the client to gain appropriate support and representation from those who understand the client's culture, needs and preferences;
- consult with members of cultural and other groups as requested and approved by the client;
- reflect on his/her own practice and values that impact on nursing care in relation to the client's ethnicity, culture and beliefs;
- avoid imposing prejudice on others and provide advocacy when prejudice is apparent

2.4 The Aotearoa New Zealand Association of Social Workers (ANZASW)

The cultural competencies required by registered social workers are described in the

- The Auckland Region Allied/Public Health/Technical MECA and;
- The ANZASW Standards of Practice

The ANZASW Standards of Practice

The ANZASW is the professional body which provides the structure for accountability of social workers to their profession. The ANZASW sets ten practice standards for the assessment of practitioner competency. The following standards of practice pertain to cultural competence:

Standard 3

The social worker establishes an appropriate and purposeful working relationship with clients, taking into account individual differences and the cultural and social context of the client's situation.
This standard is met when the social worker;

- Uses cultural and gender appropriate verbal and non-verbal communication
- Is able to work with a variety of individuals and groups and
- When the social worker demonstrates a knowledge of: the concepts of culture, class, race, ethnicity, spirituality, sex, age and disability and understands the impact of racism, poverty and sexism at a personal and institutional level

Standard 7

The social worker has knowledge about social work methods, social policies, social services, resources and opportunities and acts to ensure access for clients.
This standard is met when the social worker demonstrates a knowledge of:

I. Social work practice with Pakeha, Maori and Pacific Islands peoples and other ethnic groups, including the following aspects:
    a. Communication processes
    b. Planned, purposeful social work processes
    c. Groups processes
    d. Change strategies
    e. Preventative strategies
    f. Social planning, social action

    - g. Community work and community development
    - h. Power and authority issues
    - i. Privacy and confidentiality
    - j. Empowerment strategies
- II. Social services, including the following aspects:
    - a. The role of government
    - b. The role of non-governmental organisations (NGOs)
    - c. The role of volunteers
    - d. Teamwork and multidisciplinary processes
    - e. Organisation and management practice
    - f. Research principles and practice
- III. Social policies including the following aspects:
    - a. Policy issues for people who may be disadvantaged on the grounds of race, gender, economic status, disability, sexual orientation and age
    - b. Contemporary social policy directions
    - c. Strategies for influencing policy
    - d. Strategies for the promotion of informed participation
- IV. Resources and opportunities including the following aspects:
    - a. The identification of needs including gaps in existing services
    - b. The expansion and promotion of a range of choices and opportunities
    - c. The use of networks to support clients, colleagues and communities in meeting social needs
    - d. The availability of funding sources and procedures for obtaining funds
    - e. The significance of culturally appropriate resources and personnel

Standard 7

The social worker supervisor has knowledge about social work and supervision methods, social policies, social services, resources and opportunities and acts to ensure access for clients.

This standard is met when the social worker supervisor demonstrates knowledge of:
Social work and supervision practice with Tangata Whenua and Tauiwi, including Pacifika peoples and other ethnic groups, including the following aspects:

- a. Communication processes
- b. Planned, purposeful social work processes
- c. Groups processes
- d. Change strategies
- e. Preventative strategies
- f. Social planning, social action
- g. Community work and community development
- h. Power and authority issues
- i. Privacy and confidentiality
- j. Empowerment strategies

2. 5 Occupational Therapy Board of New Zealand

The Occupational Therapy Board of New Zealand makes the following statement on cultural competence (2009)

Cultural Competence

The Board is in the process of developing a statement about cultural competence - this is an interim guideline.

Culture is not just about ethnicity - nor solely about our own bicultural context, although this has necessarily been the starting point for broader considerations of culture in Aotearoa/New Zealand. The Board's Competencies for Registration as an Occupational Therapist (2000) document includes 'gender, ethnicity, religious belief, sexual orientation, ability, and life stage' in considerations of culturally safe practice. Some texts also include language, spirituality as a broader concept, socio-economics, and the experience of trauma as dimensions of culture.

Cultural competence consists of both culture-specific skills and knowledge, and more generic attitudes, beliefs, values, experience, and approaches to perceived difference; awareness of the potential impact of these on practice; and skills which equip a practitioner to work effectively with people who may come from different cultural contexts.

It involves awareness of ones own cultural embeddedness, and although it may incorporate knowledge of and experience with discrete cultural norms and practices, is argued by some to be more closely related to qualities such as respect, empathy/being other-centred, sensitivity, openness to not knowing and learning, suspending assumptions, acknowledging personal limitations, and accessing relevant expertise.

For occupational therapists, a competence area entitled 'Culturally Safe Practice' is incorporated into the Board's Competencies for Registration as an Occupational Therapist (2000) document, although other components of culturally safe practice are embedded in other competence areas (e.g. 'Communication').

Essentially, when considering your own cultural competence, include evaluation of your own attitudes and beliefs; knowledge of other cultural worldviews and practices; and the range of culturally appropriate strategies at your disposal, including the all-important interpersonal ones, in relation to all the dimensions of culture noted above.

2.6 Physiotherapy Board of New Zealand

The Physiotherapy Board of New Zealand (2009) *Physiotherapy competencies for physiotherapy practice in New Zealand* include cultural competency in Competency 1: “Analyse and discuss the biomedical, behavioural and social science bases of physiotherapy and integrate bases into physiotherapy practice”. Section 1.9 requires the physiotherapist to:

- Explain the principles of the Treaty of Waitangi from an historical perspective
- Explain the relevance of the Treaty of Waitangi to a physiotherapist
- Describe the cultural differences of the current population in New Zealand in relation to health
- Understand the complexities of giving and receiving a therapeutic intervention such as cultures, beliefs, behaviours, age, gender and social structure

3. Models of Organisational Cultural Competence

Goode (2000, p 2) provides a useful overview of what is required when a "system, organisation and programme" becomes culturally competent. "At the systems, organisational or programme level, cultural competence requires a comprehensive and coordinated plan that includes interventions on levels of: policy making; infra-structure building; programme administration and evaluation; the delivery of services and enabling supports; and the individual. This often requires the re-examination of mission statements; policies and procedures; administrative practices; staff recruitment, hiring and retention; professional development and in-service training; translation and interpretation processes; family/professional/community partnerships; care practices and interventions including addressing ethnic disparities and access issues; education and promotion practices/materials; and community and state needs assessment protocols".

Summary

Systemic models of cultural competence

- Hospitals, Language, and Culture: A Snapshot of the Nation (HLC) is a cross-sectional qualitative study, funded by The California Endowment, designed to explore how 60 American hospitals provide health care to culturally and linguistically diverse patient populations (Wilson-Stronks et al., 2008). There is no "one size fits all" solution to providing culturally appropriate care for diverse populations, and the road map to cultural competence is unique for each organisation. However, based on data gathered from the HLC study, Wilson et al's (2008) recommendations are that organisations:

    - Identify the needs of the patient population being served and assess how well these needs are being met through current systems
    - Bring people across the organisation together to explore cultural and language issues by sharing experiences, evaluating current practices, discussing barriers, and identifying gaps
    - Make assessment, monitoring, and evaluation of cultural and language needs and services a continuous process
    - Implement a range of practices spanning the themes: building a foundation; collecting and using data to improve services; accommodating the needs of specific populations and establishing internal and external collaborations, in a systemic manner aligned with patient needs and organisational resources

Policies to promote and sustain cultural and linguistic competence in child disability and family support services

Bronheim et al. (2006) recommend that at a minimum, organisations should commit to the following:

- A mission statement that articulates values and principles for culturally and linguistically competent services
- The establishment of policy, structures, and resources to conduct organisational self-assessment of cultural and linguistic competence
- Strategic planning processes that incorporate the principles and practices of cultural

and linguistic competence into all aspects of programme design, implementation and evaluation.

- An understanding of the beliefs and values that make it difficult for some families to access services and support including:

  - A cultural and family sense of stigma associated with disability,
  - Traditions that discourage going outside the family for support,
  - Cultural beliefs about issues such as the cause of disability, child rearing, gender and generational roles; community inclusion and the integration of individuals with disabilities, affect the services that families will choose

Bronheim et al. (2006) recommend that organisational policies emphasise strengths-based assessments that identify and value the family's contributions to the care of their children

- Goode et al (2006) explored issues related to client safety. Patients with limited English proficiency had significantly more adverse events, such as inaccurate or incomplete information, questionable advice, questionable tracking and follow-up, incorrect diagnosis, and questionable intervention. Hospitalised children of families with language barriers were more likely to experience medical errors than those from families without language barriers.
- Many authors (Lee et al., 2003; NSW Department of Ageing, Disability and Home Care, 2005;) have emphasised that providing culturally-appropriate services includes consideration of cultural factors in all aspects of service delivery: child find, system entry, Individualised Education Programme (IEP)/ Individualised Family Service Plan (IFSP) development, service coordination, intervention, follow-up and case evaluation.

The role of the cultural broker

Families of children and youth with disability care needs encounter fragmented and complex health care, mental health care, and other service systems (Bronheim et al., 2006). The processes of care involve families in form filling, discharge plans, care plans, information about health plans, health and disability information and resources. Families often implement medical and behavioural treatment plans at home and have to learn about and access community resources. They need to keep records about their child's or youth's treatments and the services sought. Service planning and delivery that provides trusted cultural brokers in providing family supports helps ethnic minority families access needed services (Bronheim et al., 2006).

The use of cultural brokering to bridge service gaps

- Jezewski and Sotnik (2001) define cultural brokering as the act of bridging, linking, or mediating between groups or persons of different cultural backgrounds to effect change.
- Over the past ten years, the concept of cultural brokering has gained momentum internationally in disability services and rehabilitation sectors.
- Disability and rehabilitation sectors internationally are applying cultural brokering in practice as a mechanism to minimise disparities and to improve outcomes for peoples from ethnic minority backgrounds
- Jones and Thomas's (2009) US study found that cultural brokers have a critical role in extending services and supports to families of children and youth with disabilities

especially for new and emerging community and cultural groups.

- Cultural brokers are uniquely positioned to shape the perspectives of family leaders and family organisations and to assist in tailoring engagement and outreach activities to ensure appropriateness (Jones & Thomas, 2009).
- When discussing cultural brokering, it is important to understand that many factors originating from either side can facilitate or impede the process. To achieve the best outcomes, health professionals may need to improve their intercultural skills while, conversely, community leaders may need to improve their skills in informing and engaging their communities so that individuals with disabilities and their families can best benefit from available services (Hasnain et al. 2008).

- Four years after the introduction of the cultural brokerage project to primary and secondary health care services in Seattle Jackson-Carroll et al's (1998) paper describes the following learnings:

    - Negotiating and maintaining productive relationships with ethnic communities, case managed families, cultural brokers, and other team members requires "great expenditure of time and emotional energy". However, the rewards are great
    - Differing ethnic community agendas and cultural and political issues will inevitably arise during programme development
    - Institutional support is essential. To make the cultural brokerage model a success all levels of the health and disability system must participate to eliminate barriers to access. This includes key department heads, managers, team leaders, professional leaders, front line staff, clerical and reception staff.
    - The cultural broker model has proven to be highly effective in facilitating dialogue about health and social issues between providers and their patient populations.
    - Clients have greater access to culturally knowledgeable providers and access to health services in their own language; providers receive more cultural and social feedback during interpreted patient encounters
    - The model encourages more appropriate use of medical services and a decreasing use of inappropriate urgent and primary care services. It also encourages opportunities for increased visits from patients who might otherwise not be seen.

Professional development/Cultural competency training and education

- There is excellent evidence to suggest that cultural competence training increases the knowledge, skills and attitudes/behaviours of healthcare providers (Beach et al., 2004).
- There is good evidence that cultural competence training improves client satisfaction and poor evidence that it affects client adherence or health outcomes (Beach et al., 2004).

Beach et al (2004)

- Curricular objectives need to be measurable and linked to outcomes that can be measured objectively.
- There is a dire need for standardised, reliable, and valid instruments to measure aspects of cultural competence.
- Studies should also measure the effect of the curricular interventions on healthcare process and patient outcomes.
- For the results to be meaningful studies need to have a pre- and post-intervention

evaluation and/or a comparison group

The role of staff from ethnic backgrounds

- Gany et al (2007) study concluded that clients' preferences were for the availability of language concordant providers.
- Ethnic matching of the clinician/doctor and patient is neither necessary nor always desirable, but it is essential that clinicians are aware of the interactions between the parties **(**O'Hara, 2003).

3.1 Systemic Models of Cultural Competence

Bronheim, S., Goode, T, & Jones, W. (2006). *Policy Brief: Cultural and Linguistic Competence in Family Supports*. Washington, DC: National Center for Cultural Competence, Georgetown University Center for Child and Human Development.

What are family supports (US federal Family Support for Children with Disabilities Act, 2000)

"Family Support for Families of Children with Disabilities means supports, resources, services, and other assistance provided to families of children with disabilities pursuant to State policy that are designed to:

A Support families in the efforts of such families to raise their children with disabilities in the home;
B Strengthen the role of the family as primary caregiver for such children
C Prevent involuntary out-of-home placement of such children and maintain family unity; and
C Reunite families with children with disabilities who have been placed out of home, whenever possible"

Cultural factors that impact supports for families with children with disabilities

- A number of factors impact the way in which family supports are conceptualized, designed, and delivered. These factors include: ethnic background, language, national origin, tribal or clan affiliation, gender, age, education, literacy, socioeconomic status, class, religious beliefs, legal status and level of acculturation
- Newly immigrated families have different needs from families of the same background who have lived in the country of settlement for longer periods or generations
- Providing supports to fathers is different from providing supports to mothers

Linguistic competence and health literacy

Linguistic competence is the capacity of an organisation and its workforce to communicate effectively and convey information in a manner that is easily understood by those with limited English proficiency or low or no literacy skills. The linguistic competency of the organisations providing disability services impacts on the family's ability to meet the demands of care. As well, health literacy or the ability to read, listen to, understand and act on complex medical and health information impacts a family's ability to access the services that they need and to make appropriate health decisions. Families from ethnic minority backgrounds are less likely to participate in decision-making about the services that they and their children receive (Bronheim et al., 2006)

Cultural factors

- Family patterns related to decision-making and help-seeking behaviours affect the way in which supports are sought and chosen.
- The US National Centre for Cultural Competence (NCCC) recommends that organisational policies emphasise strengths-based assessments that identify and value the family's contributions to the care of their children.

Policy implications

Service planning and delivery that supports effective community engagement and provides trusted cultural brokers in providing family supports would help ethnic minority families access needed services

Department of Ageing, Disability and Home Care (2005). *Strategy to improve services for people from culturally diverse communities.* NSW Department of Ageing, Disability and Home Care CALD Strategy 2005-2008.

The plan for improving the responsiveness of child disability services in NSW is to:

- Improve data on CALD clients
- Research the support needs of, and culturally appropriate service models for people form CALD backgrounds
- Plan individual services in consultation with CALD clients and their families to reflect cultural needs and personal goals
- Audit respite services to determine CALD service utilization and identify gaps in service access for specific CALD communities
- Develop respite models to increase culturally appropriate support to CALD children and young people with a disability
- Develop respite leading practice models for CALD children with a disability in consultation with CALD and disability NGOs
- Develop cultural competencies for staff in Respite and Child Disability Services
- Provide on-going cultural competency training in respite and child disability services in staff orientation and as part of professional development to improve staff ability to provide culturally competent assessment
- Recruit qualified staff experienced in working with people from CALD backgrounds
- Promote the use of interpreter services at points of contact and when developing/reviewing individual plans for low English speakers
- Develop disability and carer awareness training module for interpreters and negotiate with language services to implement the module

- Review the written multilingual resources provided to clients, their families and/or carers from CALD backgrounds. Develop culturally appropriate methods of information dissemination to CALD communities about Child Disability Services
- Develop culturally appropriate support services for families with a child with a disability from CALD communities
- Increase the use of early intervention and community support services by CALD communities. Develop mechanisms for disseminating information about community support services
- Include consideration of the needs of CALD people in the development and implementation of Leaving Care Transition Plans
- Review the cultural appropriateness and availability of existing information and support for CALD carers
- Increase the cultural competency of community support workers. Identify culturally competent case management and service coordination practice guidelines
- Increase support to CALD families caring for children with a disability with a particular focus on children and young people with high and complex needs. Research the needs and service models which are appropriate
- Recruit people from CALD backgrounds in the community support workforce as “children’s casework consultants”

Harris, P. (2004). *Culturally Competent Disability Support: Putting it into Practice.* NSW, Australia: Multicultural Disability Advocacy Association of NSW (MDAA)

Cultural competence in disability services at the systemic and organisational level

- The Australian disability service delivery system is a cultural system, currently reflecting Anglo-Australian cultural values. For people working in the system, this culture has an impact on how disability is understood and the way services are designed and subsequently delivered to support those with disability. In addition, this culture can influence how people as individuals understand and respond to people from different cultures.
- For people from CALD groups, the Anglo-Australian values based system is difficult to understand. This difficulty includes what is provided, how it is provided, or how to get access to it. Some CALD groups and families may have different ways of understanding disability and caring for people with disability that may or may not include support being provided by a disability service system. For many, such a system may not have existed in their country of origin.
- Goode (2000) provides a useful brief overview of what is required when a “system, organisation and programme” becomes culturally competent. This indicates areas that can be influenced by an individual “At the systems, organisational or programme level, cultural competence requires a comprehensive and coordinated plan that includes interventions on levels of:

  1. policy making;
  2. infra-structure building;
  3. programme administration and evaluation;

4. the delivery of services and enabling supports; and
5. the individual

- This often requires the re-examination of mission statements; policies and procedures; administrative practices; staff recruitment, hiring and retention; professional development and in-service training; translation and interpretation processes; family/professional/community partnerships; care practices and interventions including addressing ethnic disparities and access issues; education and promotion practices/materials; and community and state needs assessment protocols” (p. 2).

National Health and Medical Research Council (2005). *Cultural competency in health: A guide for policy, partnerships and participation.* Australian Government, National Health and Medical Research Council

A model for change

The National Health and Medical Research Council, Australia (2005) present a four-dimensional model for increasing cultural competency in the health sector. The dimensions are systemic, organisational, professional and individual — which interrelate so that cultural competence at an individual or professional level is underpinned by systemic and organisational commitment and capacity. Integral to the model is the need for:

- Capacity and conviction at systemic and organisational levels to direct, support and acknowledge culturally competent practice at an individual or professional level; and
- Clear delineation of levels of responsibility and the interrelationship between these levels.

Systemic

- Effective policies and procedures, mechanisms for monitoring, and sufficient resources are fundamental to fostering culturally competent behaviour and practice at other levels. Policies support the active involvement of culturally diverse communities in matters concerning their health and environment.

Organisational

- A culture is created where cultural competency is valued as integral to core business and consequently supported and evaluated. Management is committed to a process of diversity management including cultural and linguistic diversity at all staffing levels.

Professional

- Over-arching the other dimensions, at this level cultural competence is identified as an important component in education and professional development. It also results in specific professions developing cultural competence standards to guide the working lives of individuals.

Individual

- Knowledge, attitudes and behaviours defining culturally competent behaviour are maximised and made more effective by existing within a supportive health organisation and wider health system. Individual health professionals feel supported to work with diverse communities to develop relevant, appropriate and sustainable services

Lewin Group (2002). ***Indicators of Cultural Competence in Health Care Delivery Organisations: An Organisational Cultural Competence Assessment Profile.*** **USA: The Health Resources and Services Administration, U.S. Department of Health and Human Services.**

"How do we know cultural competence when we see it?"

This project aimed to contribute to the methodology and state-of-the-art of cultural competence assessment. The product – *An Organisational Cultural Competence Assessment Profile* serves as a future building block that advances the conceptualization and practical understanding of how to assess cultural competence at the organisational level.

The specific objectives of this project were to:

1. develop an analytic framework for assessing cultural competence in health care delivery organisations;
2. identify specific indicators that can be used in connection with this framework; and
3. assess the utility, feasibility and practical application of the framework and its indicators.

About the Organisational Cultural Competence Assessment Profile

- The Assessment Profile is an analytic or organizing framework and set of specific indicators to be used as a tool for examining, demonstrating, and documenting cultural competence in organisations involved in the *direct delivery* of health care and services.
- The Profile addresses whether an organisation has or exhibits the particular features that should be evident or manifest in a culturally competent organisation across the spectrum of critical areas or domains of organisational functioning.
- Use of the Profile is most appropriate for a health care delivery organisation's *internal* assessment of cultural competence. At a general level, the Profile can help organisations frame and organize their perspectives and activities related to the assessment of cultural competence. More specifically, the Profile can be used in routine performance monitoring, regular quality review and improvement activities, assessment of voluntary compliance with cultural competence standards or guidelines, and periodic evaluative studies.

Wilson-Stronks, A., Lee, K.K., Cordero, C.L., Kopp, A.L., Galvez, E. (2008). ***One Size Does Not Fit All: Meeting The Health Care Needs of Diverse Populations.*** **Oakbrook Terrace, IL: The Joint Commission**

Framework Overview

The thematic framework presented in this report was derived from current practices that hospitals are employing to provide care and services to diverse patients.

1. Building a foundation
   Policies and procedures that systemically support efforts to meet the needs of diverse patients can help elevate the priority of these issues within the organisation, drive efforts, and draw staff support

2. Collecting and using data to improve services
   Data collection and use allows the effectiveness and utilisation of cultural and language services to be monitored, measured, and evaluated, which can be useful for planning and designing services
3. Accommodating the needs of specific populations
   Developing practices that address the challenges of certain populations contributes to providing safe, quality care and decreasing health disparities
4. Establishing internal and external collaborations
   Collaborations can provide hospitals with additional opportunities for developing cultural and language programmes and services when resources are limited or help them engage the community to share information and resources

The *One Size Does Not Fit All: Meeting the Health Care Needs of Diverse Populations* report provides a framework for hospitals to develop and employ practices for meeting diverse patient needs. There is no “one size fits all” solution, and the road map to cultural competence is unique for each organisation. However, based on data gathered from the HLC study, this report recommends that organisations:

- Identify the needs of the patient population being served and assess how well these needs are being met through current systems
- Bring people across the organization together to explore cultural and language issues by sharing experiences, evaluating current practices, discussing barriers, and identifying gaps
- Make assessment, monitoring, and evaluation of cultural and language needs and services a continuous process
- Implement a range of practices spanning all four themes in a systemic manner aligned with patient needs and organisational resources

Wu, E. & Martinez, M. (2006). Taking cultural competency from theory to action. USA: California Pan-Ethnic Health Network

This paper provides principles and recommendations for implementing cultural competency in the field. The following six principles underpin organisational cultural competency efforts:

1. Community representation and feedback at all stages of implementation;
2. Cultural competency integrated into all systems of the health care organisation, particularly quality improvement efforts;
3. Ensuring that changes made are manageable, measurable, and sustainable;
4. Making the business case for implementation of cultural competency polices;
5. Commitment from leadership; and
6. Staff training on an ongoing basis.

3.2 The Role of the Cultural Broker

Abrahamsson, A., Andersson, J. & Springett, J. (2009). Building bridges or negotiating tensions? Experiences from a project aimed at enabling migrant access to health and social care in Sweden. *Diversity in Health and Care, 6,* (2), 85-95

- A current challenge for many European countries is to enable refugees to access health and social care. One solution is to use paraprofessionals - that is, trained individuals who are not professionals - to act as bridge-builders between minority communities and the health and social care sectors.

- This paper explores the development of a quality improvement project in Sweden. The project aimed to recruit and train refugees who had lived in Sweden for more than five years to act as bridge-builders.
- The aim was to use their experiences and knowledge to work with service staff in developing new ways of working, and to become culturally competent paraprofessionals working with their own communities.
- This paper focuses on the development of three possible models of what the task of a bridge-builder should be in developing culturally appropriate health and social services that are responsive to the needs of refugees.

Bronheim, S., Goode, T, & Jones, W. (2006). *Policy Brief: Cultural and Linguistic Competence in Family Supports*. Washington, DC: National Center for Cultural Competence, Georgetown University Center for Child and Human Development

The National Survey of Children with Special Health Care Needs in 2001 found disparities in core outcomes for children and youth with special health care needs and their families from ethnic minority backgrounds including:

- Satisfaction with the services delivered
- Partnership in decision making
- Co-ordinated care
- Accessing community-based services
- Provision of services necessary to support the transition to adulthood

Service planning and delivery that supports effective community engagement and provides trusted cultural brokers in providing family supports would help ethnic minority families access needed services

Carlson G. & van Kooten Prasad, M. (2001). Services for people with intellectual disability of culturally and linguistically diverse backgrounds. *International Journal of Practical Approaches to Disability, 2001, 25,* (1)

- This study was carried out in the Brisbane South region of Australia. Brisbane has a population of approximately 2 million people. The Brisbane South region includes the highest proportion of people of culturally and linguistically diverse backgrounds.
- The study focuses on services for people with intellectual disability and high support needs from culturally and linguistically diverse backgrounds.
- Data was collated through group interviews and individual interviews. Participants in the group interviews were 18 disability workers or ethnic community workers with experience working with people with intellectual disability and high support needs of CALD backgrounds.
- Five issues emerged from the data. These were classified as:
    - isolation
    - cultural differences
    - linguistic differences
    - inter-sectoral links
    - access

- Participants identified a range of personal and organisational strategies that they had successfully utilised in relation to each of these issues. Strategies to improve access to disability services for culturally and linguistically diverse groups included:
    - disseminating local examples of effective practice throughout disability services;
    - providing family brokerage options and some services for people from particular cultural or linguistic groups;
    - improving data collection about service users' cultural or linguistic background;
    - fostering feedback and consultation processes within ethnic communities;
    - identifying the needs of family carers;
    - planning ahead with families to facilitate their acceptance of gradual transitions to support options beyond the immediate family;
    - using ethnic community venues and involving ethnic community leaders when providing services;

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

Harris, P. (2004). ***Culturally Competent Disability Support: Putting It into Practice.*** **NSW, Australia: Multicultural Disability Advocacy Association of NSW (MDAA).**

- Harris (2004) conducted a review of the literature on cultural competence in order to propose key culturally competent tools, strategies, and skills by which disability service managers and staff could provide quality services and improve outcomes for consumers
- The review included, studies, reports, articles and documents in Australian and in the international literature focused on culturally competent practice and related strategies.
- Two principal yet overlapping disciplines emerged: Social Work (disability, aged care, children and family studies, welfare); and Health (clinical, primary care, nursing, occupational therapy, aged care, rehabilitation and mental health)
- The review included perspectives on the roles of 'cultural experts', 'cultural guides', 'ethnic community workers', 'cultural brokers' and 'diversity consultants' which are summarised as follows:

Cultural experts and cultural guides

- A number of authors argue that people are often the best source of information.
    - Sue (1998, p.446) points out that it is important to seek out culture-specific experts – from different cultures, who "are effective in their own cultures because they know the cultures and have the skills to translate this knowledge into effective interventions"
    - Green (1982; in Rounds et al., 1994) recommends the use of 'cultural guides', who are community members who can assist outsiders with an

understanding and appreciation of community members' attitudes towards help seeking, historical events that may have influenced these attitudes and how various cultural groups view and access formal services

Ethnic community workers

- Ethnic community workers and organisations are also useful people to work with. Formal collaboration not only with individual staff and other agencies is recommended by the US government as a key mechanism to develop culturally competent services (US Department of Health and Human Services, 2001).
- Work on best practice both in culturally competent healthcare in the US (Betancourt et al., 2002) and in disability services in the UK (Mir et al., 2001) has identified partnerships with both ethnic community-based workers and the organisations they work for to help establish culturally appropriate support.
- In Queensland, Australia, research with intellectual disability service providers indicated that 'inter-sectoral collaboration' (links between the intellectual disability service sector and the ethnic communities' service sector) would improve service delivery to consumers from non-English speaking backgrounds (Carlson & Prasad, 2001).
- Strategies suggested by participants to facilitate this collaboration were for workers to:

    - find out more about local ethnic community services and disability services;
    - provide information about local disability services to ethnic community services and vice versa;
    - organise joint individual support work between disability and ethnic community services; and
    - organise inter-sectoral forums (Carlson & Prasad; 2001 p. 9).

- Ethnic community workers can relay community concerns to the service or programme, while educating the community about services and programmes (Brach & Fraser, 2000)

- Partnerships with ethnic community workers or ethnic services provide both culture specific expertise and useful access to the 'experts' in ethnic communities (Mir et al., 2001).

Cultural brokers

- The National Centre for Cultural Competence (2004) in the US suggests using 'cultural brokers' as people who can bridge the gap between services and the communities they serve.
- The aim of the cultural broker is to build an awareness and understanding of the cultural factors of the diverse communities they serve and of the ways such factors influence communities.
- Cultural brokers may not necessarily be members of a particular cultural group or community. However, they must have a history and experience with cultural groups for which they serve as broker including:

    - the trust and respect of the community;
    - knowledge of values, beliefs and health practices of cultural groups;

  - an understanding of traditional wellness and healing networks within diverse communities; and
  - experience navigating health care delivery and supportive systems within communities.

Particular tasks of the cultural broker are to:

  - assess the values, beliefs and practices related to health in the community being served;
  - enhance communication between patients/ consumers and other providers;
  - advocate for the use of culturally and linguistically competent practices in the delivery of services; and
  - assist with efforts to increase access to care and eliminate ethnic disparities in health.

As with bi-cultural staff, cultural brokers need to be culturally competent if they are to be effective.

Diversity consultants

- Similar to cultural brokers another example of culturally competent community participation is an outreach project in the US that used *diversity consultants* to improve vocational rehabilitation services for people from ethnic minorities with disabilities (Hasnain et al., 2003).
- The approach used was ‘person-centred planning’ defined as focusing on the needs and values of the individual, which incorporates cultural beliefs and traditions “understood on their terms, rather than based on a standard set by the dominant culture” (p. 11). The goal was “…inclusion of individuals with disabilities and their families within all aspects of the vocational rehabilitation system, with the ultimate goal being full community participation” (p. 11).
- The initiative recruited individuals from a variety of communities, who represented people with disabilities, their families, or both, to serve as a pool of diversity consultants to implement various project activities. These consultants observed training and made recommendations to ensure that all project materials and activities were culturally sensitive. They also acted as translators and interpreters, enabling the project to be conducted in each person’s language.
- In addition, they were trained to conduct:
  - marketing and outreach activities
  - person-centred career planning meetings
  - cultural sensitivity and networking training for health professional and community groups, where they acted as co-trainers.
- As a result, over a three year period, numbers of Black, Asian, Hispanic, and non-Caucasian consumers served by the project increased from 14% to 22.8 %.

Hasnain, R., Cohon Shaikh, L. & Shanawani, H. (2008). Disability and the Muslim Perspective: An Introduction for Rehabilitation and Health Care Providers. Center for International Rehabilitation Research Information and Exchange

The Use of Culture Brokering to Bridge Service Gaps

- In the case of Muslim communities a cultural broker is someone familiar with the experiences of Muslims who helps bridge the gap between service providers and clients and their families.
- The cultural broker advocates on behalf of a Muslim with a disability and his or her family.
- Hasnain et al (2008) suggest five directions for action based on the culture brokering framework:

1. Better understand the demography of Muslims, including issues of identity, immigration, country of origin, gender (see Appendix 3), and educational level.
2. Identify the barriers, challenges, and successes that face Muslims with disabilities and those with medical conditions as they access services and supports of all types.
3. Solicit the participation of Muslim people with disabilities and those with medical conditions and their families in various aspects of service delivery and planning.
4. Promote collaborative research and support for disability-specific development activities that can help build lasting links between mainstream health and disability services and Muslim institutions.
5. Cultivate a broader cultural understanding and mutual respect concerning the inclusion of persons with disabilities through strategic partnerships and collaborations with Muslims and non-Muslims.

Conceptual models vary by culture

- Another key issue is that many ethnic and minority populations, including Muslims, have their own long-standing beliefs and practices and their own support systems; as a result, they do not define or address disability and chronic illness in the same way as mainstream cultures.
- Because the concerns and values of Muslim populations are not necessarily identical to those of mainstream society their solutions are not always the same.
- Many cultural groups can offer alternative and sometimes superior ways of addressing needs that merit careful attention.
- Muslim families are not all structured in the same way. Their needs and circumstances may differ. They can vary greatly in their cultural heritages and religious practices. Their patterns of immigration and migration will vary.
- The differences among Muslim individuals and families are as important as larger community issues

Jackson-Carroll, L.M., Graham, E. & Jackson, J. C. (1998). *Beyond medical interpretation: The role of interpreter cultural mediators (ICMs) in building bridges between ethnic communities and health institutions.* Community House Calls, Harborview Medical Center

- The Interpreter Cultural Mediators (ICMs)/cultural broker model described in this manual is part of a demonstration programme at the Harborview Medical Centre in Seattle, Washington which provides services to primary, mental health and hospital services for non-English speaking ethnic populations
- The ICM/Cultural broker role includes:

    - Use of ICM and community advisors as part of the health care team, allowing access to information about cultural health care practices and beliefs

    - Development of a structure which allows the clinical and public health aspects of care to be addressed at the same time
    - The ICMs provide a range of services including interpreting, cultural mediation, case management, advocacy, follow up, assistance in accessing ESL classes, coordination of client care, health education and home visits
    - The case management role allows the ICM to follow a client and family over a period of time, becoming fully aware of the family's needs, problems, and strengths. The approach enables the ICM to provide cultural interpretation and mediation, to advocate for appropriate treatment based on a more thorough understanding of the client and family, and to communicate valuable insights to the provider which can positively impact patient care.
    - Problems such as poor housing, lack of child care or support for new parents, depression, isolation, and mental health problems can be identified and addressed using the interpreter cultural mediator approach.

- The paper describes the learnings four years after the introduction of the ICM project which include:

    - Negotiating and maintaining productive relationships with ethnic communities, case managed families, ICM's, and other team members requires "great expenditure of time and emotional energy". However, the rewards are great
    - Differing ethnic community agendas and cultural and political issues will inevitably arise during programme development
    - Institutional support is essential. To make the ICM/ cultural brokerage model a success all levels of the health and disability system must participate to eliminate barriers to access. This includes key department heads, managers, team leaders, professional leaders, front line staff, clerical and reception staff.
    - The ICM/cultural broker model has proven to be highly effective in facilitating dialogue about health and social issues between providers and their patient population.
    - Clients have greater access to culturally knowledgeable providers and access to health services in their own language; providers receive more cultural and social feedback during interpreted patient encounters;

- The model encourages more appropriate use of medical services and a decreasing use of inappropriate urgent and primary care services. It also encourages opportunities for increased visits from patients who might otherwise not be seen.

Jones, W., & Thomas, T. (2009). *Growing Your Capacity to Engage Diverse Communities by Working with Community Liaisons and Cultural Brokers*. Albuquerque, NM: National Center for Family Professional Partnerships, Family Voices, Inc

- An American study conducted by the *Family Voices National Center for Family Professional Partnerships (NCFPP)* partnered with the *National Center for Cultural Competence's Children and Youth with Special Health Care Needs Project (NCCC-CYSHCN)* to improve access for all children with special needs and disabilities to

the information and support they need to ensure the highest quality care for their family.
- The study found that cultural brokers have a critical role in extending services and supports to families of children and youth with special health care needs and disabilities from diverse communities and cultural or ethnic backgrounds, especially new and emerging communities and cultural groups.
- Cultural brokers are uniquely positioned to shape the perspectives of family leaders and family organisations and to assist in tailoring engagement and outreach activities to ensure appropriateness.
- Cultural brokers are often able to enhance the capacity of services to meet the preferences and needs of the range of families from diverse populations served

National Center for Cultural Competence (2004). *Bridging the Cultural Divide in Health Care Settings: The Essential Role of Cultural Broker Programmes. National Center for Cultural Competence*. Georgetown University Child Development Center: Washington D.C.

- Cultural brokerage is promoted as a legitimate way to reduced disparities for underserved populations in the US
- The roles of the cultural brokers include:

1. Liaison: Cultural brokers are knowledgeable about:
    - the health values, beliefs, and practices within their cultural group or community
    - the health care system that they have learned to navigate effectively for themselves and their families. They communicate and liaise between clients and providers of services

2. Cultural guide:
    - cultural brokers may serve as guides for health care settings that are in the process of incorporating culturally and linguistically competent principles, values, and practices.
    - having the respect and trust of the community is a critical requisite

3. Mediator: Two elements are essential to the delivery of effective services
    - the ability to establish and maintain trust
    - the capacity to devote sufficient time to build a meaningful relationship between the provider and the client/family

4. Catalyst for change: Cultural brokers are change agents
    - cultural brokers model and mentor behaviour change which can improve intergroup and interpersonal behaviour, so that organisations can build the capacity to respond to the new and emerging communities served

- Cultural brokers must have the capacity to:

    - assess and understand their own cultural identities and value systems
    - recognise the values that guide and mould attitudes and behaviours
    - understand a community’s traditional health beliefs, values, practices and changes that occur through acculturation

    - understand and practice tenets of effective cross-cultural communication, including the cultural nuances of both verbal and non-verbal communication and
    - advocate for the patient, to ensure the delivery of effective health and disability services

- Cultural brokers aim to build an awareness and understanding of the cultural factors of the diverse communities they serve and of the ways in which such factors influence communities.
- Cultural brokers may not necessarily be members of a particular cultural group or community. However, they must have a history and experience with cultural groups for which they serve as broker including:
    - The trust and respect of the community
    - Knowledge of values, beliefs and health practices of cultural groups
    - An understanding of traditional concepts of wellness and of healing practices
    - Experience navigating health and disability services and social support systems within communities.
- Cultural brokerage programmes can facilitate clinical encounters with more favourable outcomes, enhance the potential for more rewarding interpersonal experiences, and can increase the satisfaction with services received
- A cultural broker in a child disability service can:
    - Assess the values, beliefs, and practices related to health and disability in the community being served
    - Enhance communication between clients/families and providers
    - Advocate for the use of culturally and linguistically competent practices in the delivery of services
    - Assist with efforts to improve access to care and reduce disparities

3.3 Professional Development

Beach, M.C., Cooper, L.A., Robinson, K.A., Price, E.G., Gary, T.L., Jenckes, M.W., Gozu, A., Smarth, C., Palacio, A., Feuerstein, C.J., Bass, E.B. & Powe, N.R. (2004). ***Strategies for Improving Minority Healthcare Quality. Evidence Report/Technology Assessment No. 90.***

- The purpose of this report is to systematically review the evidence to determine the effectiveness of interventions designed to improve the quality of healthcare and/or to reduce disparities for ethnic minorities. It focuses on evaluations of interventions aimed at healthcare providers or organisations, as recent work suggests these factors contribute substantially to the inequities.
- The review examined broadly any type of strategy aimed at improving the quality of care in an ethnic minority population of patients, and then looked more specifically at strategies designed to improve the cultural competence of healthcare providers or organisations.

Methods

The study question was what strategies have been shown to improve the cultural competence of healthcare providers or organisations?

- Researchers performed electronic searches of MEDLINE, the Cochrane Collaboration's CENTRAL Register of Controlled Trials, EMBASE, and the following three specialty databases: the specialised register of Effective Practice and Organisationof Care Cochrane Review Group (EPOC), the Research and Development Resource Base in Continuing Medical Education (RDRB/CME), and the Cumulative Index of Nursing and Allied Health Literature (CINAHL).

Results

- Sixty four articles addressed the specific question of strategies to improve cultural competence.

Results of Reviewed Studies

- The study focused on the 34 studies with the strongest study design (studies that either had a comparison group and/or did a pre- and post intervention evaluation).

Research on Cultural Competence

- Curricular objectives need to be measurable and linked to outcomes that can be measured objectively. There is a dire need for standardised, reliable, and valid instruments to measure aspects of cultural competence. Studies should also measure the effect of the curricular interventions on healthcare process and patient outcomes. For the results to be meaningful studies need to have a pre- and post-intervention evaluation and/or a comparison group; there is certainly a need for more randomized controlled trials in this area.
- Researchers should comprehensively describe the curricular interventions, such that they can be replicated in different settings. Studies also ought to include more comprehensive information about the resources needed and the cost of cultural competence training. Knowledge on this topic is evolving rapidly, and updated evidence assessments will be needed in the near future.

Stewart, S. (2006a). Cultural competence in health care. Sydney, Australia: Diversity Health Institute.

Key features/elements of effective training

Much is still contested in the field of cultural competence learning and teaching. However, despite the absence of a solid evidence base in relation to what training approaches are most effective, there is a picture of what might constitute 'good practice' emerging from the literature.

The three interrelated learning domains of awareness, knowledge and skills are frequently proposed as the basis for an appropriate framework for cultural competence training.

- Awareness – The starting point for effective cultural competence training must be self-examination, rather than a focus on 'the other', as this can only perpetuate an 'us and them' way of thinking which is precisely what is to be avoided. This includes encouraging participants to become aware of their own internalised beliefs and biases (including those deriving from their organisational and professional culture) and how these might impact on interactions with client/patients.

- Knowledge – In terms of equipping learners with the necessary knowledge base, trainers need to contextualise their training to clinical settings and the policy and legislative frameworks that are relevant to the learners.
- Skills – skills development in the areas of cross-cultural communication, including, but not limited to, knowing when and how to work with professional interpreters, conflict resolution, negotiation of explanatory models and critical thinking are typically cited in the literature as integral to effective cultural competence training.
- Format/Techniques – Consistent with adult education theory, good cultural competence training will involve a range of techniques to accommodate the diversity of adult learning styles, acknowledge prior learning experiences, and be tailored to meet the specific needs of the participants. The approach taken and the balance of activities addressing each of the learning domains (affective, cognitive, psychomotor) will obviously vary depending on a number of factors, including the time available. However, evidence suggests that practical and experiential activities yield the best results when facilitated skillfully.

3.3.1 Cross-Cultural Training and Education

Lee, H., Ostrosky, M.M., Bennett, T. & Fowler, S.A. (2003). Perspectives of early intervention professionals about culturally-appropriate practices. *Journal of Early Intervention, 25* (4), 281-295

Background

- This study examined the extent to which early intervention (EI) professionals in a midwestern metropolitan area of the USA considered cultural factors important; the extent to which their practice reflected recommendations for providing culturally-appropriate services. The characteristics of EI professionals and the barriers they faced in providing services to children and their families were also examined.

Results

- Although professionals considered recommendations for providing culturally-appropriate services important, they reported that multiple barriers often hindered implementation.
- To provide high quality services for families who are culturally diverse, early intervention professionals need assistance such as professional development opportunities and administrative support.
- A challenge in the next decade is to continue to diversify the population of early intervention professionals.

Betancourt, J.R., Weissman, J.S., Kim, M.K. Park, E.R. & Maina, A.W. (2007). Resident physicians' preparedness to provide cross-cultural care: Implications for clinical care and medical education policy. USA: Health Workforce Information Centre.

- In a national study of resident physicians in their final year of training residents reported feeling unprepared to care for patients with specific cultural characteristics, including those who hold health beliefs and/or religious values that may conflict with western models of health care.

- Recommended reforms include integration of cross-cultural training into curricula (both during and after medical school) in accordance with standard principles, the appropriate training of faculty (to ensure useful instruction, as well as mentors and role models), and the mandatory and formal evaluation of residents' cross-cultural communication skills.

Manderson, L. & Allotey, P. (2003). Cultural politics and clinical competence in Australian health services. *Anthroplogy & Medicine, 10* (1), 71-85

- Medical competence is demonstrated in multiple ways in clinical settings, and includes technical competence, both in terms of diagnosis and management, and cultural competence, as demonstrated in communication between providers and clients. In cross-cultural contexts, such communication is complicated by interpersonal communication and the social and cultural context. To illustrate this, Manderson & Allotey (2003) present four case studies that illustrate the themes from interviews with immigrant women and refugees from Middle Eastern and Sub Saharan African backgrounds, conducted as part of a study of their reproductive health.
- In their analysis, they highlight the limitations of conventional models of communication. Manderson & Allotey (2003) illustrate the need for health providers to appreciate the possible barriers of education, ethnicity, religion and gender that can impede communication, and the need to be mindful of broader structural, institutional and inter-cultural factors that affect the quality of the clinical encounter.

Conclusions

- As Manderson & Allotey (2003) demonstrate in the case studies, ideas of professional competence are culturally informed. While clinicians and other health providers may interpret competence in terms of scientific evidence, skills and outcome, patients see competence as linked to their own sense of positive well-being, with respect to process (the subjective feeling of being cared for) and outcome (such as not dying). This has implications in terms of training and the ability of providers to diagnose, treat, get results and explain satisfactorily to the patient what is happening. Conversely, the inability to demonstrate clinical competence in terms of diagnostic capacity and therapeutic outcomes is interpreted by women from Sub Saharan Africa and Middle Eastern background as examples of medical mismanagement, often wilful.

- One step towards addressing difficulties in clinical encounters, and, importantly, in the management and care of people who seek medical advice, is through appreciating that cultural, historic, economic and other factors contribute to misunderstandings of information and assessments of skill and competence.

- Manderson & Allotey (2003) highlight the need to take account, in ethnic minority families, of individual differences in background and in expectations of patient–provider relationships, clinical consultations and competence.

3.2.2 Measuring Individual Cultural Competence

Stewart, S. (2006a). Cultural competence in health care. Sydney, Australia: Diversity Health Institute.

Various tools/instruments to assess competence at the individual level

- One approach to assessment has been the development of a number of tools or instruments for individual practitioners/clinicians to assess their own cultural competence. The results of such self-assessments are intended to encourage self-reflection and to give the individual some 'baseline data' about their own cultural competence. Embedded in such tools is the notion that there are a number of personal characteristics or attributes that a culturally competent individual demonstrates and which, presumably those who are not yet competent can develop.

- Other possible ways of measuring individual cultural competence include clinical case file audits and the incorporation of cultural competence into staff orientation and performance management processes. However, in the absence of agreed practice standards, the value of such assessment tools is questionable.

- In addition to individual checklists, there are a number of models (mainly developed in the USA) that provide useful practical frameworks for implementing and assessing cultural competence at both the individual and the organisational level. Most of these are based on a developmental continuum approach.

3.4 The Role of Staff from Ethnic Backgrounds

Gany, F., Kapelusznik, L., Prakash, K., Gonzalez, J., Orta, L. & Changrani, J. (2007). Patient satisfaction with different interpreting methods: A randomized controlled trial. *J Gen Intern Med, 22* (Suppl 2), 312-8

Background:

- This study evaluates the impact of interpreting method on patient satisfaction.

Conclusion:

- The study concluded that clients' preferences were for the availability of language concordant providers.
- Where language concordant providers were not available telephone interpreting improved patient satisfaction and privacy among non-English speaking patients. Implementing telephone interpreting RSMI should be considered an important component of a multipronged approach to addressing language barriers in health care.

Matthews, C., Klinken Whelan, A., Johnson, M. & Noble, C. (2008). A piece of the puzzle — the role of ethnic health staff in hospitals. *Australian Health Review 32* (2), 236-245

- The role of ethnic health staff in hospitals has not been clearly articulated for managers and practitioners.

- This paper describes findings from a study based on ethnic and allied health staff interviews and observations of ethnic health staff interactions.

- Care was provided to language concordant patients directly and by assisting practitioners to work within the patient's cultural paradigms and family schema.

- The scope of practice involved: engaging patients in a therapeutic relationship, patient assessment, linking assessment with care options, facilitating communication between patients and practitioners, education, smoothing hospital experiences, referral and interpreting.

Ethnic health staff displayed a range of specialised skills that managers need to harness within multidisciplinary teams to reach patients from diverse backgrounds

O'Hara, J. (2003). Learning disabilities and ethnicity: achieving cultural competence. *Advances in Psychiatric Treatment, 9,* 166-174

Ethnic matching of the clinician/doctor and patient is neither necessary nor always desirable, but it is essential that clinicians are aware of the interactions between the parties

4. CALD Families Recommendations for Improving Disability Service Provision

Ethnic minority populations reflecting their own unique and long-standing cultural beliefs, practices, and support systems, may not define or address disability in the same manner as 'mainstream' cultures (Groce & Irving, 1993). Ethnic groups' concerns are not necessarily identical, their solutions are not always the same, and the strengths shown in families and communities may present alternative ways of addressing needs that merit attention. For disability services to be culturally responsive there must be a real understanding of the differences within and between cultures. Goode et al. (2006) in a review of the evidence base for cultural and linguistic competency in health care conclude that the literature reflects promise and illustrates the positive benefits of cultural and linguistic competence as a critical component of quality and effective care.

Summary

- Based on families' recommendations Garwick et al. (1998) developed an acronym TAILOR that summarises strategies for providing family-centred care that is culturally sensitive

> **T**arget services to individual family needs
> **A**ssess the needs and preferences of the child and his/her family
> **I**nform families and providers
> **L**isten to families
> **O**rganize and coordinate services
> **R**espect the family's cultural background
> *Garwick et al., 1998*

- Families recommended that health care professionals focus on fitting services and programmes to the particular family's needs and to their cultural background by listening to specific child and family needs and tailoring interventions to fit (Garwick et al, 1998)
- In Bailey & Skinner's (1999) study the data did not delineate a "Latino" style of needs and supports, and it is likely that understanding individual histories and styles of adaptation may be as important as an understanding of broad cultural characteristics in designing services
- The following three issues seem to be almost universal, appearing prominently and consistently in cross-cultural studies (Groce & Irving, 1993):
  - The culturally perceived *cause* of a disability is significant in all cultures studied to date.
  - The expectations for survival for the infant or child with a disability will affect both the immediate care the child receives and the amount of effort expended in planning for future care and education.
  - The social role(s) deemed appropriate for disabled children will help determine the amount of resources a family and community *invest* in an individual.

Mainstreaming versus Ethnic Specific Service Delivery

- There were no recommendations from families that separate support services need to be provided for specific ethnic groups. Instead participants from all three ethnic groups focused on mainstream services individualising care to meet the particular needs of child and family, which is an effective strategy for providing culturally competent care, considering the many variations that exist within and between cultural groups (Garwick et al. 1998)

- Garwick et al. (1998) concluded that given the complex nature of caring for children with disabilities and the need for family caregivers to interact with health and disability, education, and social service providers it is not surprising that caregivers from different cultural backgrounds placed most emphasis on changing systems of care and reducing a broad range of barriers to mainstream services and programmes than on the cultural sensitivity of the health care professional
- For organisations focused on family-centred care who are using cultural brokers the partnership between families and professionals builds on family’s strengths, and respects the cultural traditions of the family (Jones & Thomas, 2009).
- It is easiest for families to link with cultural brokers when they are part of the organisations that are providing services to families of children with disabilities and with whom families already have a relationship (Jones & Thomas, 2009).
- It is more challenging when the cultural broker is working in an agency with whom the family is unfamiliar (Jones & Thomas, 2009).

Bailey, D.B. & Skinner, D. (1999). Needs and supports reported by Latino families of young children with developmental disabilities. *American Journal on Mental Retardation, 104* (5), 437-451.

- Bailey & Skinner (1999) interviewed 200 Latino parents living in the United States to determine needs and supports related to raising a child with a disability and to identify variables related to reported needs and supports.
- More support was reported from family and formal sources than from friends and informal sources
- English language proficiency was the only variable to account for significant variance in needs and supports
- The data did not delineate a “Latino” style of needs and supports, and it is likely that understanding individual histories and styles of adaptation may be as important as an understanding of broad cultural characteristics in designing services

Garwick, A.W., Kohrman, C., Wolman, C. & Blum, R.B. (1998). Families’ recommendations for improving services for children with chronic conditions. *Arch Pediatr Adolesc Med, 152*, 442-448

- One of the few studies to investigate how services should be delivered from the family’s point of view. Inherent in the philosophy of family-centred care is involving families in the development and evaluation of services and programmes
- The objective of the qualitative study was to identify recommendations from urban care-giving families from three major ethnocultural backgrounds for improving the care of children with chronic conditions (ie, chronic illnesses and disabilities involving physical health impairments)
- All three ethnic groups had similar recommendations for improving services. There was little variation in the families’ basic needs. However, the ethnic demography of the region served, and the social models of providing disability services have changed and need to be incorporated into service planning.

- Participants stressed the importance of individualising care rather than providing culturally specific care for particular ethnic groups
- More importantly the demands of the child's chronic condition or disability overwhelmed issues of culture in families stories
- Based on families recommendations Garwick et al. (1998) developed an acronym **TAILOR** that summarises strategies for providing family-centred care that is culturally sensitive

> **T**arget services to individual family needs
> **A**ssess the needs and preferences of the child and his/her family
> **I**nform families and providers
> **L**isten to families
> **O**rganize and coordinate services
> **R**espect the family's cultural background
> *Garwick et al., 1998*

- Families recommended that health care professionals focus on fitting services and programmes to the particular family's needs and to their cultural background by listening to specific child and family needs and tailoring interventions to fit

- Suggestions for improving the cultural relevance of services included:

    - Including families in the planning and delivery of services and programmes
    - Including children from diverse cultural backgrounds in teaching materials
    - Providing resources in the languages of the ethnic groups served
    - Disseminating information to ethnic minority communities
    - Including persons with disabilities and family caregivers from ethnically diverse backgrounds in the training of health care professionals

- The authors recommended that clinicians focus on the assessment of the particular child and family to understand how the cultural context influences the child's care.

Goode, T.D., Dunne, M. C. & Bronheim, S.M. (2006). The evidence base for cultural and linguistic competency in health care. The Commonwealth Fund.

- This report assesses the current evidence base for the impact and benefits of cultural and linguistic competence in health care and mental health care.

- The authors conducted a structured search of Medline from January 1995 to March 2006 to identify primary research articles for review on health outcomes and well-being. They also performed an exploratory search of multiple databases to identify evidence related to the business case, including primary sources, selected reviews, technical reports, and conceptual papers.

- A review of the health outcomes literature indicates that the field is in the early stages of development, with a preponderance of the literature exploring and defining the concepts and issues and identifying important research questions. There is now some movement towards pilot and controlled studies to test the impact of cultural and linguistic competence on the quality and effectiveness of care.

- Analysis of costs and benefits of culturally and linguistically competent care is complex and not yet well documented. The literature documents specific costs for services associated with linguistic competence but few studies document the cost of cultural competence.

- The authors explored issues related to client safety. Patients with limited English proficiency had significantly more adverse events, such as inaccurate or incomplete information, questionable advice, questionable tracking and follow-up, incorrect diagnosis, and questionable intervention. Hospitalised children of families with language barriers were more likely to experience medical errors than those from families without language barriers.

- An essential element of cultural competence is the capacity of an organisation to involve patients, families, and their communities systematically in designing, implementing, and evaluating services and supports. None of the methodological approaches used participatory action research models, and patient, community, or key stakeholders were involved only as subjects.

Groce, N.E. & Irving, K.Z. (1993). Multiculturalism, Chronic Illness and Disability. *Pediatrics, 91, (5),* 1048-1054

- Many ethnic and minority populations, reflecting their own unique and long-standing cultural beliefs, practices, and support systems, do not define or address disability and chronic illness in the same manner as “mainstream” culture.
- Their concerns are not necessarily identical, their solutions are not always the same, and the strengths shown in many ethnic and minority groups may present alternative ways of addressing needs that merit our careful attention.
- Each ethnic group develops a unique mix of cultural roles, expectations and conceptual frameworks that, in part, determines how its members view its social networks, support systems and communities
- For a programme to be truly multicultural, there must be a real understanding of the differences within and between cultures

Three key issues

The understanding and clinical application of cultural difference is a new task for health care professionals. Our current state of knowledge allows us now to begin to identify key issues concerning the social implications of chronic illness and disability. Among these, the following three issues seem to be almost universal, appearing prominently and consistently in cross-cultural studies:

1. The culturally perceived *cause* of a chronic illness or disability is significant in all cultures studied to date. The reason why an illness or disability is believed to have occurred in a particular individual and/or family will play a significant role in determining family and community attitudes toward the individual.
2. The expectations for survival (usually conceptualized in terms of actual *physical* survival) for the infant or child with a chronic illness or disability will affect both the immediate care the child receives and the amount of effort expended in planning for future care and education.
3. The social role(s) deemed appropriate for disabled or chronically ill children and adults (often based on a consensus about their productive potential and beliefs about how the disability is transmitted) will help determine the amount of resources a family and community *invest* in an individual. This includes issues of

education and training, participation in family and community social life, the latitude permitted for individual autonomy, and the long-range planning done by, or undertaken for, the individual over the course of a lifetime.

Culturally Perceived Causes of Disability

- The first of these issues, the culturally perceived cause of a chronic illness or disability, is of particular importance because it tends to colour all other aspects of the family's and the community's attitudes toward the affected child.
- Chronic illness and disability is seen by many cultures as a form of punishment. The individual with a disability, his or her family, or an ancestor, according to the particular belief system, has been either cursed by God or the Gods, sinned, or violated a taboo.
- Support for the individual or the immediate family in such cases might be half-hearted or lacking. 0thers may seek to distance themselves from those who have incurred such "evil." This is more than the simple distancing of former friends and relatives frequently reported in the literature by parents of children with disabilities. In some ethnic groups, the child is seen as tangible evidence of divine displeasure, and their arrival is accompanied throughout the community by prolonged public and private discussions about what wrongs the family may have committed
- In many countries, the very notion that a disabled child can be helped by early intervention or stimulation has not become a part of the standard knowledge base. Unfortunately, particularly in the case of pre-school-age children who may not receive needed interventions and services until they reach mandatory school-age, important developmental years are frequently lost in the process.
- In addition to the particular beliefs and understandings of the immediate family, service providers and advocates must be aware that in those ethnic and minority groups where disability is regarded as unacceptable, there is often enormous social pressure placed not only on the disabled child and adult but also on his or her immediate and extended family.
- Even when families are aware of the need for special services, they may be reluctant to participate in programmes, fearing that these will call attention to their members' physical or intellectual limitations. For example, when the traditional belief is that a disability runs in a family or is evidence of divine retribution, a family with siblings of marriageable age may be more likely to hide their disabled member away so as not to lessen the chances of finding suitable mates for the other children.
- It would benefit service providers to make allowances for extended as well as alternative family systems.
- It is thus not practical to learn in detail all the details of specific cultures, but rather to assume that such variations occur and learn how they might affect one's health practices. Rather than teaching every health practitioner to be a mini-medical anthropologist, it is more important for practitioners to be sensitive to the patient's heritage, to their own heritage, and to what happens when different heritages and belief systems come together.
- Consulting members of a particular ethnic group may prove to be valuable when trying to determine whether a particular individual's choices and actions are the result of cultural differences or true pathology. It is possible to dismiss potentially serious social and psychological reactions of an individual from another ethnic or minority group as simply being the result of cultural differences, when in fact the individual may be in need of direct and immediate assistance. It is also quite possible that an individual may display evidence of both cultural differences *and* individual distress.

Ngui, E. M. & Flores, G. (2006). Satisfaction with care and ease of using health care services among parents of children with special health care needs: The roles of race/ethnicity, insurance, language and adequacy of family centred care. *Pediatrics, 117*, (4), 1183-1196

- The aims of this study were to examine whether there are ethnic disparities in parent-reported satisfaction with care and ease of using health care services in Milwaukee, Wisconsin among parents of children with special health care needs (CSHCN) and to identify factors that contribute to disparities among parents

- The findings of the study were that:
  - On family-centred care measures, minority parents of CSHCN were significantly more likely than white parents to report that the provider sometimes or never spends enough time with their child, listens to the family carefully, is sensitive to family values/customs, provides enough information to the family, or helps the family feel like partners in the child's care.
  - Parents who reported that their child's health care provider did not spend enough time with their child and did not provide enough information had more than twice the odds of reporting that services were not easy to use.
  - Language barriers was a key determinant of dissatisfaction with access and the services provided

Limitations of the study

  - The study did not measure organisational or practice factors, such as provider and patient attitudes, cultural competency policies, or the limited availability of providers and specialised services in minority communities CSHCN services provided did not provide
  - The authors suggest the need for further studies of how to make health and disability services easier for ethnic minority clients and their families to use

4.1 Mainstreaming versus ethnic specific service delivery

Garwick, A.W., Kohrman, C., Wolman, C. & Blum, R.B. (1998). Families' recommendations for improving services for children with chronic conditions. *Arch Pediatr Adolesc Med, 152*, 442-448

- Garwick et al's (1998) study identified recommendations from urban care-giving families from three major ethnocultural backgrounds for improving the care of children with chronic conditions (i.e., chronic illnesses and disabilities involving physical health impairments)
- There were no recommendations from families that separate support services need to be provided for specific ethnic groups.
- Instead participants from all three ethnic groups focused on mainstream services individualising care to meet the particular needs of child and family, which is an effective strategy for providing culturally competent care, considering the many variations that exist within and between cultural groups
- Garwick et al. (1998) concluded that given the complex nature of caring for children with disabilities and the need for family caregivers to interact with health and disability, education, and social service providers it is not surprising that caregivers from different cultural backgrounds placed most emphasis on changing systems of

care and reducing a broad range of barriers to mainstream services and programmes than on the cultural sensitivity of the health care professional

- Family caregiver's recommendations suggest that providing culturally competent care includes informing the family about aspects of medical culture (eg how health care professionals understand chronic conditions and disability and their management; how to access resources and services; who provides services; what rules and regulations cover how services are delivered) that influence the child's care. With this information, families can access the care they need more effectively

Jones, W., & Thomas, T. (2009). *Growing Your Capacity to Engage Diverse Communities by Working with Community Liaisons and Cultural Brokers*. Albuquerque, NM: National Center for Family Professional Partnerships, Family Voices, Inc.

- In Albuquerque, New Mexico linking families of children with disabilities to other families for information, resources and support has proven to be a successful model for supporting parents and assisting them to navigate complex systems
- Working with cultural brokers and family brokers can play a key role in informing service providers about culturally appropriate ways of joining ethnic minority families with children with disabilities
- Community liaisons and cultural brokers can act as relationship brokers, providing information and linkages between families and communities and the organisations that seek to provide services and supports
- For organisations focused on family-centred care who are using cultural brokers the partnership between families and professionals builds on family's strengths, and respects the cultural traditions of the family.
- It is easiest for families to link with cultural brokers when they are part of the organisations that are providing services to families of children with disabilities and with whom families already have a relationship
- It is more challenging when the cultural broker is working in an agency with whom the family is unfamiliar

O'Hara, J. (2003). Learning disabilities and ethnicity: achieving cultural competence. *Advances in Psychiatric Treatment, 9,* 166-174

A strategic approach is required to ensure that the needs of people from ethnic minority communities are not overlooked in planning services for children with learning disabilities. These needs are complicated by issues of power, race and gender politics but they must not be overlooked just because they affect only 'small numbers' within a given population.

Service principles and action plan for service development

The requirements of service development include:

A strategic approach

Meaningful consultation with families, carers and community workers

Going beyond consultation to real empowerment

Developing advocacy and self-advocacy, recognising family structures that differ from those of the majority ethnic community

Appropriate publicity for and full access to all service provision

Recruitment of ethnic minority and bilingual staff at all levels and ensuring their adequate support and training

Training for all staff, to increase competence in cultural awareness, sensitivity and flexibility

Person-centered planning, acknowledging discrimination and racism and its impact on the person; drawing up support plans to empower people from ethnic communities

Accurate information about need – effective monitoring processes, patterns of use, identifying unmet need

Targeting housing and placement opportunities within ethnic communities

Commissioning single-culture treatment options, including in-patient and residential facilities, self-help groups, social and psychological therapies

Working with provider agencies that specify ‘cultural competence’

Integrated services: the ideal is quality mainstream services sensitive to the needs of all users

- Ethnic specific organisations offering ‘Special-needs’ initiatives can provide a much needed focus on the issues to be addressed, but they are often structurally disadvantaged, with inadequate funding. They may appear to meet a need but in fact act as a surrogate form of racism while absolving mainstream services of responsibility.

- Ethnic specific specialist services do not eliminate the need to remove discriminatory practices and attitudes from mainstream services. This situation is reflected in the wider debates and philosophies underpinning the provision of health care in general, and mental health care in particular, for people with learning disabilities.

5. Implications for Research and Practice

There are several reasons why a disability service may wish to evaluate the quality of services provided to clients and families from CALD backgrounds. Services may want to validate their understandings of the needs of the ethnic communities that they serve; they may want to ensure that there is equitable access, appropriate intervention and care; and effective communication between providers and clients and their families. Services may seek feedback from families on ways in which service provision could be improved.

Summary

- An essential element of cultural competence is the capacity of an organisation to involve patients, families, and their communities systematically in designing, implementing, and evaluating services and supports. Goode et al. (2006) in a review of the evidence base for cultural and linguistic competency found that none of the methodological approaches used participatory action research models, and that patient, community, or key stakeholders were involved only as subjects.
- Hasnain et al. (2008) recommend using an assets-based approach with an emphasis on case studies of individuals and families that have succeeded as a result of innovative culture brokering interventions.
- Carlson & van Kooten Prasad (2001). While many of the issues and strategies identified in this study are similar to those identified in the literature, there appear to be benefits from gathering local data because:

    1. Specific strategies were identified that could be implemented by an individual within an organisation, without needing to wait for large scale organisational change (e.g. organising joint individual/family support work and using ethnic community venues for services).
    2. Local differences and emphases can be identified (such as the need to develop inter-sectoral links).
    3. Information about needs and issues may be more likely to be “owned” by local organisations and more likely to provide an impetus for change, than more remotely gathered information.

- Similar action research processes, requiring modest resources, could be undertaken in other locations.
- Fitch (1991) suggested that, “the impetus from one relatively small pilot study can ultimately influence wider programme planning and delivery”.
- Davis (2000) promoted direct links between research and service development or change in the disability and health sectors.
- To further complete the action research cycle it would be appropriate to evaluate any new services or changes to service delivery that occur in relation to the above impetus.

Andrulis, D. Delbanco, T. Avakian, A. & Shaw-Taylor, Y (2007). *Conducting a cultural competence self–assessment.* Brooklyn, New York: Downstate Medical Centre

The Cultural Competence Self Assessment Protocol for Health Care Organisations and Systems, developed by Andrulis et al. (2007) is an approach to assessing organisational cultural competence. The protocol builds upon the Georgetown University, Child Development Center's Continuum of Cultural Competency. The protocol which can be used as an audit tool allows organisations to score responses and then place themselves on a five point spectrum of cultural competence, ranging from inaction to a fully realized "learning" organisation.

The protocol can serve as a department- or clinic-specific assessment instrument. While the protocol is intended to be administered as a self-assessment, it is possible to use it in conjunction with an external organisation. In addition, the protocol's format requires actively engaging a broad spectrum of health care staff and encourages the use of focus groups with patients. In all, the protocol can provide a health care organisation an opportunity to assess what it does well in providing care to diverse populations, where there are gaps and how it can create an agenda for improving its services.

Carlson G. & van Kooten Prasad, M. (2001). Services for people with intellectual disability of culturally and linguistically diverse backgrounds. *International Journal of Practical Approaches to Disability, 2001, 25,* (1).

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The consistent local acceptance of the findings of the project suggests that this process is appropriate despite the small number of participants involved. However, the following recommendations are made:

1. It would be preferable to involve a larger number of family carers as participants.
2. When services to people with a broader range of disabilities were being considered, then the involvement of people with disabilities themselves would be vital (and that this is occurring during the establishment of the advocacy and resource service).
3. More emphasis on the development of a concrete action plan at the forum stage of the process would possibly facilitate the impetus for service based changes.

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

Goode, T. (1999/2003). ***Getting started…Planning, implementing and evaluating culturally and linguistically competent service delivery systems for children with special health care needs and their families.*** **Washington, DC: National Center for Cultural Competence, Georgetown University Center for Child and Human Development.**

Implications for Policy Makers and Administrators

The following checklist was developed by the US National Center for Cultural Competence (NCCC). It is designed to assist organisations and systems of care to develop policies, structures and practices that support cultural and linguistic competence. The checklist focuses on systems of care and organisations concerned with the delivery of services and supports to children with special health care needs and their families

- **Create a structure.**
  - Convene a work group within your organization with the sole purpose of addressing cultural and linguistic competency.
  - This group can serve as the primary body to plan, implement and provide oversight to the organisation's cultural competence efforts.
- **Clarify values and philosophy.**
  - Ensure that the organization has values, principles and/or mission that incorporate culture as an integral aspect of all of its endeavors.
  - The inclusion of families, youth and community constituency groups can enrich this process.
- **Develop a logic model for cultural and linguistic competence.**
  - Reach consensus on a definition or framework for cultural competence and linguistic competence within the context of your organization and the communities it serves.
  - Engage key stakeholders in this process. The work group may assume leadership or facilitate this effort.

- **Keep abreast of community demographics.**
  - Determine the ethnically, culturally and linguistically diverse populations served by your programme, and those that live in the geographic area.
  - Determine and address any disparity in access and utilisation of services. Be cognisant of the sub-cultures and within group differences among these populations.
- **Assess consumer satisfaction.**
  - Use multifaceted approaches to assess the degree to which youth and families are satisfied with services they receive. Include probes that elicit the extent to which consumers feel their belief systems and cultural practices are respected and integrated in the health care they receive.
  - Telephone interviews, written surveys and focus groups are commonly used processes.
  - Key informants or cultural brokers can provide guidance on approaches to best assess consumer satisfaction that are consistent with the cultural norms of youth, families and communities.
- **Create structures for family and youth involvement.**
  - Consumers should be integrally involved in the design and implementation of services they receive.
  - Establish governance boards, advisory committees, task forces and work groups to facilitate the meaningful involvement of families and youth in all aspects of your organisation.
- **Conduct a self-assessment.**
  - Assessing attitudes, policies, structures and practices is a necessary, effective and systematic way to plan for and incorporate cultural and linguistic competence in organisations.
  - Determine which instruments best match the needs and interests of your organisation.
  - Use self-assessment results to develop an organisational plan for achieving and/or enhancing cultural and linguistic competence.
- **Determine staff development needs/interests.**
  - Conduct periodic assessments of organisational personnel to determine what they perceive as their training or professional development needs and interests related to cultural and linguistic competence.
  - The assessment should query personnel on the preferred methods, approaches and formats for increasing awareness and acquiring new skills and areas of knowledge.
  - Ensure that resources are budgeted to support these efforts.
- **Engage communities.**
  - Develop partnerships that acknowledge strengths and build upon the resiliency and many networks of support within diverse communities.
  - Communities have the inherent ability to recognise their own problems, including the health of their members, and intervene appropriately on their own behalf (Goode, 2002).
  - Expand collaborative relationships to include natural helpers, community informants, cultural brokers, faith-based organisations, ethnic-specific and advocacy organisations
- **Adopt “lessons learned”.**
  - Network within and dialogue with other organisations or systems of care that focus on children special health care needs and their families that

have begun the journey of achieving cultural and linguistic competency. Consider the following:
(1) reviewing their policies and practices,
(2) adapting those that are consistent with your philosophy of care, and
(3) negotiating opportunities for mentoring, training, consultation and technical assistance. Access resources from public and private sector centers and programmes that have expertise in cultural and linguistic competence (e.g., integrated therapies, traditional practices, in-home services, culturally defined approaches for health education and literacy, advocacy and community

  - Gather and categorize resource materials to expand your organisation's library/resource center.

- **Create a refuge for sharing and learning.**
  - Provide safe, non-judgmental forums for personnel to honestly explore cultural considerations—their own and those of the children, youth, families and communities they serve. Including youth, families and community partners can inform and enhance these experiences.

Goode, T., Jones, W. & Mason, J. (2002). *A guide to planning and implementing cultural competence organisation self-assessment.* Washington, D.C.: National Center for Cultural Competence, Georgetown University Child Development Center

Essential Elements in Achieving Cultural Competence
The US National Center for Cultural Competence (NCCC) utilises a conceptual framework and model for achieving cultural competence adapted from the work of Cross et al. (1989). Cultural competence requires that organisations and their personnel have the capacity to:

1. value diversity,
2. conduct self-assessment,
3. manage the dynamics of difference,
4. acquire and institutionalise cultural knowledge, and
5. adapt to the diversity and cultural contexts of the individuals and communities served.

Consistent with this framework, a major focus of the NCCC is the provision of technical assistance to conduct self-assessment within health care and human service agencies. The focus includes the development of assessment instruments and processes for both organisations and individuals.

The Benefits of Self-Assessment
The NCCC supports the concept that cultural competence is a developmental process and evolves over an extended period. Both organisations and individuals are at various levels of awareness, knowledge and skill acquisition along the cultural competence continuum. The capacity to engage in self-assessment helps organisations to:

- gauge the degree to which they are effectively addressing the needs and preferences of culturally and linguistically diverse groups;

    - establish partnerships that will meaningfully involve families/consumers and key community stakeholders;
    - improve family/consumer access to and utilisation of services and enabling supports;
    - increase family/consumer satisfaction with the services received;
    - strategically plan for the systematic incorporation of culturally and linguistically competent policies, structures and practices;
    - allocate personnel and fiscal resources to enhance the delivery of services and enable supports that are culturally and linguistically competent; and
    - determine individual and collective strengths and areas for growth.

There are numerous benefits to self-assessment.

- Such processes can lead to the development of a strategic organisational plan with clearly defined short-term and long-term goals, measurable objectives, identified fiscal and personnel resources, and enhanced consumer and community partnerships.
- Self-assessment can also provide a vehicle to measure outcomes for personnel, organisations, population groups and the community at large.
- The NCCC views self-assessment as an ongoing process, not a one-time occurrence. It offers organisations and their personnel the opportunity to assess individual and collective progress over time.

Goode, T.D., Dunne, M. C. & Bronheim, S.M. (2006). The evidence base for cultural and linguistic competency in health care. The Commonwealth Fund.

- Future directions for research include:

    - use of validated and shared definitions of cultural and linguistic competence;

    - refined population definitions to include cultural variables other than ethnicity or language;

    - use of designs that test the specific effects of cultural and linguistic competence;

    - implementation of longitudinal and large sample studies to investigate ultimate health outcomes;

    - and use of methods and measures that examine the relationship among organisational policies, structures and practices, quality and effectiveness of care, and health outcomes and well-being.

Hasnain, R., Cohon Shaikh, L. & Shanawani, H. (2008). Disability and the Muslim Perspective: An Introduction for Rehabilitation and Health Care Providers. Center for International Rehabilitation Research Information and Exchange

- Historically, research on ethnic minority groups has focused on a deficit perspective in which European American standards are used to determine success.

  - If non-mainstream populations such as Muslims vary from these standards, they may be seen as unsuccessful or deficient. As a result, using non-minority counterparts as a standard, researchers traditionally have evaluated minority individuals with disabilities without considering the many ways in which their lives and worldviews may differ, given their different cultural, sociopolitical, financial, and religious contexts
  - Moreover, it is critical that any research in the field consider individual and group beliefs, values, language system, traditions, customs, and worldviews.
  - For interventions to be effective, health care providers must not only understand various issues that originate from within the Muslim communities, but also look at the variables that are part of mainstream health and disability systems, and how those variables colour various views and assumptions.
  - Hasnain et al. (2008) recommend using an assets-based approach with an emphasis on case studies of individuals and families that have succeeded as a result of innovative culture brokering interventions.

Research recommendations

  - Build and establish trust and practice respect with the Muslim community and research study participants.
  - Develop culturally validated health and rehabilitation services to address current health disparities among Muslims.
  - Increase outcome-based research in Muslim ethnic communities to identify and address needs that remain unmet as a result of the lack of outreach and understanding from disability and health systems.
  - Conduct forums and focus groups to identify the authentic needs of Muslims with disabilities and their families and to incorporate those findings into future interventions.
  - Develop data collection instruments and surveys that reflect cultural values and differences rather than using mainstream standards and norms to make comparisons.

Telfair, J., Bronheim, S.M. & Harrison, S. (2009). Implementation of culturally and linguistically competent policies by state title v children with special health care needs (CSHN) programmes. *Matern Child Health J,* 13 (5), 677-86

Objective

- This descriptive study was intended to identify actual actions, steps and processes of Children with Special Health Care Needs (CSHCN) programmes to develop, implement, sustain and assess culturally and linguistically competent policies, structures and practices.

Methods

- An online 52-item mixed format survey of Maternal and Child Health (MCH) CSHCN directors was conducted. Standard quantitative and qualitative analyses of the data were conducted to address key questions linked to the study's overall objective.

Results

- Findings indicated that almost all respondents are implementing some actions to provide culturally and linguistically competent services including:
  - adapting service practices
  - addressing workforce diversity
  - providing language access
  - engaging communities

  - including requirements in contracts.
- These individual actions were less often supported by processes such as self-assessment and creating an ongoing structure to systematically address cultural and linguistic competence. Programmes are challenged to implement cultural and linguistic competence by state agency organization and budget restrictions.

Conclusions

- The results of the study indicate a continued need for support within state MCH CSHCN programmes in order to maintain or enhance the systematic incorporation of culturally and linguistically competent efforts.

Stienstra, D. (2002). *The Intersection of DISABILITY and Race/Ethnicity/Official Language/Religion.* Prepared for the "Intersections of Diversity" Seminar March 8, 2002. Canada: Canadian Centre on Disability Studies, University of Winnipeg

- Research should pay less attention to how to provide better 'culturally competent' services, and more to what causes the inequities that result in the need for differing services for culturally and linguistically diverse families. Better ethnicity data on users of disability services are needed

- Research needs to use methods that allow ethnic community voices to be heard authentically, and develop research in partnership with communities in ways that will benefit them.

- Much more research is needed to develop understandings of the different perspectives on disability and the inequalities faced by refugee and migrant groups.

- More research is needed on how disability support including respite and home care programmes could attract workers from culturally diverse backgrounds and the implications of this for disabled people from culturally diverse backgrounds.

Lewin Group (2002). *Indicators of Cultural Competence in Health Care Delivery Organisations: An Organisational Cultural Competence Assessment Profile.* USA: The Health Resources and Services Administration, U.S. Department of Health and Human Services.

"How do we know cultural competence when we see it?"

This project aimed to contribute to the methodology and state-of-the-art of cultural competence assessment. The product – *An Organisational Cultural Competence Assessment Profile* serves as a future building block that advances the conceptualization and practical understanding of how to assess cultural competence at the organisational level.

Knowing Cultural Competence when we see it: Components of the Profile

The Assessment Profile has three major components:

1. *domains* of cultural competence;
2. *focus areas* within domains; and

3. *indicators* relating to focus areas, by type of indicator.

A: Domains and Focus Areas: Where to Look for Evidence of Cultural Competence

The Profile's seven domains are described below.

1. *Organisational values:* An organisation's perspective and attitudes with respect to the worth and importance of cultural competence and its commitment to provide culturally competent care.
2. *Governance:* The goal-setting, policy-making, and other oversight vehicles an organisation uses to help ensure the delivery of culturally competent care.
3. *Planning and monitoring/Evaluation:* The mechanisms and processes used for: a) long and short-term policy, programmatic, and operational cultural competence planning that is informed by external and internal consumers; and
   b) the systems and activities needed to proactively track and assess an organisation's level of cultural competence.
4. *Communication:* The exchange of information between the organisation/providers and the clients/population, and internally among staff, in ways that promote cultural competence.
5. *Staff development:* An organisation's efforts to ensure staff and other service providers have the requisite attitudes, knowledge and skills for delivering culturally competent services.
6. *Organisational infrastructure:* The organisational resources required to deliver or facilitate delivery of culturally competent services.
7. *Services/Interventions*: An organisation's delivery or facilitation of clinical, public health, and health related services in a culturally competent manner.

B. Indicators by Type: Specific Evidence to be Used in Assessing Cultural Competence

Indicators in the Profile were classified into four types:

1. structure indicators,
2. process indicators,
3. output indicators, and
4. intermediate outcome indicators.

Structure indicators are used to assess an organisation's capability to support cultural competence through adequate and appropriate settings, instrumentalities, and infrastructure, including staffing, facilities and equipment, financial resources, information systems, governance and administrative structures, and other features related to the organisational context in which services are provided.

Process indicators are used to assess the content and quality of activities, procedures, methods, and interventions in the practice of culturally competent care and in support of such care.

Output indicators are used to assess immediate results of culturally competent policies, procedures, and services that can lead to achieving positive outcomes.

Intermediate outcome indicators are used to assess the contribution of cultural competence to the achievement of *intermediate* objectives relating to the provision of care, the response to care, and the results of care.

A. Key Observations

Assessment is not an isolated event

- The assessment of cultural competence should not be considered an isolated event, but rather a continuous process that is emphasised and integrated in an organisation's overall assessment activities.
- Cultural competence assessment, like other significant management activities, should be clearly identifiable and targeted to garner the leadership and resources required, while being an integral part of an organisation's regular performance and quality assessment activities.

Importance of assessing institutionalisation

- It is important to assess the "institutionalisation" of cultural competence in an organisation, i.e., the extent to which cultural competence is an integral part of the organisation's service, management and business functions.

Validation of the components of the profile

- The perspectives and activities of the health care sites visited for this project give credence to the Profile's seven evidence-based domains as appropriate performance areas for assessing cultural competence.
- The sites emphasised the importance of assessing the domain of Organisational Values as the necessary precursor to culturally competent performance. In particular, dedicated leadership for championing and implementing cultural competence and cultural competence-related data collection and analysis were noted as two critical indicators of an organisation's commitment to cultural competence.

6. References

Abrahamsson, A., Andersson, J. & Springett, J. (2009). Building bridges or negotiating tensions? Experiences from a project aimed at enabling migrant access to health and social care in Sweden. *Diversity in Health and Care, 6,* (2), 85-95

Andrulis, D. & Delbanco, T., Avakian, L. & Shaw-Taylor, Y. (2007). Conducting a cultural competence self-assessment. USA: Department of Health and Human Resources. Retrieved 20 May, 2009, from http://erc.msh.org/provider/andrulis.pdf

Argyris, C. & Schon, D. A. (1989). Participatory action research and action science compared: A commentary. *American Behavioural Scientist, 32*, 612-623.

Australian Research Alliance for Children & Youth (2008). *Achieving Outcomes for Children and Families from Culturally and Linguistically Diverse Backgrounds*. Western Australia: Australian Research Alliance for Children & Youth. Retrieved 20 May, 2009, from www.aracy.org.au

Bailey, D.B. & Skinner, D. (1999). Needs and supports reported by Latino families of young children with developmental disabilities. *American Journal on Mental Retardation, 104* (5), 437-451.

Beach, M.C., Cooper, L.A., Robinson, K.A., Price, E.G., Gary, T.L, Jenckes, M. W. Gozu, A., Smarth, C., Palacio, A., Feuerstein, C.J., Bass, E.B. & Powe, N.R. (2004). *Strategies for improving minority healthcare quality.* Summary, Evidence Report/Technology Assessment: Number 90. AHRQ Publication Number 04-E008-1. USA, Rockville, MD: Agency for Healthcare Research and Quality. Retrieved 20 May, 2009, from http://www.ahrq.gov/clinic/epcsums/minqusum.htm

Beach, M.C., Saha, S. & Cooper, L.A. (2006). The role and relationships of cultural competence and patient centredness in health care quality

Bell, D. (ed.) (2005). *New to New Zealand: A guide to ethnic groups in New Zealand (4th edition).* New Zealand: Reed Publishing (NZ) Ltd

Betancourt, J.R., Green, A.R. & Carrillo, J.E. (2002). *Cultural Competence in Health Care: Emerging Frameworks and Practical Approaches*. The Commonwealth Fund. Retrieved 20 September, 2009, from http://www.cmwf.org/usr_doc/Betancourt_cultural_576.pdf

Betancourt, J.R., Green, A.R., Carillo, J.E. & Ananeh-Firempong, O. (2003). Defining cultural competence: A practical framework for addressing racial/ethnic disparities in health and healthcare. *Health Affairs*, *24* (2), 499-505

Betancourt, J.R., Green, A.R., Carillo, J.E. & Park, E. R. (2005). Cultural competence and health care disparities: Key perspectives and trends. *Health Affairs*, *24* (2), 499-505

Betancourt, J.R., Weissman, J.S., Kim, M.K. Park, E.R. & Maina, A.W. (2007). Resident physicians' preparedness to provide cross-cultural care: Implications for clinical care and medical education policy. USA: Health Workforce Information Centre.

Retrieved 20 May, 2009, from http://www.commonwealthfund.org/usr_doc/1026_Betancourt_resident_MDs_preparedness_provide_cross-cultural_care.pdf

Bhui, K., Warfa, N., Endonya, P., McKenzie, K. & Bhugra, D. (2007). Cultural competence in mental health care: A review of model evaluations. *BMC Health Services Research, 7,* 15. Retrieved 20 May, 2009, from http://www.biomedcentral.com/1472-6963/7/15

Brach, C., & Fraser, I. (2000). Can cultural competency reduce racial and ethnic health disparities? A review and conceptual model. *Medical Care Research and Review*, 57 (Suppl. 1) 181 – 217.

Brach, C. & Fraser, I. (2002). Can cultural competency reduce racial and ethnic health disparities? A review and conceptual model. *Medical Care Research & Review, 57* (suppl.1), 181-217

Bronheim, S., Goode, T, & Jones, W. (2006). *Policy Brief: Cultural and Linguistic Competence in Family Supports*. Washington, DC: National Center for Cultural Competence, Georgetown University Center for Child and Human Development. Retrieved 20 May, 2009, from: http://www11.georgetown.edu/research/gucchd/nccc/documents/FamilySupports.pdf

Carlson, G. & Prasad, M. (2001). Services for people with intellectual disability of culturally and linguistically diverse backgrounds. *International Journal of Practical Approaches to Disability*, 25 (1), 3 - 14

Carlson G. & van Kooten Prasad, M. (2001). Services for people with intellectual disability of culturally and linguistically diverse backgrounds. *International Journal of Practical Approaches to Disability, 2001, 25,* (1). Retrieved 20 September, 2009, from http://www.ijdcr.ca/VOL01_02_AUS/articles/article1.pdf

Cross, T., Bazron, B., Dennis, K., & Isaacs, M. (1989). *Towards a culturally competent system of care volume I.* Washington, D.C.: Georgetown University Child Development Center, CASSP Technical Assistance Center.

Goode, T. & HarrisonDavis, J. M. (2000). Disability studies as ethnographic research and text: Research strategies and roles for promoting social change. *Disability and Society, 15*, 191-206.

Department of Ageing, Disability and Home Care (2005). *Strategy to improve services for people from culturally diverse communities.* NSW Department of Ageing, Disability and Home Care CALD Strategy 2005-2008. Australia: New South Wales Government. Retrieved 20 May, 2009, from www.dadhc.nsw.gov.au

Department of Human Services (2006). *Health service cultural diversity plans.* Victoria, Australia: Victorian Government. Retrieved 20 May, 2009, from http://www.health.vic.gov.au/cald/hlth-service

Department of Human Services (2006). *Cultural diversity guide.* Victoria, Australia: Victorian Government. Retrieved 20 May, 2009, from http://www.dhs.vic.gov.au/multicultural/downloads/cultural_diveristy_guide_2006.pdf

DHBNZ (2008) Health workforce information: base data report (Snapshot at 30 September 2008). Wellington: DHBNZ. Retrieved 20 May, 2009, from http://www.dhbnz.org.nz/Site/Future_Workforce/HWIP/DHB_Base_Data_Reports.aspx

Diversity Health Institute (2006). *Cultural competence in healthcare*. Diversity Health Institute Position Paper. Sydney: Australia: Sydney West Area Health Service, Diversity Health Institute. Retrieved 8 February, 2008 from http://www.dhi.gov.au/wd...ltural%20competence.pdf

Ethnic Communities' Council of Victoria. (2006). Cultural Competence: Guidelines and protocols. Victoria, Australia: Statewide Resources Centre. Retrieved 20 May, 2009, from http://eccv.org.au/doc/CulturalCompetenceGuidelinesandProtocols.pdf

Fitch, S., Papanicolaou, E. & Maligeorgos, G. (1992). *Developing Accessible Services for people with a disability and of non-English speaking background: A model*. Melbourne: Action on Disability within Ethnic Communities.

Gany, F., Kapelusznik, L., Prakash, K., Gonzalez, J., Orta, L. & Changrani, J. (2007). Patient satisfaction with different interpreting methods: A randomized controlled trial. *J Gen Intern Med, 22* (Suppl 2), 312-8

Garwick, A.W., Kohrman, C., Wolman, C. & Blum, R.B. (1998). Families recommendations for improving services for children with chronic conditions. *Arch Pediatr Adolesc Med, 152*, 442-448

Goode, T. (1999/2003). *Getting started…Planning, implementing and evaluating culturally and linguistically competent service delivery systems for children with special health care needs and their families.* Washington, DC: National Center for Cultural Competence, Georgetown University Center for Child and Human Development. Retrieved 8 September, 2009 from http://gucchd.georgetown.edu/nccc

Goode, T.D. (2000). *Definitions of Cultural Competence*. National Center for Cultural Competence. Washington D.C: Georgetown University Child Development Center

Goode, T.D., Dunne, M. C. & Bronheim, S.M. (2006). The evidence base for cultural and linguistic competency in health care. The Commonwealth Fund. Retrieved 8 September, 2009 from http://www.commonwealthfund.org/~/media/Files/Publications/Fund%20Report/2006/Oct/The%20Evidence%20Base%20for%20Cultural%20and%20Linguistic%20Competency%20in%20Health%20Care/Goode_evidencebasecultlinguisticcomp_962%20pdf.pdf

Goode, T., Jones, W. & Mason, J. (2002). A guide to planning and implementing cultural competence organisationself-assessment. Washington, D.C.: National Center for Cultural Competence, Georgetown University Child Development Center. Retrieved 8 September, 2008 from http://gucchd.georgetown.edu/products/OrganisationalSelfAssessment.pdf

Groce, N.E. & Irving, K.Z. (1993). Multiculturalism, Chronic Illness and Disability. *Pediatrics, 91, (5),* 1048-1054

Gray, B. (2007). English language difficulties at general practices in Auckland, New Zealand: a major limitation to good practice. *New Zealand Medical Journal, 120* (1264). Retrieved 28 February, 2009 from http://www.nzma.org.nz/journal/120-1264/2777/

Gray, M. & McPherson, K. (2004). Cultural Safety and professional practice in occupational therapy: A New Zealand perspective. *Australian Occupational Therapy Journal, 52* (1), 34 – 42

Guerin, B., Abdi, A. & Guerin, P. (2003). Experiences with the medical and health systems for Somali refugees living in Hamilton. *New Zealand Journal of Psychology, 32,* (1), 27-32

Harris, P. (2004). *Culturally Competent Disability Support: Putting It Into Practice.* NSW, Australia: Multicultural Disability Advocacy Association of NSW (MDAA). Retrieved 28 September, 2009 from www.mdaa.org.au

Hasnain, R., Cohon Shaikh, L. & Shanawani, H. (2008). Disability and the Muslim Perspective: An Introduction for Rehabilitation and Health Care Providers. Center for International Rehabilitation Research Information and Exchange. Retrieved 28 September, 2003 from: http://cirrie.buffalo.edu/monographs/muslim.php

Hasnain, R., Sotnik, P. & Ghiloni, C. (2003). Person centred planning: a gateway to improving vocational rehabilitation services for culturally diverse individuals with disabilities. *Journal of Rehabilitation*, *69* (3), 10 – 17

Hepburn, K.S. (2004). *Building culturally & linguistically competent services to support young children, their families and school readiness.* US, Baltimore:The Anne E. Casey. Foundation. Retrieved 28 September, 2009 from: http://www.eric.ed.gov/ERICDocs/data/ericdocs2sql/content_storage_01/0000019b/80/29/db/0a.pdf

Jackson, K. (2006). *Fates, Spirits and Curses.* Auckland, New Zealand: Refugees as Survivors.

Jackson-Carroll, L.M., Graham, E. & Jackson, J. C. (1998). *Beyond medical interpretation: The role of interpreter cultural mediators (ICMs) in building bridges between ethnic communities and health institutions.* Community House Calls, Harborview Medical Center. Seattle, Washington, USA. Retrieved 28 April, 2003 from: http://healthlinks.washington.edu/clinical/ethnomed/icm/index.html

Jezewski, M. A. & Sotnik, P. (2005). Disability service providers as cultural brokers. In J. H. Stone (ed.). *Culture and Disability: Providing Culturally Competent Services* pp 31-65. United States of America: Sage Publications.

Jezewski, M.A & Sotnik, P. (2001). *Culture Brokering: Providing culturally competent rehabilitation services to foreign-born persons.* Center for International Rehabilitation Research Information and Exchange. CIRRIE Monograph Series.

Jones,W., & Thomas,T. (2009). *Growing Your Capacity to Engage Diverse Communities by Working with Community Liaisons and Cultural Brokers*. Albuquerque, NM: National Center for Family Professional Partnerships, Family Voices, Inc. Retrieved 28 September, 2009 from: http://www.familyvoices.org/pub/general/CommunityBrokers_04-27-2009.pdf

Lawrence, J. (2007). *Placing the lived experience(s) of TB in a refugee community in Auckland, New Zealand.* Unpublished PhD thesis. University of Auckland: Auckland

Lee,H., Ostrosky, M.M., Bennett, T. & Fowler, S.A. (2003). Perspectives of early intervention professionals about culturally-appropriate practices. *Journal of Early Intervention, 25* (4), 281-295

Manderson, L. & Allotey, P. (2003). Cultural politics and clinical competence in Australian health services. *Anthroplogy & Medicine, 10* (1), 71-85

Matthews, C., Klinken Whelan, A., Johnson, M. & Noble, C. (2008). A piece of the puzzle — the role of ethnic health staff in hospitals. *Australian Health Review 32* (2), 236-245

Medical Council of New Zealand (2006). *Statement on cultural competence.* Wellington: Medical Council of New Zealand

Ministry of Health (2008). *Pacific Peoples' experience of disability: A paper for the Pacific Health and Disability Action Plan review.* Wellington: Ministry of Health. Retrieved 28 April, 2009 http://www.moh.govt.nz

Mir, G., Nocon, A., Ahmad, W. & Jones, L. (2001). *Learning Difficulties and Ethnicity.* Report to the Department of Health by the Centre for Research in Primary Care, University of Leeds. UK: Department of Health.

National Center for Cultural Competence (2004). *Bridging the Cultural Divide in Health Care Settings: The Essential Role of Cultural Broker Programmes. National Center for Cultural Competence*. Georgetown University Child Development Center: Washington D.C. Retrieved 28 September, 2009 from: http://data.georgetown.edu/research/gucchd/nccc/documents/Cultural_Broker_Guide_English.pdf

National Health and Medical Research Council (2005). Cultural competency in health: A guide for policy, partnerships and participation. Australian Government, National

Health and Medical Research Council. Retrieved 20 May, 2009, from http://www.nhmrc.gov.au/publications/synopses/_files/hp19.pdf

Ngui, E. M. & Flores, G. (2006). Satisfaction with care and ease of using health care services among parents of children with special health care needs: The roles of race/ethnicity, insurance, language and adequacy of family centred care. *Pediatrics, 117*, (4), 1183-1196

Northern District Health Board Support Agency (2006). *Improving mental health services responsiveness to Asian communities: Auckland Regional Asian Mental Health and Addictions Implementation Plan 2006 to 2010*. Prepared Northern Region Asian Mental Health & Addiction Advisory Group. Auckland: NDSA

Nursing Council of New Zealand (2007). *Competencies for registered nurses.* New Zealand: NZNC. Retrieved 14 February, 2009 from http://www.nursingcouncil.org.nz/RN%20Comps%20final.pdf

Occupational Board of New Zealand (2004). *Continuing competence framework for recertification:Practitioner handbook.* Wellington, New Zealand: Occupational Board of New Zealand. Retrieved 14 September, 2009 from http://www.otboard.org.nz/pdfs/Continuing_Competence.pdf

O'Hara, J. (2003). Learning disabilities and ethnicity: achieving cultural competence. *Advances in Psychiatric Treatment, 9,* 166-174

Pearson, E. & Cologon, K. (2009) Advancing inclusive and culturally sensitive approaches in service support for people with disability. *Development Bulletin, 73,* 83-88

Pinto, P.E. & Sahur, N. (2001). *Working with People with Disabilities: An Indian Perspective.* Center for International Rehabilitation Research Information and Exchange. Retrieved 20 September, 2009 from: http://cirrie.buffalo.edu/monographs/india.php

Potocky-Tripodi, M. (2002). *Best practices for social work with refugees and migrants*. New York: Columbia University Press.

Rasanathan, K., Ameratunga, S. & Tse, S. (2006). Asian health in New Zealand—progress and challenges. *The New Zealand Medical Journal, 119* (1244). Retrieved 11 February, 2009 from http://www.nzma.org.nz/journal/119-1244/2277/

Ripple Trust (2003). *Feasibility Study for a Disability Empowerment, Advocacy and Support Service (DEAS) for Refugees and New Settlers.* Auckland: Assured Directions Project Report by Assured Directions for Ripple Trust

Rounds, K.A., Weil, M. & Bishop, K. (1994). Practice with culturally diverse families of young children with disabilities. *Families in Society*, 75 (1), 3.

Stienstra, D. (2002). *The Intersection of DISABILITY and Race/Ethnicity/Official Language/Religion.* Prepared for the "Intersections of Diversity" Seminar March 8, 2002. Canada: Canadian Centre on Disability Studies, University of Winnipeg

Stewart, S. (2006a). Cultural competence in health care. Sydney, Australia: Diversity Health Institute.

Stewart, S. (2006b). Ringing in the changes for a culturally competent workforce. Australia: Multicultural Mental Health, Australia. *Synergy, 3*, 8-12

Sue, S. (1998). In search of cultural competence in psychotherapy and counselling. *American Psychologist*, 53 (4), 440 – 448

Telfair, J., Bronheim, S.M. & Harrison, S. (2009). Implementation of culturally and linguistically competent policies by state title v children with special health care needs (CSHN) programmes. *Matern Child Health J,* 13 (5), 677-86

The Lewin Group (2002). Indicators of Cultural Competence in Health Care Delivery Organisations: An Organisational Cultural Competence Assessment Profile. USA: The Health Resources and Services Administration, U.S. Department of Health and Human Services. Retrieved 20 May, 2009, from http://www.culturallycompetentmentalhealthnj.org/docs/2006-12-training/CC-LewinReport.pdf

The Physiotherapy Board of New Zealand (2009). Physiotherapy competencies for physiotherapy practice in New Zealand. Wellington, New Zealand: The Physiotherapy Board of New Zealand Retrieved 20 September, 2009, from http://www.physioboard.org.nz/docs/PHYSIO_Competencies_09_for_web.pdf

Tse, S. Sobrun-Maharaj, A. & Hoque, E. (2006). *Research and evaluation of barriers to Asian people accessing injury related services and entitlements.* Centres for Asian Health Research and Evaluation, Auckland Uniservices Limited, University of Auckland. Prepared for Accident Compensation.

US Department of Health and Human Services (2001). *Cultural Competence Works*. Health Resources and Services Administration. Retrieved 20 September, 2009, from http://www.hrsa.gov/financeMC/cultural-competence.pdf

Wepa, D. (2005). Culture and ethnicity: What is the question. In D. Wepa (Ed.), *Cultural safety in Aotearoa* (pp 30-38). Malaysia: Pearson Education New Zealand

Walker, R. (2006). People with disability at Taikura Trust. Auckland: Taikura Trust

Wu, E. & Martinez, M. (2006). Taking cultural competency from theory to action. USA: California Pan-Ethnic Health Network. Retrieved 28 May, 2009 from www.cmwf.org

7. Appendices

Appendix 1: Statistics New Zealand Level 2 ethnicity codes

Level 2 Codes (Statistics New Zealand, 2006)

– Level 2 – alphabetical order		–	– Level 2 – code order	
– Description	– Code	–	– Code	– Description
– African (or cultural group of African origin)	– 53	–	– 10	– European NFD
– Asian NFD	– 40	–	– 11	– New Zealand European / Päkehä
– Chinese	– 42	–	– 12	– Other European
– Cook Island Maori	– 32	–	– 21	– Mäori
– European NFD	– 10	–	– 30	– Pacific peoples NFD
– Fijian	– 36	–	– 31	– Samoan
– Indian	– 43	–	– 32	– Cook Island Maori
– Latin American / Hispanic	– 52	–	– 33	– Tongan
– Mäori	– 21	–	– 34	– Niuean
– Middle Eastern	– 51	–	– 35	– Tokelauan
– New Zealand European / Päkehä	– 11	–	– 36	– Fijian
– Niuean	– 34	–	– 37	– Other Pacific peoples
– Not stated	– 99	–	– 40	– Asian NFD
– Other	– 54	–	– 41	– Southeast Asian
– Other Asian	– 44	–	– 42	– Chinese
– Other European	– 12	–	– 43	– Indian
– Other Pacific peoples	– 37	–	– 44	– Other Asian
– Pacific peoples NFD	– 30	–	– 51	– Middle Eastern
– Repeated value * not used	– 96	–	– 52	– Latin American / Hispanic
– Response outside scope * not used	– 98	–	– 53	– African (or cultural group of African origin)
– Response unidentifiable * not used	– 97	–	– 54	– Other
– Samoan	– 31	–	– 96	– Repeated value * not used
– Southeast Asian	– 41	–	– 97	– Response unidentifiable * not used
– Tokelauan	– 35	–	– 98	– Response outside scope * not used
– Tongan	– 33	–	– 99	– Not stated

Appendix 2: Pacific People's Experience of Disability

Ministry of Health (2008). *Pacific Peoples' experience of disability: A paper for the Pacific Health and Disability Action Plan review.* Wellington: Ministry of Health.

Executive Summary

There is limited information available about Pacific peoples' experience of disability, and few sources of reliable data. Differing definitions of disability across surveys and service areas further complicate the picture. This paper attempts to describe the current situation, drawing on the most recently published information. The following is a summary of the main points.

- Eleven percent of Pacific people in New Zealand in 2006 had a disability. Of these, three quarters were adults and one quarter were children. Physical disabilities are the most common type of disability experienced by Pacific people, followed by other disabilities and then sensory disabilities. In 2001, a greater proportion of disabled Pacific people had severe disability than disabled non-Pacific people (24 and 12 percent, respectively). Disease or illness is the most common cause of disability for both Pacific adults and Pacific children.
- Disabled Pacific people are less likely to have received a needs assessment than non-Pacific people with disability: in 2001 8 percent of Pacific adults with disability had received a needs assessment, compared with 15 percent of non-Pacific adults. That year nearly half (48 percent) of Pacific adults with disability received some kind of help with everyday activities from other people, compared with 39 percent of non-Pacific adults with disability. Some reports suggest that disabled Pacific people often do not continue on after needs assessments to access the recommended support services. Reasons for this may include lack of co-ordination between disability providers and health services, and the difficulties experienced navigating a complex disability support system.
- A much higher proportion of disabled Pacific people live in the most socioeconomically deprived areas compared with disabled non-Pacific people (72 percent and 42 percent, respectively). This makes it important that they access financial assistance for their disability costs, which might otherwise have to be either neglected or prioritised over other basic needs. Some evidence suggests that financial assistance is not getting through; for instance, parents or caregivers of disabled Pacific children are less likely to receive the child disability allowance than parents or caregivers of disabled non-Pacific children (11 percent compared to 19 percent). Pacific people also claim ACC at a lower rate than the non-Pacific population (45 percent of the rate of the general population).
- Some disabled Pacific people and their families may experience discrimination. Positive family and community attitudes to disability, and community support for families and individuals with disabilities, need to be encouraged and developed. This may also provide career opportunities for disabled Pacific people themselves, who are in an ideal position to share their experiences and knowledge of disability.

Cultural perspectives and attitudes to disability

- Some Pacific people continue to believe that a person's impairment is the result of an affliction or curse brought about by their own (or their parents' or ancestors') marital infidelity, breach of tapu or sin (PIASS 2005). In addition, certain words denoting disability in Pacific languages have negative connotations. For example, in the Samoan language a blind person is commonly referred to as ‘tau aso’, meaning ‘your days are numbered’

- Discrimination can come from all parts of the Pacific community, including the church, and stems from the notion that disabilities are linked to divine punishment. The church plays a major role in the life of most Pacific families and is often a centre of support, so it can become a source of distress or embarrassment for many disabled individuals and their families.
- Health and Disability National Services Directorate (DNSD) have identified stigma (negative mind sets and stereotypes towards people with disabilities) as a significant problem in Pacific families and communities. Experienced Pacific disability practitioners consider that Pacific people in general have a long way to go in terms of addressing and changing these entrenched stereotypes, attitudes, and beliefs regarding people with disabilities. The increasing number of Pacific people born and educated in New Zealand is expected to contribute, in time, to a more inclusive attitude towards disability and to reduce traditional prejudices.
- Ministry of Health initiatives to address the problem of disability stigmatisation have included funding a pilot Pacific disability awareness promotional campaign, similar to the Like Minds Like Mine mental health campaign. This campaign first aired on Radio 531PI in November 2005, and was continued through to June 2006. This campaign, as part of the NZDS, has contributed towards improved disability awareness in the Pacific community of Auckland. HDNSD is currently developing a proposal to explore the potential for continuing the campaign, including the potential for a national roll-out.
- Workforce development

Options for Future Work

Based on the information presented in this paper, the following options for future work are proposed for further consideration and discussion.

Improvements in service delivery and quality of care

1. Investigate options for more relationship-based advisory and advocacy approaches to help Pacific people to navigate the available disability support services.

2. Encourage providers and the disability workforce undertaking training to improve cultural competence so that they better understand Pacific people’s perceptions and experiences of disability.

3. Develop career pathways that attract disabled Pacific people to join and progress within the disability workforce.

4. Introduce targets for Needs Assessment and Services Co-ordination to report against; for example, set a target percentage of clients to have re-assessments to check on their uptake of services following their initial assessments.
5. Investigate the synergies and co-ordination between needs assessment agencies, disability providers and mainstream primary health organisations, and how these work for Pacific people, and make improvements as indicated from this investigation.

6. Establish more community-based initiatives to help overcome isolation and provide a safe environment for discussion, information sharing and mutual support.
7. Research the experiences of disability of Pacific disabled children and youth and their families, and appropriate models of care.

8. Describe Pacific family and community attitudes towards disability, and the influence of traditional beliefs and attitudes.

9. Examine the issues that disabled Pacific people and their families face when navigating the disability support service system.

10. Identify the workforce needs of disabled Pacific people and the barriers to entering and re-entering the workforce.

Appendix 3

Cross-Gender Interactions

Hasnain, R., Cohon Shaikh, L. & Shanawani, H. (2008). Disability and the Muslim Perspective: An Introduction for Rehabilitation and Health Care Providers. Center for International Rehabilitation Research Information and Exchange.

- Muslims may have views concerning proper interactions between genders that are different from those held by Western society. Their views, however, generally are not difficult to understand and accommodate.
- Many would accept an opposite-sex provider but likely would be more comfortable and open with a same-sex provider. These desires should be accommodated where possible because doing so is likely to improve the quality of the interaction, the client's and their family's satisfaction and comfort and compliance with recommended
- treatment.
- When caring for any patient of the opposite-sex, Muslim or not, providers must be careful to follow the patient's lead in the interaction and should tend toward a manner that is more professional and less familiar. Providers also should recognise that practices such as shaking hands have varying acceptance among Muslims.
- Providers should consider investing in relatively modest hospital garments for all patients, and they should help and encourage patients to find ways to supplement the garments with their own clothing in a way that will not impede treatment.
- Patients will appreciate this respect for their preferences, and this appreciation will facilitate better interaction.