

Chapter 5

Intellectual Disabilities And Multicultural Issues

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Cultural and linguistic factors add an additional layer of complexity to family coping and resilience in the context of intellectual disability. To explore this issue, this chapter gives an introduction to the concepts of culture, and cultural and linguistic diversity. It then looks at how culture interacts with intellectual disability, and how this can affect access to health and mental health services. Finally, it explores cultural awareness in clinical practice, and provides a practical example of culturally-skilled practice using a case study based on the experiences of a specialist cultural consultant working at a tertiary children's hospital in Sydney, Australia. In combining knowledge of the significance of culture, its interaction with concepts of disability and the clinical implications of this for practitioners, the chapter aims to provide a framework for enhancing cultural competence in clinical practice in intellectual disability.

Culture, and Cultural and Linguistic Diversity

Culture refers to those elements which collectively characterise a particular society or group and their way of life, encompassing factors such as customs and traditions, teaching and parenting style, beliefs and attitudes, manners, and values. Culture is influenced by both internal and external factors, both contemporaneously and over time; with a culture evolving gradually but constantly in response to the interactions it has with its circumstances and environment, and also as it is passed from one generation to the next. Cultural overlap also exists, for example, between groups that share elements of religious, linguistic, ethnic, migrational, educational or socioeconomic experience, and it is possible for an individual or family to identify with more than one cultural group.

Cultural and linguistic diversity (CALD) refers to the variability both within and between groups and individuals, in terms of the language they speak, and how they identify with different cultural practices. Factors such as increased personal mobility, skilled migration, family reunification programs, and politically and socially mandated asylum, have seen ethnic, linguistic, and cultural diversity become increasingly common across Western developed nations. Australian society, for example, is becoming increasingly ethno-culturally diverse, with the 2006 Australian Bureau of Statistics census data (ABS, 2006) revealing that approximately twenty-two percent (22%) of the Australian population identified as coming from a CALD background.

In seeking to better understand cultural and linguistic diversity, it is important to recognise that while language can be a marker of cultural difference, culture remains distinct from language. Believing that people from one country or region only speak one language can obscure the variability which exists within groups. For example, Wong and Fuji (as cited in Echemendia & Westerveld, 2006) estimated that there were thirty-two different cultural groups within the Asian culture. Arabic and Latino speaking people can also come from a broad range of countries that share a common language but differ greatly in their cultures, religious beliefs and practices, education, values, experiences, socio-cultural, and socio-political perspectives, and identities.

Culture And Access To Health Services

The influx of immigrants and refugees entering countries such as Australia has brought with them different cultural experiences, religious beliefs, values, attitudes, and perspectives about health and mental health. Competence in working in a healthcare setting with families from CALD backgrounds requires an appreciation of this diversity,

alongside specific knowledge of cultural factors such as language, client attitudes and values, culturally-based remedies and beliefs about illness and disability, the cultural interface between the clinician and client, and the assumptions of normative cultural values (Flores, 2000). This can present a significant challenge to clinicians and services, who remain vastly English speaking, and who draw predominantly from the Western models of mind-body relationships in which they were raised and trained. Culturally attuned practice also requires an awareness of potential issues pertinent to the migrant experience, including factors such as acculturation, transition, socioeconomic status, experience prior to and after settlement, language, and education (Echemendia & Westerveld, 2006).

It is also important for clinicians to be mindful of the social and environmental influences that affect whether and how families access health services. For example, in countries like Australia, children for whom there are early concerns about development or behaviour are typically able to access a general medical practice or paediatric clinic. This enables timely developmental screening followed by referral to more specialist assessment or early intervention services as appropriate. In contrast, health systems in many other countries do not offer this level of care; for example, in places like Afghanistan and Africa where people have lived amongst wars for a long time, there is limited opportunity for children to access health screening. Families arriving as migrants or refugees from these regions may thus have no awareness that such early childhood services even exist, and so would not seek such support even where they did have concerns about their child's development.

A similar contrast can exist even within national boundaries. For example, in China, while Hong Kong retains a health service system adopted from Western culture

(a legacy of its previous status as a British colony), this is not the case for health service systems on the Chinese mainland (Fung & Wong, 2005). Further, while the focus of programs for children with developmental delays in Hong Kong is modelled on British approaches to early intervention, comprehensive rehabilitation programs for children on the mainland include many Eastern influences such as acupuncture, traditional herbal medicines, and massage. Yet further contrast exists in China between services available in the larger cities, as compared to that which can be accessed by families who live in rural areas. For the latter, services of any kind are often not available (Wong, Wong et al., 2004). This diversity in health experiences and practices can have a large impact on how families from these cultures access health and mental health services in Australia, and the expectations that they have about these services.

Different cultural experiences, perceptions about health, and family relations may also bear upon willingness of families to access mental health and other support services, independent of their availability. Language barriers, racism, negative stereotypes, and attitudes all contribute to CALD families' experiences of disadvantage (Cho, Singer, & Brenner, 2003; Trute & Hiebert-Murphy, 2002). There can also be a tendency to rely on informal networks such as extended family, friends from the same culture, and religious networks, in dealing with the consequence of a disability.

Culture And Intellectual Disability

Having a child with developmental delay has been shown to increase family strain (Trute & Hiebert-Murphy, 2002). However, for many CALD families this can be compounded by additional psychosocial stressors such as settlement issues, trauma, pre- and post-immigration experiences, unemployment, limited social support, and poverty.

These factors indirectly influence how families are able to meet the needs of their children with an intellectual disability.

Cultural factors also affect coping more directly, in that cultural differences in the family perception and response to intellectual disability have been found to influence the level of family stress and involvement, which in turn affects long term outcomes (Echemendia & Westerveld, 2006). A family's way of explaining and understanding their child's disability, and the meaning that they ascribe to its occurrence, will be influenced by their cultural world view. For example, regardless of whether a biomedical cause for their child's disability is identified, some CALD families may simultaneously also hold a traditional or folk explanation for their children's difficulties, which may influence their openness to different therapeutic interventions, or their willingness to seek professional assistance (Diken, 2006).

Attitude and values in family and social life can also highlight significant differences between the model held by the predominant culture, as compared to the CALD groups within a community. Collectivism, for example, in which the responsibilities of the individual rest with the welfare, needs, and expectations of the group, can run counter to the strongly individualistic values that are embraced by many Western cultures. This has particular implications in the case of intellectual disability, where issues of dependence and interdependence are especially salient, and may lead to differences with respect to the longer-term goals for the person with a disability, as well as in the expectations that the family holds in terms of service entitlement and longer-term responsibility of care.

Cultural attitudes will also influence the life experiences and expectations for a person with an intellectual disability. Certainly, where racism, negative stereotypes, or

more broadly negative social attitudes towards disability exist, this creates an additional level of social disadvantage that restricts access to services and opportunities, and contributes to the complexity of the emotions experienced by both the individuals and their families (Summers & Jones 2004; Yuan, 2003).

Cultural Awareness In Clinical Practice

Culturally sensitive practice in the developmental disability field firstly involves knowledge of cultural and linguistic diversity, including a general appreciation of the different ways in which culture can impact access to healthcare, as well as more culture-specific awareness about disability. Clinicians then need to adjust the way they provide health and mental health services, using knowledge of the culturally-mediated values, attitudes, and experiences that may apply to a given case, and through effective communication skills, and a willingness to advocate on behalf of families.

Cultural Knowledge

In exploring the interaction between culture, disability, and family coping, an understanding of the family's culture of origin is important. This includes knowledge of cultural beliefs and attitudes based on factors such as gender, religion, stigma, and social norms.

Gender

The gender of the individual with an intellectual disability can have implications both in terms of coping and acceptance by the family, quality of life, and life opportunities for the individual. For example, in some regions of the Middle East, disability can be

viewed as one of multiple oppressions when combined with factors such as gender and race. Abu-Habib (as cited in Crabtree, 2007) described how girls with intellectual disabilities can be much more devalued within the setting of the family and the wider community than boys with the same disability. This was because in strict societies, girls with intellectual disabilities created an additional burden of care for their families, in needing to be kept aware of personal care routines and to maintain social decorum appropriate to their gender. They were also viewed as sexually vulnerable in those societies and perceived as needing more supervision or even containment within the family home, as a means of preserving their safety. In contrast, boys with an intellectual disability were more likely to receive some vocationally based training, and also to get married (sometimes through an arranged marriage).

Another illustration of how cultural values can interact with attitudes towards disability is evidenced in a feeling reportedly common amongst fathers of boys with an intellectual disability in the United Arab Emirates. There, despite having access to a higher quality of medical care and disability support services than is available in most other countries in the Middle East, having a boy (as compared to a girl) with an intellectual disability is experienced as a greater disappointment because of the loss of expectations usually attached to sons, such as of working, and carrying on the family name (Crabtree, 2007).

Religion & Spirituality

Beliefs and values associated with religious and spiritual practices can also have significant implications for how a child with a disability is managed. Blacher and Baker (2007) found that reliance on religious belief systems may incline parents toward

positive reframing, providing families with a spiritual framework for understanding the disability and for providing hope. In many cultures, religious principles serve to protect people with disabilities from discrimination, and encourage others to extend care to those in need. For example, in Islam, disability is generally viewed as the will of ‘Allah’, with parents expected to deal with the situation with acceptance and grace, treating the child with a disability with the same love and attention as they do his or her siblings (El Naggar Gaad, 2001). Similarly, expressions such as ‘*No hay mal que por bien no venga*’ (which translates as ‘there is nothing bad out of which good cannot come’, Zuniga as cited in Blacher & Baker, 2007, p. 151) form a part of the spiritual counsel that helps Latino parents to accept the will of God as it relates to their child’s health or disability (Flores, Abreu, Schwatz, & Hill, 2000).

Stigma

Issues around stigma and embarrassment are another recurring theme amongst many CALD families who have children with intellectual disabilities. For example, Kerr and McIntosh (as cited in Wong, Wong et al., 2004) found that many Chinese families who had children with Down Syndrome were concerned about the reactions of others to their child, while others described having difficulties disclosing their child’s condition to other people. Similar concerns about public reactions have been noted in studies of several other CALD communities, for example, amongst new immigrant families from Korea (Cho et al., 2003), Middle Eastern families (El Naggar Gaad, 2001), and within many Asian communities (Kerr & McIntosh, as cited in Wong, Wong et al., 2004). In some cultures, the presence of intellectual disability can be even more stigmatising if it does not have clear physical indications.

The issue of stigma is closely tied to families' needs for their children to be accepted into their community and by peer groups. Not surprisingly, greater community acceptance of the young person with a disability has been shown to impact positively on parental coping and resilience. Negative public reactions are thought to indicate a lack of acceptance and limited knowledge about individuals with disabilities. This fear of stigmatisation and exclusion is illustrated by one mother's comments, 'How is the world going to see my son, being an Afghani, a refugee, and delayed, that's three negatives when you deal with a big society that doesn't look very positively upon Afghani people'. Similarly, El Naggar Gaad (2001) commented that despite progressive Islamic precepts that teach tolerance and equality of treatment for people with a disability, the social stigma of disability remains a relatively widespread phenomenon among Middle Eastern families. As such, although discriminatory attitudes may officially draw censure, the social pressures remain such that the birth of a child with disability (including intellectual disability) is frequently accompanied by parental feelings of guilt and shame (Crabtree, 2007).

Social Mores

Another important cultural consideration is the recognition that many CALD families derive from collectivist societies (Parette Jr., Brotherson, & Huer, 2000). This ascribes a value system that places the needs and rights of the group ahead of those of the individual, a framework that can be at odds with the predominantly individualistic value set of Western developed nations. This collectivist orientation places emphasis on ensuring the needs of extended family and siblings are factored into any decision making around treatment for the child with an intellectual disability. It also assumes an

ongoing obligation and commitment for the family to provide support, protection, and education for the person with an intellectual disability. In this context, the child with intellectual disability is integrated into the family experience, navigating their life journey supported by a web of connections that include the family unit of parents and siblings, and also the extended family, faith, and sometimes friends from the same community (Hodapp, 1995).

Accordingly, clinicians working with CALD families should recognise that the presence of intellectual disability can affect all family members within both the immediate and extended family (Aldwin, 1994; Parette Jr. et al., 2000). Establishing a rapport with each member of the family may thus be necessary to establish compliance with medical recommendations. This can require the clinician to meet a large number of people from several generations, including grandparents, uncles, aunties, and other relatives. Families need to feel that they are integral to the treatment planning and decision making, with this sense of involvement critical in reducing potential frustration with professionals, and improving compliance with intervention strategies (Parette Jr. et al., 2000). For example, in a Western model of care, it is typically the mother and father who are seen as the family unit responsible for the child, whereas in a collectivist culture, while it may be the parents who attend for the clinic appointment, the medical advice will be further processed and evaluated amongst the child's extended family at home, often with particular deference to the grandparents. As such, much of the decision making around treatment and service engagement can occur outside of the clinic setting, with influence from family members whom (unless this is specifically addressed by the treating clinicians) may not have had any direct contact with the service provider.

Communication

Guidance provided by the clinician around the provision of psychosocial, education, and specific services can strengthen family coping and positive adjustment (Brinchmann as cited in Trute & Hiebert-Murphy, 2002; Ello & Donovan, 2005; Larson, 1998).

Psychoeducation has also been shown to improve family engagement and involvement with treatment (Bailey Jr., Armstrong, Kemper, Skinner, & Warren, 2009). Being able to communicate effectively, and having access to appropriate information about services and resources increases CALD families' confidence in being able to understand and meet the needs of young people with an intellectual disability.

Barriers to effective communication include overt factors such as language and literacy levels, as well as more subtle factors such as the presiding normative cultural values (for example, the expected roles of the professional versus the patient during a consultation). In ensuring effective communication with CALD families, it is important for clinicians to consider each of these factors.

Engaging the services of an accredited interpreter is always recommended. Clinicians should pay attention to details such as dialect. They should also be alert to the fact that CALD families may not be aware that they can request an interpreter, or may minimise the need on the basis that at least one member of the family has an adequate command of English. For example, parents may bring one of their children along to interpret for them, or between a couple, may have the English-speaker interpreting for his or her spouse. As a clinician it is important to consider the social and power dynamics that this can engender; in using an accredited interpreter, these influences are significantly reduced.

Clinicians should aim to speak in plain English and avoid jargon, as even professional interpreters can have difficulties with highly technical language. Using appropriate body language and gesture to accompany verbal explanations can aid comprehension. The use of analogy can also be helpful for explaining concepts, provided examples are drawn from experiences that the family can relate to.

Clinicians also need to facilitate access to information for CALD families, particularly when considering an area such as intellectual disability, where the quality and accessibility of information can be highly variable, even in English. This can be addressed by strategies such as sourcing translated psychoeducation materials, referring families on to professionals in the field who speak their preferred language, providing details of foreign-language websites, and linking families in with culturally-based support groups and services. Clinicians should also be mindful that parents from CALD backgrounds may have experienced interrupted or limited access to schooling in their homelands. As a consequence, these parents may present with literacy problems of their own, even in their own language, making written psychoeducation materials of limited value. In such circumstances, use of strategies such as gestures and visual supports can be very effective in sensitively supporting better communication.

Advocacy and Systemic Awareness

In addition to responsiveness at the level of individual clinicians, client advocacy and a greater systemic awareness regarding cultural issues is also important. Despite the rhetoric of equity of access, CALD families are frequently at a disadvantage when it comes to connecting into care systems. Advocacy can target specific elements of this, for example, in educating families about existing disability services and how to access

them, acting as an intermediary for families for whom language issues can protract and confound referral processes, and ensuring that where families are successfully referred, they are well informed as to why and how a service may be able to assist them.

Ensuring that systems remain aware of the CALD family's circumstances can be a further advocacy role, putting them on more equal footing with those who are able to persist with asserting their needs more directly to service providers.

At a systemic level, culturally competent practice needs to be integrated into the model of service delivery for clients at all levels. An illustration of this can be found in a model of care at a leading Australian children's hospital, which includes a consultative clinic at a quaternary level for children who present with extremely complex developmental psychiatric issues. A multidisciplinary team with clinical expertise in developmental disability consults with the family and their treating service team, working together to formulate an intervention plan to address the longer term support needs of the client and their family. Professional representation at this clinic includes specialist psychiatric, paediatric, behavioural, psychological, pharmacological, disability, educational, allied health, and cultural consultation, wherein the expertise of a specialist cultural clinical consultant is integral to the provision of culturally appropriate service for those families who come from a CALD background.

Case Study

The following case-study of Yaseen, a 15 year-old male from an Afghani background, provides an illustration of how culturally sensitive practice can enhance assessment, treatment engagement, and outcome.

Background Information

Yaseen was referred to the psychiatry department of a tertiary level children's hospital in Sydney, Australia, following a spate of anger outbursts, physical and verbal aggression, and episodes of antisocial behaviour and larceny that had resulted in police involvement. At the time of referral limited information was available, however, through the course of the assessment it was revealed that he had a mild to moderate level of intellectual disability, history of speech and language impairment, short-term memory deficits, Attention Deficit Hyperactive Disorder (ADHD), and a probable frontal lobe syndrome. Yaseen's early history included health complications around his birth, possible head injuries in early childhood, and exposure to potentially life-threatening events in war-torn Afghanistan. The family and social history was also complex, with repeated experience of war-related violence, and their eventual seeking asylum in Australia (nine years prior). Yaseen was the seventh of nine children, and the only one to experience significant learning or behavioural difficulties.

Assessment and Intervention

Expert consultation and reflective clinical practice was sought around culturally-based issues at several points during the assessment and intervention process. The first occurred prior to the initial appointment with the family, as part of preparing appropriately for the assessment. Issues identified at that time included ensuring an interpreter was arranged (Dari language) and researching factual information relevant to the social and political circumstances of the family in Afghanistan. Further reflection with respect to cultural factors followed the initial assessment, due to difficulties in engaging with the family. It transpired that there were concerns around using an

interpreter from particular cultural groups, due to sensitivities stemming from the political circumstances in Afghanistan, and concerns about confidentiality and potential discomfort associated with using an interpreter who was socially from the same community as the family. There were also difficulties within the family due to differences in beliefs and expectations related to disability. There were further issues within the family around expectations and responsibility attributed to different family members, for example, Yaseen's grandparents felt that his mother was responsible for many of his behavioural and learning problems. This in turn triggered strong feelings of parental responsibility and shame, particularly around Yaseen's challenging behaviours. Finally, there were issues with establishing a clinical rapport, resulting in parental ambivalence about whether and how Yaseen's difficulties could be treated, and affecting compliance with medication and other treatment recommendations.

Intervention around the cultural issues identified incorporated a number of elements. Yaseen's family came from a Hazara ethnic background (Shiite Muslim minority) in Afghanistan, a minority that was persecuted by the Taliban. Many from this community consequently missed out on an education, which had implications for how information was communicated to the family in the clinic setting. It also meant that the family was more at ease with an interpreter from a non-Afghani background. An Iranian Dari speaking interpreter was therefore engaged, improving both direct communication and therapeutic rapport.

A number of other issues were also addressed to improve communication with the family. Firstly, in providing psycho-education regarding Yaseen's diagnoses, clinicians were encouraged to avoid jargon and medical terminology, to use clear descriptions in ordinary language, and to use accompanying body language, gesture,

and visual supports in their explanations with the family. This included putting a hand to different parts of the head when referring to different parts of the brain, as well as pointing to different areas on a picture of a brain. The use of analogy and metaphor to explain some of the more abstract concepts was also very effective (for example, in describing executive functioning, using a musical analogy relevant to background information that Yaseen's father had provided regarding his own interests and musicality). More practical issues were also addressed, for example, having the interpreter assist the family with writing down Yaseen's medication, dosage and instructions in their own language. A referral was also made to a specialist transcultural mental health service, that were able to provide a bilingual therapist from Iranian background who spoke Dari, and who was able to provide follow-up to the hospital consultation with home-visits to the whole family, including siblings and grandparents.

Stigma and embarrassment contributed to the family's reluctance to use an interpreter, despite the evident communication challenges. As in many CALD communities, Yaseen's parents felt judged by the way their child behaved. The family became more comfortable and more engaged after it was explained to them that Yaseen's criminal activities were not going to be discussed, but rather the team was interested in helping the family to improve his condition.

Thus, a careful evaluation of the cultural background and concerns helped the treating clinical team better identify and respect the problems of communication, comprehension, and treatment compliance. Accommodating and integrating knowledge of the influence of cultural factors, including language, beliefs about disability, and social mores, the family became more involved in the decision making process and

more engaged with Yaseen's treatment, and a more effective partnership was established between the family and the treating clinicians.

Conclusion

To effectively support a child with an intellectual disability, integrating cultural knowledge and understanding into clinical practice provides a powerful mechanism through which family acceptance, coping, and resilience can be enhanced. The capacity to work with cultural and linguistic diversity is increasingly a requirement of all professionals working in health and mental health services, highlighting the need for clinicians to develop skills in cultural competence that will enable them to provide culturally sensitive and effective services for clients regardless of their cultural background. Cultural competence incorporates an awareness of cultural diversity and its impact, as well as specific knowledge about the values, beliefs and other cultural practices of clients. This requires attention to issues such as language spoken, as well as knowledge of factors such as religious practices, beliefs and value systems, political issues, and social structures.

Beyond knowledge, cultural competence also requires sensitivity and attunement to the interaction between client and service provision, encompassing an awareness of the clinician's own culture and values, and the influence this has in professional interactions. This is critical because irrespective of the quality of the technical clinical knowledge and recommendations offered, best practice is based on partnership, and the overall success of a clinical consultation relies on maintaining a level of engagement and commitment with the family. At a systemic level, cultural competence includes acknowledgement of the discrepancies that can exist between what is recognised as best

practice and what is implemented in service systems, and requires an active commitment from practitioners to client advocacy.