



Are You Talking To Me?

Negotiating the Challenge of Cultural Diversity
in Children's Health Care

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Foreword

Children's hospitals and paediatric services have been recognised for their leadership in developing family-centred and child-friendly models of care. These models place particular emphasis in addressing not only the specific episode of care or, indeed, the individual patient but the entire family. This is especially so when the child's illness is prolonged, complex or life threatening, in order to limit the inevitable disruption to family life. Parents/carers are on the one hand, recipients of care and on the other hand, partners in care. The emphasis is to engage families, support parents and carers, share information and encourage collaborative decision making and care planning. Equally, paediatric models have exemplified multidisciplinary team-based approaches to service delivery that comprehensively address all aspects of care.


A logical consequence of this philosophy is to acknowledge limitations and actively explore gaps that arise when applied to families of diverse cultural backgrounds. Paediatric health care is therefore delivered in a dynamic interplay between many cultural influences, including those relating to staff. This context calls for not only a genuine respect of cultural heritage but also an openness to new understandings and a preparedness to learn from the experiences of service recipients.

This project was conceived in this spirit of open enquiry and the acknowledgement that paediatric services need to continuously learn from feedback. The research team at the Centre for Cultural Research at the University of Western Sydney have developed a constructive and rewarding partnership with the two Sydney-based Children's Hospitals. This project builds on prior collaborative work and has attracted the support of the Australian Research Council. Other partners include: NSW Department of Health, the Multicultural Health Service of South East Sydney Illawarra Health and Community Paediatrics in Sydney South West. The multi-method research approach employed in the study has produced compelling findings that need to be considered seriously by all paediatric services. The findings and recommendations are highly useful in informing future policy and practice development, educational programming and service planning.

The findings alert us to shortcomings and opportunities for improvement despite the overall sense of commitment and compassion among professionals caring for children and their families. Misunderstandings and gaps in communication remain a significant challenge. The particular vulnerability for more recently arrived migrants, especially refugee families, is also highlighted. The issues associated with adolescent development add an extra dimension to the complexity of the challenges. Our capacity to understand and flexibly respond will test our workforce. Children's hospitals and paediatric services take justifiable pride in their commitment to "total care", delivered equitably across the entire community, with particular emphasis on those most in need. This project provides an opportunity to strengthen that commitment, to address identified gaps and limitations and to maintain a leadership role in comprehensive health care.



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The Steering Committee comprised representatives from all the above partners as well as the Chief Investigators, Research Associate and a postgraduate candidate. The success of the project was due to the on-going commitment of the steering committee members who consistently demonstrated their strong support to this project. This generosity was also reflected in the collaboration process which involved working across institutions and disciplines that traditionally have not always resulted in easy alliances. However, for all those involved, there was the preparedness to step outside of our respective comfort zones. Sincere thanks go to the following members of the Committee for their contributions to the planning, design, logistical assistance, analysis and feedback throughout the 3 years of the project.

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- Ms Cathy O'Callaghan, Doctoral Candidate (APAI), CCR, UWS

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Disclaimer – The final views and analysis expressed in this report are entirely those of the authors and do not necessarily represent those of our research partners or funding agencies.

Dr Sharon Chalmers is a Research Fellow with the Centre for Cultural Research at the University of Western Sydney. She has led the Centre's work in the area of cultural diversity, community relations and health care and was the lead researcher on this project. She has worked over the past six years on health-related projects and has researched and authored several reports on diversity health care issues in relation to women, carers, parenting, children and young people. Dr Chalmers also has a doctorate in Japanese contemporary culture and society and has written extensively across a range of subjects including diversity health care, ethnicity, sexuality, and gender relations.

Dr Amanda Rosso-Buckton worked as a Research Associate in the Centre for Cultural Research at the University of Western Sydney. She assisted with the coordination and management of the ARC Linkage project and recently co-authored a report for the CHW (Chalmers & Rosso-Buckton, 2007). Dr Rosso-Buckton completed her PhD, *Feed a Cold and Starve a Demon: The Poetics of Madness in Kefalonia in Sociology and Anthropology* at the University of Newcastle in 2006. Her research interests include women, madness and the church, folk healing, folk biologies, cultural diversity and health care.



Executive Summary


Are You Talking to Me?: Negotiating the Challenge of Cultural Diversity in Children's Health Care is the culmination of a 3-year Australian Research Council (ARC) Linkage Grant Project. The project examined health interactions between families from culturally and linguistically diverse (CALD) backgrounds (1st and 2nd generation) and health professionals, with a particular focus on the potential cultural 'mismatches' in health service provision. The aim was to explore evidence of the need for a conceptual shift and practical changes to locate diversity health care as core business within paediatric health care services. To achieve this end, the project brought together the expertise of paediatric health care consumers, health care service providers, policy makers and academics in a collaborative, integrated approach.

The project employed a multi-method approach utilising quantitative and qualitative techniques. The research was located at the two tertiary paediatric hospitals in Sydney: Sydney Children's Hospital (SCH) at Randwick and the Children's Hospital at Westmead (CHW). Supported by previous findings, the researchers mapped the attitudes and opinions of parents/carers from CALD backgrounds through a multi-lingual telephone survey. The survey was structured to dovetail with an in-depth qualitative study that explored the experiences of seven families from CALD backgrounds whose children were living with a chronic illness or injury. Semi-structured open-ended interviews occurred over 3-4 months with individual family members, including the young people themselves and their respective health team members. Clinical and family meetings were also observed over the same time period.

Are You Talking to Me brings to light the experiences of CALD families, whose diversity is not marked by ethnicity alone but by intersecting factors including gender, class, migration history, and settlement experiences as well as English language proficiency. As CALD families access children's hospital services, their ability to effectively navigate this health terrain may be compromised by a combination of factors - including their lack of familiarity with the NSW health care system, diverse cultural beliefs, values and practices, as well as socio-economic and language issues. Thus, what is at stake is patient safety and the quality of short and long-term health care outcomes for CALD children/young people and their families.

The report's findings reveal that communication issues were a predominant concern including the ability to express oneself clearly, understanding medical jargon and communicating effectively with health professionals. Indeed, these cultural mismatches affected the partnership between health care providers and families in caring for children/young people. Staff also faced their own set of communication barriers in seeking to understand family needs and impart health information. While the use of professional health interpreters partly resolved language barriers, both families and staff cited access and usage problems with this service.

CALD families with children who had long-term illnesses presented staff not only with both specific health needs affecting day-to-day interactions within the hospitals, but also with the associated needs in relation to broader social support services. These families also experienced challenges around the requirement for ongoing long term hospital care. Included among these were transport and access issues, adolescent adjustment to treatment regimes, compliance concerns, the needs of young people and their families to normalise the child's illness and the transition to adult services.



Finally, this report has avoided an explicit debate about competing definitions of cultural competence, primarily because others have done so and there are several excellent definitions and discussions in current circulation (Cross et al., 1989; Cultural Competency and Nursing: A Review of Current Concepts, Policies, and Practices, 2004; Eisenbruch, 2001; Johnstone & Kanitsaki, 2007; Proctor, 2004). Suffice to say, cultural competence is not a set of pre-existing tools or a check-list of competencies that can be simply learned in a classroom setting or in orientation lectures. Rather, it is the on-going professional development of curiosity-driven reflective values and practices at all levels of health care service delivery. One of the major drawbacks in the existing literature, as Johnstone & Kanitsaki note, is the lack of a strong evidence base on which to 'demonstrate the nature, possible implications, or practical outcomes of providing cultural competence education for health professionals' (2008: 136). This research has attempted to contribute significantly to this evidence base through documenting and analysing the experiences and viewpoints of young people's, parents/carers' and staff's understandings of accessing and using the Australian paediatric hospital system.

1. Key Findings

- ▶ An overarching finding in the study was that the concept of 'ethnicity' is itself nebulous and continues to be open to multiple definitions. Our research, supported by other international work, demonstrated that the notion of ethnicity can be influenced by numerous factors including cultural heritage, language background, inter-generational issues, class, gender, sexuality, education and regional variation. We also argue that cultural identity is highly contextual so that simply naming one's country of birth does not sum up or reflect a young person or their family's cultural values or practices.
- ▶ Families from CALD backgrounds overall were very satisfied with the level of care their children received at both the SCH and the CHW. However, 'satisfaction' did not always translate into good communication.
- ▶ Initial anecdotal evidence from staff pointed to CALD families using tertiary paediatric facilities more often as their first 'port-of-call' compared to Anglo-Australian families. However, both the qualitative and quantitative findings indicated the opposite.
- ▶ Families from CALD backgrounds tend not to complain or express dissatisfaction for fear of repercussions or appearing to stand out.
- ▶ There was evidence to suggest that hospital staff erroneously assumed that some 'ethnic' families were inclined to over-use or mis-use hospital facilities.
- ▶ Primary carers in CALD families, mainly women, are more likely to use public transport and/or need someone to drive them to the children's hospitals.
- ▶ Young people living with a chronic condition overwhelmingly wanted to normalise their lives, that is, separate themselves from being different. This included distancing themselves from their cultural heritage, their ability to speak languages other than English and at times resisting their treatment/medications.
- ▶ Transition from child to adult health services is premised on a Western construct of childhood and adulthood with a focus on developing total independence, irrespective of the young person's familial structure. This notion of gaining autonomy from one's family is culturally specific and to some cultures is an anathema to what constitutes becoming an adult and the role of family.
- ▶ All families who have children with a chronic illness/injury live with constantly reorganising and adapting their lives to fit in with the hospital system. For those families who have recently arrived, there are the added pressures of finding suitable accommodation, organising schools, accessing social services and simply finding one's way around unfamiliar geographical, linguistic and institutional terrains.
- ▶ From a staff perspective, care can involve the direct involvement of several staff members in the coordination of multiple social and educational services. These complex arrangements can be overwhelming for both staff and the families concerned.

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- ▶ Some CALD adolescents and their families were at times labelled, based on a combination of moral and ethnic stereotypes. How these stereotypes were expressed depended on whether the young person and/or family was being described as 'good/compliant' or 'difficult/non-compliant'. In the latter case, it more often than not involved some kind of challenge to or transgression of the hospital/medical system.
 - ▶ Hospital staff in general and medical officers in particular, tended not to acknowledge the inherent hierarchies of their respective professions within the hospital organisation. While health teams prided themselves on 'working together as a team', allied health and nursing expertise in relation to 'living with a condition', was often subordinated and seen less valued than the 'curative' process.
 - ▶ Multiple communication issues emerged for some CALD parents who accessed these hospitals. These included problems with negotiating the physical and administrative logistics of the hospital as well as communicating with a broad range of hospital staff.
 - ▶ Primary carers, usually women, are more likely to present at the hospital with their children. As they are the ones who also tend to stay at home, it is often they who need interpreters. In the case of young people with a chronic illness, this can mean on-going interpreting is needed.
 - ▶ Young people/children from CALD backgrounds who have recently arrived in Australia and who do not speak English become extremely isolated when spending long periods of time in hospital.
 - ▶ The role of interpreters as well as access and availability were constant issues of concern raised by both staff and families.
 - ▶ More attention needs to be paid to ways of including the opinions of children around issues of their illness and treatment in the hospital system. To hear the voices of children and young people where there may be linguistic, communication and/or cognitive difficulties requires considerable skill.



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BACKGROUND

2. Background

2.1 What do we know?

Over the past few decades, increasingly complex multicultural societies have developed in Australian metropolitan centres (Ang et al., 2002). This social diversification has enormous impact on how effectively Australian public institutions – including the health system – meet the needs of this diverse and ever-changing population. Across Australia an array of multicultural health initiatives respond to the challenge of cultural diversity, and this project will contribute to these efforts by enlarging our understanding of how culturally and linguistically diverse (CALD) families and their children fare within the health care system in metropolitan Sydney.

Most approaches to the question of cultural diversity and health care attribute 'culture' and 'diversity' to clients, while overlooking the culture(s) amongst providers. Health policies have often located multicultural or 'ethnic' health services at the margins of general health policy (Garrett & Lin, 1990).

In what has been described as a 'problem-centred' or 'ethnic sensitivity' model (Ahmad, 1993; Morrissey, 1997), special measures are developed to address specific health 'problems' faced by minority ethnic groups (often newly-arrived immigrants from non-English speaking backgrounds), whose behaviours are explained in terms of unique characteristics, risk factors or pathologies. This 'checklist' or 'cookbook' account of diversity supposes that members of an ethnic community will behave in a fixed and culturally determined manner, a supposition that reinforces homogenising stereotypes.

2.2 Child and adolescent health

Cultural variations are particularly important in child and adolescent health, which is acknowledged to be an outcome of multifarious interacting factors including the nature and understanding of illness, ethnicity, gender, religion, and urban or rural background (Aspinall, 2001), as well as different experiences amongst first, and subsequent generations (Hernandez & Charney, 1998). Such complex differences need to be accounted for if we are to understand people's ability to effectively communicate and access health and other essential services both now and in the future. Children and adolescents from CALD backgrounds sometimes act as conduits between their parents and dominant cultural and linguistic formations.



The migration process can also place pressures on customary care-giving practices, through such factors as displacement of family members, fracture of family structures, legal status, sole parenting (Cheung, 2003), disruption of social and community ties, and changing roles of gender, authority and responsibility within the family, which can all combine to diminish access to formal and informal support services (Neufeld et al., 2002).

Children are socialised in line with parenting practices and responses to health, illness, and the health system that are generally accepted as 'common sense' in their own community. Cultural mismatches can arise over different understandings of what counts as 'good', 'normal' or 'common sense' behaviours and attitudes, because being a 'good child' or 'good parent' is not a universal known but is culturally and historically specific (Airhihenbuwa, 1995).

Since decision-making and control for children's health care is distributed between the health professionals and parents/caregivers within the family, what defines 'good' or 'bad' care can readily become contentious when health professionals expect uniform client 'compliance' or 'adherence' to a Western bio-medical model of health and illness (Sawyer & Aroni, 2003). Different cultural understandings of what constitutes appropriate care are often disregarded or seen as secondary to the aetiology of the illness, with negative impacts upon the quality and effectiveness of care and treatment.

Previous research (Chalmers, 2006; Chalmers & Allon, 2002) identified issues around who is deemed to be the appropriate family member(s) to look after a sick child, how specific religious and cultural practices influence the intersection of parenting and health practices as well as potential and actual resistance to Western medical models.

Misinformation, inappropriate or incorrect assumptions about the quality of parenting, and communication barriers based on linguistic, cultural and religious differences were also factors mentioned which cause stress, frustration and friction amongst staff, parents and children. For those from different backgrounds who may have had minimal experience with the Australian, or indeed any, health care system, the question of what constitutes good quality health care along with individual perceptions of entitlement can translate into uncertainty, fear and feelings of loss of control. In the long term, these mismatches diminish equity of access to best practice in health care, a situation in which parents, children and staff all become the losers.

2.3 What has been missing from the research?

- Most studies that examine children/young people, are undertaken in the US and UK, and tend to focus on parenting and education outcomes in relation to intergenerational change and migration.
- Available paediatric studies emphasise obstetric and early paediatric care while there is a dearth of information around children/young people's health journey.
- There is an over-emphasis on 'measuring' the importance of ethnicity on health determinants as an indicator of health outcomes.
- Existing research rarely considers the cultural relationships or everyday interactions between individual children, family dynamics and the provision of the health care services.
- There is a lack of research within specific Australian health sites relating to cultural diversity and children's and adolescents' health care outcomes.

2.4 A relational approach to cultural research

A relational approach to cultural research reconceptualises issues of cultural diversity and health care in terms of cross-cultural interactions at an interface to which all parties bring certain cultural frameworks incorporating varying kinds of difference and diversity. 'Culture' is therefore understood not as a set of fixed differences, but a dynamic and multifaceted process situated within specific macro and micro contexts, whether geographical, institutional, symbolic, historical, or familial.

A relational approach moves us away from the reification of essentialist cultural differences and the flattening of important specificities ... and a shift towards contemplating the relationships produced in and through various encounters within specific contexts. (Pedwell, 2008:98-99)

Yet, 'cultural diversity' is still conceived narrowly as others' 'ethnicity', 'language' and/or 'religion'. Indeed, as mentioned, social and epidemiological health literature has raised many of the difficulties in deciding which dimensions of a person's identity should be collected to provide meaningful data around inequalities in health, including ethnicity (Aspinall, 2001; Bhopal, 1994; Nazroo, 1998). Currently, both hospitals view interpreter statistics and admission forms that indicate 'preferred language' as the main mechanisms to plan for services (Sydney Children's Hospital, 2006; The Children's Hospital at Westmead, 2006). Problems have emerged from this method including lack of reliable documentation and auditing. Moreover, there are significant limitations of employing single language factors as a representation of one's ethnicity. This category assumes people are homogenous regardless of other factors which may take on more of an association with determining health outcomes (Nazroo, 1998).

Just as it is frequently presumed that mainstream Anglo-Australian culture is neutral or 'culture-free' (Chalmers & Allon, 2002; Kolar & Soriano, 2000; Morrissey, 1997), the values and assumptions underlying Western health care are uncritically understood by many as objective and value-free. It is also widely assumed that culture does not play a role in health care provision, and that health knowledge is separate from cultural knowledge (Bryan & Batch, 2002). Yet, health care services themselves are not neutral institutions but are large, complex social organisations operating within cultural frameworks that may not always match those of the communities they service (Aldrich & Mooney, 2001). The result is that health care workers often believe it is incumbent upon the client to fit in or assimilate into the mainstream Australian health culture (MacIntyre, 1994).

Children's hospitals and paediatric units have led health care systems in developing family centred and child friendly models of care. The philosophy places particular emphasis in addressing not only the specific clinical issues presenting in individual episodes of care but also the wider family context and the social and emotional impact of the illness on the child. This applies especially when the illness is prolonged, complex or life threatening. Within this approach, parents/carers are viewed on the one hand as recipients of care and on the other hand as partners in planning and providing the child's health care. The emphasis is to engage with families, share information, support parents and carers, and involve them where possible in decision making in all aspects of care. A child and family centred approach also recognises the individual voices of children and adolescents as consumers of health care. This becomes particularly important in adolescence when the quest for identity and autonomy requires a highly sensitive and flexible approach to health care.



The above philosophy notwithstanding, there is still a tendency for adults – whether that is parents or service providers – to articulate the young person's position primarily because final decisions about their treatment, or, how they feel about their treatment and care are seen to be ultimately out of their control. This was succinctly articulated by one young participant:

Like, I will just be sitting there and the doctor and my mum will just be talking. I'll just be sitting there, listening in sometimes. (Reena, 13)

Thus, the practical application of this approach is highly challenging, given the pressures on families and staff associated with the management of the child's illness, and the complexity of communication styles, family roles and dynamics. It is also important to recognise that hospital staff as well as patients and families represent a wide range of cultural backgrounds. Particular challenges arise with variable English language skills, cross generational conflicts, and differing practices around parenting and the health care of children. Moreover, cultures are constantly changing in response to new circumstances and opportunities.

Given the dynamic interplay of cultures within which paediatric health care is delivered, a child and family centred approach also needs to continuously evolve in response to emerging needs. To engage with families from diverse backgrounds and ensure safe and effective clinical care, it is now critical that staff develop not only an awareness of their own cultural influences but also the skills required to communicate across cultural differences. It is not surprising that this study found significant limitations and deficiencies in both the awareness and interactive skills of staff. One of the primary ways some of these shortcomings were identified was by developing a research process that involved the children and adolescents themselves. This is a method that has traditionally been left out of research and in particular out of health research (Bassett et al., 2008; Irwin & Johnson, 2005; Pole et al., 1999).

This silence is partly about not knowing how and what to ask but is equally associated with the perception that children and young people are not seen to inhabit and negotiate a range of cultural contexts themselves. Indeed, 'the family' is more often than not understood and described as an undifferentiated cultural unit. As such, young people are either, as suggested above, not conceived of as cultural beings, or by default, are seen to simply reflect their parents' identities, experiences and values.

2.5 Pilot studies

Preliminary studies based on a relational approach to cultural diversity research in children's health care were undertaken both at SCH and the CHW. These studies conducted in 2002, 2006 and in the first phase of this research (2007) utilised qualitative interviews and surveys with staff to explore the perceptions of parents/carers from CALD backgrounds and hospital staff. The findings of these previous studies are documented in separate reports.

2.6 Aims of the current project

This project brought together a range of health care services, providers, policy makers, and academics in a major Australian city – Sydney – that would facilitate collaboration and exchange towards a more integrated approach in the care of children, young people and parents/carers from CALD backgrounds.

The aims of this project went beyond a 'checklist' approach to diversity health care by paying attention to patterns of engagement with health services alongside the socio-cultural factors and economic demands experienced among families with diverse migration and settlement histories. It was not focussed narrowly on either service delivery or special client needs. Rather, it considered the broader effects of the relationship between and within culturally diverse family practices and organisational and professional health cultures. It aimed at revealing multiple points of interaction at the dynamic interface between providers and users of health services, each of whom bring to that interface their own cultural specificities and varying capacities to negotiate differences.

In line with this approach, a series of studies were designed to:

- Illuminate multiple points of interaction at the dynamic interface between providers and users of health services, as they negotiate difference.
- Identify health care issues that arise in these interactions based on cultural specificities and varying capacities to negotiate differences.
- Explore the implications for children and young people of current practices and cultural 'mismatches' at the interface of health service provision.
- Utilise the findings to examine the need for a conceptual shift by health services towards a more integrated approach to 'cultural diversity' within the paediatric health system. This change involves both a philosophical and material shift that recognises the specific needs and differences of all children and young people and their families as core business and actively responds to them.



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METHODOLOGY

3. Methodology

3.1 Location of Research

The two primary locations for the research project were Sydney Children's Hospital (SCH) at Randwick and The Children's Hospital at Westmead (CHW). Interactions with the young people only took place at the hospitals, however, researchers occasionally undertook interviews with the parents and other significant carers in their homes.

3.2 Sydney Children's Hospital (SCH)

SCH is located in Randwick, in Sydney's eastern suburbs and is part of the South Eastern Sydney and Illawarra Area Health Service (SESIAHS). This area health service includes the urban areas of eastern and southern Sydney, Wollongong, Port Kembla along with the regional areas of Kiama, Shellharbour and Shoalhaven. According to the 2006 Census of Population and Housing, the population of the SESIAHS is increasing with an estimated projection for 2011 of over 1.2 million people. The area includes 18% of people who come from non English speaking backgrounds (NESB) as well as an Aboriginal and

Torres Strait Islander population of 1%, in total over 11,000 people.

SCH is part of the Greater Eastern and Southern Child Health Network (GESCHN) linking in with local paediatric networks that provide children's health services. The hospital provides acute care facilities, community and outreach services, including tertiary paediatric services for children and adolescents. SCH's services are accessed by children and families who live locally within the area, as well as those who come from regional, rural, interstate and from overseas destinations.

3.3 The Children's Hospital at Westmead (CHW)

The CHW is located at Westmead in Western Sydney. Greater Western Sydney (GWS) has a current population of 1.85 million people, which is 43% of the Sydney metropolitan total, providing a home to 1 in 10 Australians. It is projected that the regional population will reach 2.2 million by 2026. The greater part of this growth will be in the new North West and South West Growth Centres and developing regional centres.





One third of the GWS population has migrated to Australia and half of the world's nations are represented amongst its residents. In Fairfield Local Government Area (LGA), a key developing area, over 70 different languages are spoken. The largest urban communities of Aboriginal and Torres Strait Islander people live in the region. The GWS population is younger on average than for Sydney generally and 38% of the population is under 25 years of age with many young families beginning their lives in this region.¹

The CHW is part of the Greater Western Paediatric Network and the Western Sydney Child Health Network (WCHN) which links the hospital to local paediatric associations. The Hospital provides a range of state-wide services including community medical care and paediatric emergency as well as tertiary level paediatric services.² While a high proportion of patients reside in Western Sydney, children and their families come from all parts of NSW, with a small proportion from interstate and overseas.

3.4 A multi-method approach

This project incorporates diverse research techniques – qualitative and quantitative – into an integrated whole. This is in contrast to traditional disciplinary practices that perceive different methodologies as mutually exclusive, or, more or less scientific, valid or legitimate. In this project we seek to bring together what has been historically viewed as opposing camps. This interweaving of methodologies, we argue, brings a greater degree of sophistication both in terms of the breadth and depth in the analysis of the material (Mendlinger & Cwikel, 2008). The integration of these two methods occurs throughout the report. Despite the more obvious visual representation of the quantitative findings found in the section on interpreters, this conventional account should not detract from the substantial quantitative findings that are embedded alongside the qualitative results throughout the report. The synthesis of these two approaches draws attention to both the advantages and disadvantages inherent in both methods. Thus, dovetailing the two modes of inquiry provides a more comprehensive evidence base from which to premise practical and sustainable outcomes.

1. This information can be found at:
http://www.dpc.nsw.gov.au/mws/about_us/about_western_sydney

2. These facts can be accessed at the Hospital's website: <http://www.chw.edu.au/about/>

The project included three qualitative studies:

- Cultural diversity “at work”:
The Children’s Hospital at Westmead
- Culture, kids and health care
- Cultures of caring

4. Cultural diversity “at work”: The Children’s Hospital at Westmead

This study comprised 149 completed staff surveys and 22 in-depth semi-structured interviews and was undertaken between September 2005 and February 2006. This was the first component of the ARC Linkage Project and is documented in a separate report for the CHW. The major aims were to:

- Find out under what circumstances and in what ways health staff respond to issues of cultural diversity in their daily work practices at the CHW.

- Examine how professional and organisational cultures interact with other cultural influences in the provision of services, and
- Recommend implementation of diversity health policies that can be integrated into a hospital-wide approach.



5. Culture, kids and health care

This study was conducted with parents/carers and children/young people with chronic conditions. The focus of this study was on the health journeys of families from diverse cultural backgrounds.

5.1 Recruitment of families

Prior to recruiting the families the researchers established in-principle support from a range of health teams across several clinical units at both hospitals. Potential participants were identified by clinical teams and referred to the researchers. The researchers provided information to potential participants regarding the study and undertook consent procedures.

Seven families were interviewed in 2007. In total, 25 interviews were undertaken with parents/carers. This generally included 2-3 interviews with each carer(s). Extended family members were also interviewed when they were considered to play a significant caring role. Interpreters were used as required. The parents/carers and young people were given disposable cameras to document cultural, social and medical aspects of their daily lives. These photos were used as prompts with families during subsequent interviews. The period over which family members were interviewed was staged over a 3-4 month time span.

The cultural heritage of the families included Mainland Chinese, Egyptian, Indian, Iraqi, Samoan, Bangladeshi and Lebanese. Interviews with parents/carers were carried out in Mandarin, English, Bengali and Arabic. The choice of families was not premised on predetermined ethno-specific categories, nor was selection based on the largest ethno-specific community groups that attended the respective hospitals.

Rather, we focused on identifying families that spanned a range of migration, settlement, familial and health experiences. Premised on these diverse factors we were interested in mapping how these families negotiated the health system and interacted with their respective health teams as well as broader government services in order to facilitate positive long-term outcomes for their children. Some of these other services included public transport, housing, education and social services.

The range of visas these families held included skilled, family reunion and refugee visas and the length of time the families had lived in Australia ranged from 1 to 25 years. Among the seven families, 3 were completely reliant on family benefits and one of these parents was studying part-time. There were 2 families where both parents were working, although one parent was part-time. There was only one family in which both parents were working full-time. In the last family both parents had been full-time workers but due to their child's condition they gave up their work to care for him.

5.2 Working with children and adolescents

From the 7 families, 6 children/young people participated. One child was unable to participate due to their level of brain injury. These young participants were interviewed on two occasions each, in total 12 discussions.

The researchers experienced similar challenges of working with young people as to those described in previous research, in particular, the tendency by them to respond with minimal answers (Bassett et al., 2008). Participation for some was also made more difficult by their chronic illness/condition.



All the children and adolescents required on-going treatment, most for the rest of their lives – although with differing degrees of intervention. Their conditions included kidney failure, HIV, brain injury, spina bifida, cerebral palsy, cancer and cystic fibrosis. Moreover, as is common among young people with chronic conditions, some were either born with multiple problems or developed others from their long-term treatment (Rehm, 2003).

Access to interviewing these young people was also limited to when they were attending the hospital. This meant they were often busy presenting at clinics, sometimes several in one day, and/or they were being admitted to receive treatment because they were unwell.

It has been found that researching with children and young people can take considerable time and skills, particularly if they have linguistic, cognitive and/or communication difficulties. For example, when working within the social model of disability, Morris (2003) found that being inclusive of children's voices in research requires extensive preparation and training by the researchers, as well

as considerable time for engaging and 'being with' the children. While every effort was made by the researchers to mitigate some of the power differentials, more effective communication would have required specific expertise and a longer time-frame which we were unable to develop in this project.

6. Cultures of caring

This part of the study was conducted with staff and had three components:

6.1 Interviews with senior hospital managers

From October to December 2006, 16 semi-structured interviews with senior hospital managers at SCH (8) and at the CHW (8) were undertaken. Several of these senior managers held administrative as well as clinical roles.

These interviews sought to identify the forms of direction and leadership that senior managers provide to staff in an increasingly diverse constituency and workforce. Senior managers were asked to identify the gaps between policy and practice within their respective hospitals by exploring the problems and successes they have observed at both a clinical and governance level.

6.2 Engaging health teams

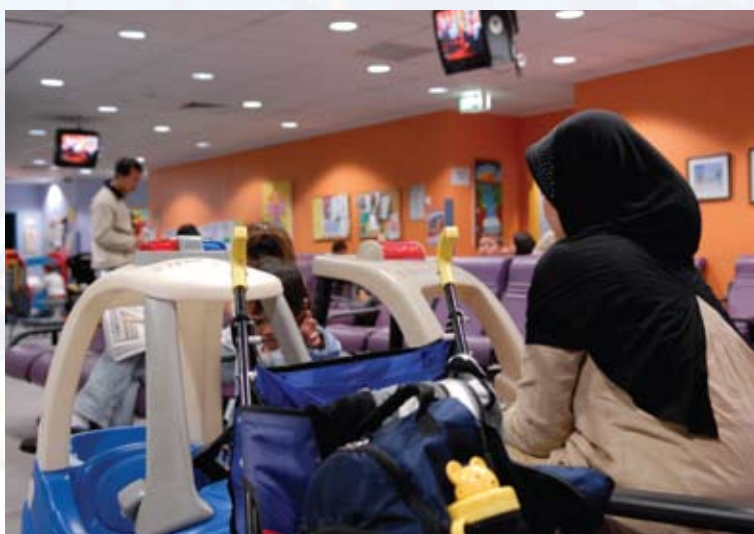
As noted above, prior to recruiting the families, the researchers established in-principle support from a range of health teams across several clinical units. Once a family consented to

participate, consent was sought from the relevant core members of that particular family's health team. In total, 25 individual interviews were conducted with health team members, and 4 health team focus groups took place.

6.3 Observation material

In addition, 25 clinical observations occurred among a range of participants. These included interactions between the following participants: young people and members of their health team; young people, parents/carers and health team members; parents/carers and health teams; and among the health team members. When required, interpreters were also present.

As one of the major aims of the project was to understand and critique the family/young person/health staff interface, observing these meeting points was crucial to the analysis. The ways in which all the interlocutors – family members, children/young people and hospital staff – expressed themselves in different settings, illuminated a broad range of emotions from gratitude and satisfaction to frustration and acute distress.



7. Accounting for culture

7.1 A multilingual survey

The major objectives of the quantitative component were to identify and quantify the impact of culture for parents/carers from diverse cultural backgrounds within the context of children's in-patient services at the two major tertiary paediatric hospitals in Sydney, the CHW and SCH. The guided telephone survey included 9 broad cultural/linguistic groupings: English, Arabic, Chinese (Mandarin and Cantonese), Vietnamese, Tamil, Farsi, Korean, Tagalog and Bahasa-Indonesian. Proportional samples of each of these community language groups – based on a child's in-patient attendance within a 3-year period (2003-2006) – were identified through the two hospitals' patient data bases.

The survey itself was the first of its kind in Australia, designed and developed over a 9 month period by the research team in consultation with health practitioners and managers, social scientists and a highly experienced statistician. The survey questions were framed by the previous qualitative research projects undertaken at SCH alongside an international literature review.

The main foci of the survey were to:

- Identify factors affecting the usage of children's hospitals and local health services among parents/carers of diverse cultural backgrounds
- Ascertain how people from diverse cultural backgrounds make use of children's health services
- Determine the cultural factors that impact on parents/carers encounters with the health system
- Reveal the everyday difficulties that families from diverse backgrounds may have experienced during their child's hospital stay

The survey was translated into the above languages and interpreters were trained to carry out the questionnaire over the phone which took on average 30 minutes to complete. The survey was directed to the primary carer of the child/young person who was hospitalised and this person was established through the consent process.

A total of 269 survey responses were conducted across the language groups. The results were analysed using the Statistical Package for the Social Sciences (SPSS). Since each of the individual language groups did not contain sufficient numbers to conduct a comparative analysis of language groups, the data were aggregated into two groups: 'Anglo-Australian' and 'Culturally and Linguistically Diverse' (CALD). The survey questions were analysed on the comparative basis of 'Anglo' versus 'CALD'. Tables and cross-tabulations were produced using SPSS. Each response was examined on the basis of the answers to questions on birthplace, language spoken, English language proficiency, religion and self-identified ethnic group.

7.2 The limits of using existing hospital data

The rationale underpinning the collection of any statistical information to a large degree influences the results and their usefulness. An examination of the information requested on the hospital admission forms at both hospitals in relation to language and country of birth raises several issues about collection consistency and to what purpose this data is accumulated. We found that there was considerable confusion and lack of consistency in the collection of basic information.

For example, at SCH the only collected data relating to cultural background is identifying the country of birth of the admitted child and their religion.

The result of the former question (child's country of birth) was that 98-99% of children are identified as being born in Australia. While this figure may be correct it indicates little about the cultural heritage of the patients and their families who use the hospital. At the same time, according to the ABS 2006 Census, the profile of South Eastern Sydney and Illawarra Area Health Service (SESAHS) where SCH is located, one finds that 27% of the population were born overseas and 22% of this population indicated that they spoke a language other than English at home.

We have really inadequate systems for identifying people who come through the door (who are from) diverse backgrounds. Our system here actually captures country of birth, so if you look at our statistics for country of birth, 99% of people are born in Australia... So what we rely on heavily are our interpreter statistics, which are probably not a great indicator. (Senior Manager)

The above issues have a direct relationship to the allocation of resources, outreach education services, and most significantly mapping an accurate 'cultural' picture of the constituency that the hospitals service. It also feeds into a false notion that multicultural sub-communities are still marginal and carry minority status in contrast to mainstream 'Anglo-Australian' hospital usage.

Conceptualising what constitutes diversity in relation to ethnicity and how one then collects significant data is a perennial conundrum for all health institutions and has been extensively debated within health literature, particularly in the UK (Aspinall, 2001; Bhopal & Donaldson, 1998; Macbeth & Prakash, 2001; Smith, 2008). Indeed, we were faced with the same inherent problems that like other studies resulted in a somewhat arbitrary decision premised on the following collected survey information.

- Self-identified cultural group
- Language spoken at home
- Language spoken at interview
- Country of birth
- Religion

Based on these five questions, we defined a respondent's 'cultural code' when at least three of the above categories were consistent. One of the main reasons for this logic was that language and ethnicity are often conflated leading to simplistic and monolithic assumptions about a person/group. At the same time the arbitrary nature of our cultural coding, while not claiming to be accurate does go somewhere to reflecting the multiple dimensions of people's inter-subjectivities.

8. Ethics

Ethics approval was gained from the University and respective Hospital and Area Health Service Ethics Committees prior to the commencement of the various components of the study.



Are You Talking To Me?

Negotiating the Challenge of Cultural Diversity
in Children's Health Care

FINDINGS & DISCUSSION

9. Negotiating the Challenge of Cultural Diversity in Children's Health Care: Findings & Discussion

9.1 Transnational movements

Globalisation is more than just the circulation of capital and technology; it is also the international movement often back and forth of people across borders and nations. People are coming into contact with each other within Australia and across the global system and this can no longer be excluded from our discussion of health care, especially children's health care. Despite mounting economic pressures to homogenise differences, the Australian health care system is attempting to respond to an already heterogeneous population that is now constituted by first, second and third generations of culturally and linguistically diverse peoples. This diversity inevitably involves and significantly impacts on the way health care professionals and institutions think about and respond to the changing needs of their clientele and how this affects safety and quality in access to and delivery of health services. And this response must take account of the complexity of people's experiences, including professional and organisational cultures.

The hospital system and staff are part of this transnational movement. As tertiary research and training health institutions, they are the nexus of cutting edge paediatric research as well as taking part in national and international studies and partnerships. They also work in collaboration with overseas health institutions in terms of sharing information on new technologies and treatment models, while senior staff regularly participate in and host international conferences.

With the advent of highly sophisticated communication systems, overseas expertise can now be easily sought.

Indeed, new medication was being sourced from overseas for one of the young people with whom we worked. Moreover, as mentioned, both these tertiary hospitals offer specialised care to overseas children and their families particularly those from the Pacific region.

The medical and nursing shortage has been the object of substantial concern and there are an increasing number of both doctors and nurses who are recruited from overseas. For example at SCH, 60% of nursing staff recruits come from overseas on an annual basis. The majority of these nurses do so as part of working holiday visas from the UK and are attracted to the hospital because of its coastal location. As such, this group of nurses tend to be a younger cohort than at the CHW. A network amongst paediatric nurse managers has also been established where nurses can subsequently access other paediatric hospitals around Australia. In contrast, the number of nurses recruited on an annual basis from overseas at the CHW is far lower at 4%, and the age cohort older. Among the medical staff, approximately 30% of junior medical officers (JMOs) are recruited from overseas at the CHW. Traditionally these doctors would have been employed on one-year short-term contracts but there has been a recent shift onto 3-year contracts. At SCH the number of JMOs is higher at 50 per cent.

These numbers notwithstanding, the range of cultural diversity of the core health teams that cared for the families in the qualitative component was extremely limited. In fact, out of 25 members of staff interviewed who ranged across 7 teams, only 2 people came from CALD backgrounds.

9.2 Family journeys

OMAR'S FATHER

My eldest son Omar is 15 years old and has spina bifida. He cannot walk. In Iraq I carried him everywhere. When he was young we had to sell our house to pay for a life-saving operation. We had to move to Jordan and it was hard to get the help we needed for Omar there. We waited in Jordan for seven years to come to Australia. Since we arrived here Omar has spent a lot of time in the children's hospital having operations and recovering. Our family lives a long way from the hospital and we get there by public transport as we do not have a car. This makes it difficult to be with him every day as we have the other children in school. My wife is pregnant and cannot stay with Omar but we telephone every night to speak with him. We know that he misses us, but the hospital told us that he had to behave better because the nurses were there to look after all the children. The hospital has taught us a lot especially about nerves, muscles and other medical things and how to look after our son. We are very grateful for their care.



The journeys that these 7 families were on did not stop when they first arrived in Australia. For those who were recent arrivals, the next step was to settle down in accommodation and to learn their way around both geographically and through the various bureaucracies. These included accessing the social security system, family and community services, education authorities as well as the health system.

When Ms Allam's husband died very suddenly Ms Allam was just lost. She was lost in the grief and bewildered by the strange country because they hadn't been here a year when it happened. And then the kids naturally started acting out [and there were] all the demands from the school, from the hospital, from Centrelink, from everywhere... She didn't know how to deal with it. (Social Worker)

Even for those families who have lived in Australia for many years, negotiating the health system when their child became suddenly ill with a chronic illness/injury impacted significantly on what they had thought was a 'settled' lifestyle. While all families facing a health crisis are often initially in a state of shock, Anglo-Australian families' familiarity with the principles, if not the practice, of the Australian health system as well as English language fluency tends to give them an advantage in terms of social and cultural capital.

All the families interviewed revealed that underpinning their varied reasons for coming to Australia was a similar desire for a 'better life' for themselves and their children.

Violence [and] unemployment are issues in South Africa ... We wanted a better future, not only for us but for the kids as well. (Mr Lahoti, father)

While not surprisingly, being attracted to a 'better life' was the common denominator, the migration stories that were collected from the families varied in where, when, how and why they made their decision to come to Australia.

We had to flee Lebanon because of the War. When Israel invaded Lebanon and then Syria came in to defend us... well, I saw the rockets go [off] outside our door, so we escaped on a little fishing boat. ... Mum was very excited about coming [to Australia], because she'd always not liked the politics [in Lebanon]. But you can't get an education; you can't get medical care if you don't belong to a political party in Lebanon. (Ms Khoury, mother)

[My wife and I] are both born of Iraqi parents and we have a normal, beautiful life. But unfortunately after Saddam things got worse so we left Iraq for Jordan and we stayed in Jordan for seven years. We were accepted as refugees by the United Nations and we were waiting to process the papers to come to any country. Then we arrived in Australia, and to be honest with you, life in Australia is much better. (Mr Aziz, father)

I was on a student visa. I came [to Australia] to study. And then I applied for residency ... We were all unhappy with the situation in China at the time [1989]. There was not much freedom. (Mr Yeung, father)

Similarly, the families differed in their experiences of settling into both Australia and under what conditions they and their children entered the health care system. The differences were far-reaching and point to the need to move beyond simplistic categorisations that collapse all non-Anglo Australians' journeys and experiences into the ubiquitous, often empty term of 'migrant' or 'refugee'. The specificities of these families' journeys and the implications for how they navigated the health care system, while not always obvious, were present in both the subtle nuances and at times more explicit expressions of their everyday values and practices. Expressions that were articulated through a combination of symbolic and material relationships embedded in the past and present, and that resonated from within and across the different locations, family structures and health cultures that the families inhabited.

We were also struck by the number of transnational journeys these families undertook to secure their family's long-term well-being. There were instances of returning to one's original homeland for periods of time and then making the final move to Australia. One refugee family's journey took over 7 years to complete, while another situation involved taking their child back to a highly acclaimed Lebanese hospital, just to check nothing had been missed in their child's diagnosis. This was not only to do the best for their daughter but to some degree lay to rest the innuendos by other family members and by their own daughter, that the family (read mother) was doing all she could for her daughter:

But everyone kept saying to me, 'Take her to Lebanon. Take her to Lebanon. You've got to go the American University [Hospital]. They'll find out what's wrong with her'. So I packed myself up again, went to Lebanon and six months later I came back. (Ms Khoury, mother)

Other families initially came to Australia to investigate the medical expertise available for their children and subsequently moved to Australia while keeping close ties and often visiting their original homeland. And for one family, a young child spent time living with his grandparents in their country to free the parents up to earn enough to establish the family financially.

There was general, indeed often great appreciation for the high quality health care offered. While understandable, the notion of 'gratitude' implicitly denotes an interaction based on an unequal power relationship, one that is premised on generosity and goodwill rather than a claim to rights (Colic-Peisker & Tilbury, 2008: 38).

The service was very good, they even gave me a blanket. (Chinese parent/carer, survey respondent)

This may also partly explain why the research findings revealed that 'satisfaction' does not always equate with good communication: (Rehm, 2003) a communication regime that tended to discourage children and carers from expressing anything but satisfaction. This was further corroborated by one senior doctor who surmised:

If you think about it, people who are immigrants are generally much more marginalised in society. They aren't people who are going to make a complaint. (Doctor)

He went on to state that it is in fact the junior doctors from non-English speaking backgrounds that are often the subject of complaints. That is, their unfamiliarity with the local (Australian) professional and institutional culture can over-ride their medical status:

It's when you have an overseas-trained doctor seen by someone who's empowered and well-spoken and aware of their rights, that's who's much more likely to complain. That's where the power imbalance is. ... That's my impression of the hospital system. (Senior Medical Officer)

All of the above point to the changing nature of health care in the 21st century. It demonstrates not only the diversity of the respective hospitals' clientele but also their ability to access an international employment pool, new medical knowledge and technologies which are all a part of this fluid, transnational landscape.

RABIAH (15 YEARS OLD)

I don't want to make too many friends, because one day I know that I might lose them. You see I only have one kidney working. I come to the hospital three times a week for dialysis. It's so boring in hospital; the treatment takes hours. And the worst thing about the dialysis is the needles. I hate needles. They've got my name down on the transplant list for a kidney, but I'm not going to have the operation because I hate needles.

My mum and brother pick me up early from school and bring me in. And I hate it because she always talks to me in Arabic and I tell her to talk to me in English. I don't like speaking Arabic, except sometimes with my friends when we don't want other people to know what we're saying. I'm a person that came from Libya, I was born there. And I don't know jack about that.

Family, school and friends were the central relationships in these young people's lives as is the case with most adolescents. Despite having a chronic illness, there was an overarching motivation for everyone to try and normalise their lives as much as possible (Rehm, 2000). From the perspective of the young people, normalising their adolescence was central to their feelings of 'belonging'. As with their parents/carers, notions of belonging are marked by diversity; diversity in terms of family and friendship experiences, popular culture, gender, location, socio-economic background, migration history and of course their specific medical condition(s). For the young people with whom we talked, these multiple cultural frameworks are part of their every day lives. Part of this balancing act is negotiating their way through the hospital system and was reflected in their and some staff's constant attempts to 'bargain' their treatment, whether that be in terms of the amount and/or frequency of taking medications or accepting/resisting on-going care.

I think Rabiah just gets fed up being nagged all the time, so if she can get out of taking her medication, she does. It's just another way of rebelling a little bit and she doesn't have much opportunity to rebel I guess, given the fact that she's not totally mobile, plus she's chained to a dialysis machine three days a week. She's got a pretty difficult life and she's at an age [15 yrs] where you would be expecting a teenager to rebel a bit too and wherever she can do something for herself and not her mum telling her what to do to do, she likes to do it. (Social Worker)

I think he [Zac] doesn't want to take it [his medication], he doesn't want to be different. ... The other day we were talking, I said to him, 'You just want me to make this go away' and he was like, 'Yeah, I do'. I said, 'I'd love to, but I can't', and I think it's really important to be honest about that. And he just broke down and sobbed and sobbed and sobbed. ... He doesn't want to think about this stuff. He just wants to be a normal boy. (Doctor)



On the other side, parents too wanted to normalise their families' circumstances, but the effort to achieve this often took its toll emotionally, economically and physically. It was reported that increasing contact with the hospital escalated the level of tension and stress experienced by families. Extended hospital care led to exhaustion as their personal, financial and social supports diminished. This was obviously more the case for families from low socio-economic positions. When these were combined with few social and family supports, there was an increase in feelings of isolation.

Families have to constantly try and rearrange and organise themselves to fit in, to undertake this treatment to save their child's life. Because someone is not working, so they're running out of money. The siblings are not getting the attention that they need. ... They're utilising every kind of resource they can. (Social Worker)

Thus, in contrast to a simplistic over-reliance on ethnicity as a stand-alone category, it became evident that the intersections of class, gender, ethnicity, language and socio-cultural capital were the key indicators of how well or poorly these families fared within the system and beyond (Manderson & Reid, 1994).

INTERPRETER

I've interpreted for this family before. I find it's more comfortable for the family if we've met before. They came from Bangladesh where the husband had a civil service position but because he doesn't have local knowledge it's difficult finding a job. The wife is university educated as well. Their little girl was diagnosed with cancer over there but they decided to have the treatment here. They're Australian citizens you know and the younger daughter was born here. The husband has been to university in Australia and his English is fine, but as you know, some administrative staff will offer interpreter services because of the way people look. No one really wants to be bothered trying to figure out what they need. Despite the fact that they have good English, when your child is



so ill it's very stressful and I think they've appreciated having an interpreter to translate the medical details about their child's condition.

Ideas about belonging for young people are strongly influenced by the discourses that circulate about the dominant language. The previous conservative Government's³ political agenda such as the defunding of Asian languages in education and introducing Australian values into the school curriculum and the new citizenship test reflect an ideology in which linguistic competence and knowledge of white Australian values and history became institutionalised as the litmus test of 'Australian-ness'. Therefore it is hardly surprising that recent first and second generation young people who are bilingual feel pressured to present themselves as English speakers and often resist communicating in their or their parents' first language. This need to un-differentiate themselves through the use of English language is also a response to their parents' marginalisation as 'CALD' in that their parents need for an interpreter is seen to take up more linguistic space than others. Thus they are designated as 'not belonging' (Gedalof, 2007), and this is particularly noticeable in public spaces. However, as Rabiah explains this is not possible with her mother who has very limited English, and is reliant on her as both a linguistic and cultural interpreter.

I don't like speaking Arabic in front of anyone because this is an English-speaking country. She [my mum] should speak English. (Rabiah)

The use of family members – particularly children/young people when they are also the patient – as interpreters has several consequences within a health setting the least of which is placing stress on the family dynamic and can involve a shift of power from adults to children (Cohen et al., 1999; Heaney & Moreham, 2002).

Rabiah often asks you not to ask her to interpret for her mother, but sometimes she will. (Nurse)

Previous research has found that the experience of having one's child interpreting 'not only impacts on the self-confidence of parents but also undermines parental authority in front of their children'. Furthermore, the 'expert' status of health professionals can be seen as a validation for verbal abuse, expressing annoyance at parents' lack of knowledge' (Chalmers, 2006). Alternatively it can be used as a strategy for ignoring or dismissing requests. While staff became very fond of Ms Chiu, she still recognised that language was a powerful tool employed by staff:

Because I don't speak the language I use hand signals most of the time. Some of the staff pretend that they don't understand me. With some of them I ask for help and they would take a long time to come. (Ms Chiu, grandmother)

The young people overwhelmingly wanted to fit in, whether this was at school or in the hospital, and displaying a non-Anglo Australian identity was just another way of saying 'I'm different'. This was in addition to the differences they faced because of their on-going chronic illnesses. The result was a general disengagement by young people from their cultural background. To some extent it was further reinforced indirectly by some hospital staff who spoke about parents being the sole carrier of different beliefs, values and practices thereby decontextualising children/young people's socio-familial influences, locating them in a cultural vacuum.

3. The Liberal/National Party Coalition, led by John Howard, was in Federal Government between 1996 and 2007.

ZAC'S UNCLE FRANK

Zac (13 years old) was diagnosed with HIV from a very early age but we thought it was some kind of cancer. We didn't know the real reason until his mum finally told us on one of her visits before moving here.

Janice knew that her former partner's family had disowned them all so she thought that's what we would do as well. I thought Samoan people don't do that sort of thing. Samoan people, they're brought up to look after each other in times like this. When they first came and stayed with us it was really hard for Zac he had so many medications to take and he was always sick with it. He would just not take his medication and we would find them under the fridge and behind the sofa.

Normalising the illness for many children/ young people in the hospital setting can go hand-in-hand with rejecting or covering up the hybrid cultural contexts in which they live. While extended family might play an important part in some of these children's lives, they want to appear to blend in as much as possible both within the hospital setting as well as at school. For Zac, resisting authority at school and in hospital as well as seemingly dismissing his Samoan heritage as insignificant allows him to 'fit in' with friends and forget about any differences he encounters. Notions of how identity is expressed within private and public spaces is also implicit in Zac's strategic decisions about where and under what conditions he recognises the different contexts in which his (cultural) identities are performed. While Zac claims he knows nothing about his Samoan heritage, in contradistinction his uncle expresses great pride in Zac's interest and active participation when Samoan friends and family gather.

We're having a cousin of mine coming over and running a workshop here to teach the kids how to speak Samoan. So that will give Zac an involvement because I know he's keen on it too. His mother speaks a bit but not a lot. ... Zac is always helpful when we do the cooking outside. ... And the best part he likes to do is when we bring the food back out of the ground again. Because I get the young boys together to get in there and Zac, I say, 'You show those boys how to pull it out', because he knows what he's doing. (Frank, uncle)

Thus, Zac does rely on his extended family that includes support for his HIV status and being taught by his uncle about Samoan culture and language. The fact that he does not disclose his illness to his friends helps him to hide his condition but limits where he can go and socialise.

No one at that school knows about Zac's HIV and I'm pretty sure he's not going to walk around and tell everybody. (Frank, uncle)

The most difficult thing is umm... not telling anybody. Like it's hard ... there's a kid at school that has an illness and like he can tell people about that whereas I can't. (Zac)

Like Zac, the other young people we talked to weren't very forthcoming about their migration journey or their cultural heritage and perhaps this is not surprising given they are usually not the decision makers about these movements. As Rabiah earlier remarked, 'I'm a person that came from Libya, I was born there. And I don't know jack about that.' While Rabiah may not have known 'jack' about Lybia, she most definitely was a cultural translator for her mother – linguistically, socially, and through the bureaucratic institutions of Australian society – including within the hospital and the broader health system. While Rabiah sometimes resented this role, staff commented on her close, often protective relationship to her mother.

I think the relationship between Ms K and Rabiah is close ... Rabiah came in one day and told me she was fighting with her friend because they'd been making fun of her mother. And then, at other times Rabiah gets annoyed if mum causes a scene here ... [then] Rabiah gets upset with her and she'll shout at her in their language and then they won't talk. (Nurse)

'Family' still remains the most significant site of cultural belonging for most young people (Butcher & Thomas, 2001). Yet identifying as culturally different alongside living with their illness, particularly among their school peers, can exacerbate feelings of social isolation. Nevertheless, these young people's ability to express their identities as fluid and provisional, guided by the specific context, albeit sometimes challenging, involved no contradictions or feelings of living in two worlds.

REGISTERED NURSE

The family have a little boy, Edmund who's been in hospital for a long time. His grandmother sits by the bedside all day and his father comes in and stays overnight. We can't really communicate with the grandmother because she doesn't speak any English, but we use sign language to get by. She looks after her grandson, bathing, feeding and helping with his exercises. We really appreciate her being there but I understand that this is typical of Chinese culture.

Edmund and grandma are very close. Sometimes the grandmother does things wrong – like with the exercises – and we have had trouble telling her how to stop. Generally we only book an interpreter to come in when the doctor's here with the family. Dad speaks English so we can talk to him. It's a bit odd that mum's not here though. It's usually the mums that we deal with and now that I think about it I don't think any of the staff have actually met her.

Parents, carers and siblings of these young people with chronic illnesses have their own respective set of pressures due to the added demands in their lives. For some of these families appropriate housing, or changes in circumstances, can impact on the whole family determining where they can live, what kind of housing is appropriate, and whether modifications can be made, for often they are limited to rental accommodation. Even priority housing can take several months to organise. In the case of one family, their housing was completely inadequate for the child's condition and was one of the main reasons for non-compliance in his ability to learn to take responsibility for some of his own care. This meant an extended period of time in hospital beyond the already lengthy stay needed.

One of the difficulties, because it's too small: I feel like I'm in a cage, you know what I mean? Like, suffocated, that kind of feeling. So I don't feel comfortable in a small house. I don't like the house, not because of my parents, my family, but I don't like the house. (Omar)

On arrival after waiting several years for their visa, this family was of course very happy to find any housing they could, particularly since all members of the family had no English, no employment and little money. Once their son had been admitted to hospital and his parents became increasingly aware of the resources and the potential for their son to become more self-sufficient, it soon became apparent that their house was inadequate for their needs. In addition, the number of children increased during the first year and the family needed more space. While they were placed on the priority housing list, finding a rental property that can accommodate a child with special needs such as wheel chair access is difficult.

One staff member also mentioned that, in one of her conversations with the Department of Housing an off-hand comment was made by the department worker that this was what happened when 'these families' had so many children.

They were still waiting several months after we last contacted them.

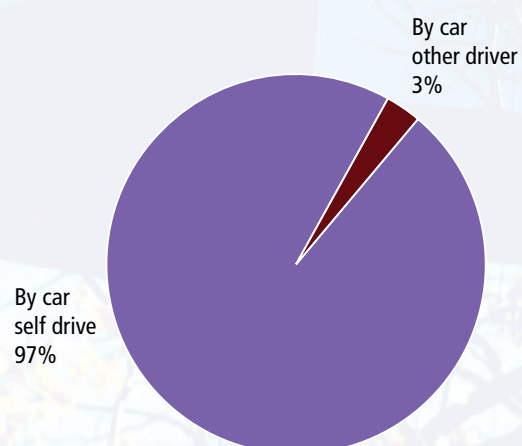
In addition to housing, access to and convenience of public transport, distance to and from bus stops and train stations to the children's hospitals are constant sources of stress for carers.

We were visiting Omar almost every day. And do you know how far [from our home] the hospital is? To take the children with me and go ... it consumed the whole day to go there. [We go] from home to the station by bus. Then we will change trains, and then we come [to the hospital] by another train and walk from the nearest station ... It wouldn't be less than one and a half hours [each way]. (Mr Aziz, father)

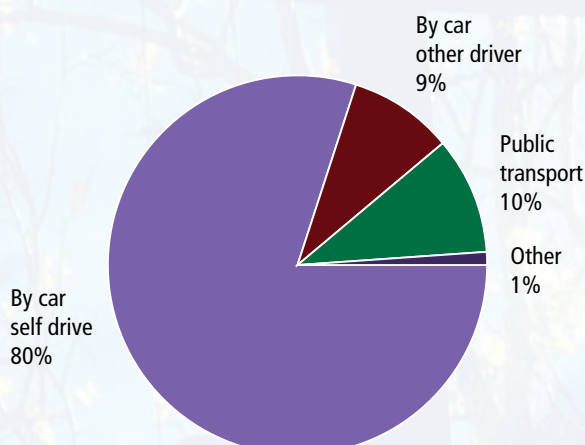
Transport to and from the hospital [for regular patients] is a big issue for many of the families we have. It's a big imposition on families, and there just aren't any transport options for them. (Nurse)

The survey identified that the use of public transport among families from CALD backgrounds (9.9%) was significantly higher than for the Anglo-Australian group who, in all cases, indicated they had use of private vehicles.

How do you usually get around with the children? (n=88 Anglo-Australian group)



How do you usually get around with the children? (n=181 CALD group)



However, even in the case of carers who had their own car, it was found that when their child needed increased hospital care, their ability to take care of other dependents, hold down employment or studies, along with the added cost of petrol and parking were regularly cited as causing increased anxiety and fatigue for all family members.

I hate going to SCH, only because financially it's hard. The clinic's always on a Monday, and Monday is not really a good day for us in this household because everyone has Mondayitis. But it's just a long way to go. ... It's hard to park. Can't always afford to park underneath, it's really expensive, the parking station. (Ms Dixon, mother)

Only three out of the seven families appeared to have any other significant family or friends to which they could turn to for social and/or economic support. To some extent this varied depending on the family member and their broader community connections. Most of the young people who attended school regularly had peer friendships, while for the parents this was somewhat more difficult. Financial, age and gender issues as well as English language ability all played a role in the extent to which they connected to their broader communities. The amount of time parents/carers had outside of caring for all the members of the immediate family also limited their opportunities to mix or access resources.

Hospital staff do encourage families to call on friends and family for support especially for those who have a child who is an inpatient for long periods. This works for some families but for other households, there is a tendency to become more isolated and withdrawn from the outside world.

A lot of Asian families are very protective of their children, and they generally are very proud of their children. ... This is a proud family, and now Edmund is injured and he's not a well boy. They are going to look after him, but they are going to look after him quietly, alone, and not speak about him too much. There's no extended family, there's no other friends, there's no school friends coming, and I've asked about this, encouraged them to come, but they don't want to. (Staff focus group participant)

Contrary to what one would expect, the length of time in Australia did not seem to affect which families had familial or other forms of social support. For example, the family from Iraq who had been in Australia for less than a year, while unable to go out due to financial and transport limitations, set up an informal system of locals coming over for free haircuts from Mr. Aziz and the local children regularly played out the front of their house. In contrast, Ms Aziz's primary outing was going out with the family to do the weekly shopping. Both parents explained that they couldn't possibly go out to 'have fun' until Omar was back home with them again, despite the many months he remained in hospital.

While it is generally acknowledged that stress plays a large role on other family members, what is often overlooked is the impact of the young person's condition and treatment on the physical health of other family members. Constant travelling to and from the hospital, sometimes with other younger dependents is exhausting and for some parents, this travelling can be over weeks, months or even years. In the case of the Yeung family, the level of active involvement in staying with and caring for their child took a massive toll on the health of all the carers involved.

Edmund's father and grandmother held vigil at Edmund's bedside for one-year, making sure there was always someone there to monitor and talk to him. The level of commitment shown by his grandmother and his parents did not go unnoticed by staff:

Very rarely do you see such a huge commitment from a grandmother ... You see [other grandparents] come and visit and give them cuddles and play, but she's committed in everything - in cleaning and feeding him, talking to him, taking him for walks, massaging him, talking to him sternly as well as being there at physiotherapy. She's there all the time and then the father comes over with his commitment of his job which is huge - he still comes every night, no matter how tired he is. (Staff focus group participant)

In the meantime Ms Yeung ran the business and took care of Edmund's siblings. All three adults lost considerable amounts of weight, were exhausted and suffered from depression.

Since Edmund's illness everyone in the family has lost weight. We're all getting very run down. There are lots of worries. There's the business, and there's non-stop work there ...

everybody gets up at 4am and it's not until 8pm that people can actually stop and go to bed. (Ms Chiu, grandmother)

The only way they could continue to take care of their son was to sell the business, relocate and begin a new life that would allow them to give their son the constant care required at home. Ms Chiu's close affinity to Edmund goes back to her caring for him as a baby. At this time Edmund went back to China on two separate occasions for a period of 6 months respectively with his grandparents.

Grandma is very worried about Edmund because she has looked after Edmund since he was born. He's spent more time with her than with us ... In the beginning my wife and I had to work and had to pay the mortgage of the house. Grandma was willing to help us. She took Edmund back to China. (Mr Yeung, father)

This practice is not unusual among Chinese parents who may have their parents come out to Australia to assist with the first few months after the birth of a grandchild or alternatively take them back to China for a period of time (Chalmers, 2006). However, once Edmund left hospital, Ms Chiu returned to China.



In other situations, there were parents who already had a pre-existing condition that, when under stress, became exacerbated.

In response to the pressure of having a daughter who is ill I sometimes get some neck pain, sometimes I cry, sometimes I stop eating and even stop talking. I don't talk to anyone. (Ms Allam, mother)

I don't have time to get sick, basically. I can't afford to get sick. But it's hard sometimes when I'm really exhausted and like, have the flu. If I know I'm going to get the flu I'm straight to the doctor and I go straight onto antibiotics ... Normally if I do get sick I'm down for 4 or 5 days and I can't leave these little ones to fend on their own and plus with Zac. But I mean, there are times when just a good night's sleep is a good thing. (Ms Dixon, mother)

Adolescents, especially as they became older, accepted the knowledge of their illness but tended to be more concerned about the day to day aspects of their condition and how it helps to obfuscate the fear and uncertainties about their futures. On the one hand, it was normal for some of these young people to feel invincible while on the other hand, they talked in terms of not being sure about whether they will live, justifying their reasons for being non-compliant with their medication or self-care.

HIV's not going to change; it's always going to be there. But it's been maintained through his medication, but it's all the other little [medical] things. And they start off as little things, ... but they become harder for him to deal with. And sometimes he doesn't know how to deal with it and he becomes really frustrated. And I feel that he thinks he's got HIV and he's going to die, so why worry about school, he's got that thought in the back of his head. (Ms Dixon, mother)

At the same time, expressing resistance is also a way of reclaiming some kind of control in an attempt to normalise their lives. And expressing bad behaviour was sometimes a demonstration of that control.

This control is more often than not put into practice within everyday activities – be it school, taking medications, relationships with family and friends. For some, performing resistance to their illness, family members, health providers and/or school authorities was their way of making their presence felt: a way of gaining a sense of self. Often, they justified their inconsistency with taking their medication as 'nearly always is good enough' and it is worth noting that some of these young people needed to take large amounts of medication every day for the rest of their lives.

Despite this former rationalisation, family and their health workers continued to chastise them because the reality is that 'nearly is not good enough'. The result is that not only can their condition become compromised but they are categorised as 'non-compliant'. This reduces their identity and subjectivity to their relationship with their illness, a constant reminder of their dissonance from 'normality'. This link to normality was particularly important for the young people within their school lives, however as Rabiah explains this was sometimes taken out of their hands:

Every teacher in the whole school knows about my illness. Even though I don't want them all to know, they all do. I don't have a choice do I?

The relationship between the hospital social workers, community liaison nurses, occupational therapists, the family and school authorities played a central role in how well these young people transitioned in and out of the hospital system. It was obvious that the type of communication and liaising between the relevant services involved could either assist or hinder general behaviour and the taking of regular medication. For example, Zac had problems adjusting his medical routines in with his school life and reports of bad behaviour resulted in Zac getting into regular trouble, including suspension. This, his uncle claims, was again related to his need to be recognised as like everyone else.

Zac was doing things [at school] that I've never known him to do and I said to him 'What are you doing that for?' He goes 'I don't know.' ... He and my youngest daughter, she and Zac get on really well. And he told her that these kids were giving him a hard time and he was just trying to fit in more than anything else. (Frank, uncle)

In another situation, an occupational therapist tried to arrange for Omar to attend an intensive English school. While the school was more than prepared to accept Omar with both short- and long-term plans in place to enable his mobility, the building section at the Department of Education said the provision of a ramp was too costly for the time he would attend.

There wasn't the will to do it. Our thought was that if we could make that particular aim, the intensive English accessible, then it would be access for the future, so it wasn't just for Omar. (Occupational Therapist)

An alternative integrated school within their area (catering for students with special needs) was found. However, while they were very supportive, intensive English classes were not offered.

9.3 Transitions and tensions

For many families from CALD backgrounds, transitioning from one cultural context to another seems like a never-ending journey. When a child/young person is admitted to hospital it can feel like yet another trauma to be navigated. The upheavals of the migration or refugee process, housing, learning a language, finding a job, understanding and organising education as well as negotiating the health system for a child with a chronic illness who may require years of on-going care can be overwhelming. As these families also tend to gravitate towards those who have gone through similar experiences, the knowledge about how to traverse the bureaucracies can often be sketchy, ill-informed or simply out-dated.



When talking to staff, there was also a common feeling that they too felt overwhelmed by the complexity of issues these families presented with and the level of organisation required to facilitate good quality care both within the hospital and after discharge. For example, one family needed the involvement of three teams of medical and allied health specialists as well as external services including the Department of Housing, Centrelink, the Education Department as well as specialist disability services.

We did not know there were so many agencies involved with the family and that is unfortunate. I mean, we needed lots of agencies but it seems to have been compounded because other people have said, 'Oh, you should get help from such-and-such'. So we really don't know who all the players are. (Occupational Therapist)

Even those families who came under skilled visas and who were well resourced still experienced high degrees of stress because of moving countries and finding employment. Two of the fathers had significant difficulties in obtaining a job despite all being highly experienced and qualified in their respective professions. Nevertheless, they were forced through economic necessity to take on alternative employment outside their expertise.

All the families demonstrated immense gratitude to hospital staff. While well-deserved, this was often contrasted with their previous experiences (or lack thereof) of other health care systems. For some families the cost of or access to health care had been either prohibitive or occurred at a high personal cost.

In Libya I spent lots of money on my daughter and I took her to the best hospitals and we spent a lot, but they didn't find the correct or proper treatment for her. (Ms Allam, mother)

In Jordan we had to buy Omar's treatment. They did not give it to us and the treatment centre was very far and to get him there was difficult. They used to give us something to spend, but it was not enough for half the month. It was not possible for us to work in Jordan, it was forbidden. We used to be hard on ourselves so that we would keep something spare for Omar. (Mr Aziz, father)

In addition, the different levels of health literacy and expectations of the health system among the families varied greatly. Expectations were influenced by factors such as English language proficiency, socio-economic position, family and community supports as well as a fear of 'asking' within an unfamiliar environment.

Everything here at the hospital is good. Every person has done his duties to his utmost best and they tell me everything. They won't hide any information from me. ... There's no complaint at all, no complaint about the staff. ... It's different in my country. (Ms Allam, mother)

Sometimes the nurses who are very busy and very stressed see a parent doing something

that they don't think is quite appropriate and I remind them that they have come from a very difficult background ... so we try and understand why they might be behaving somewhat differently to some of the other parents. (Social Worker)

These 'different behaviours' by parents/carers were usually linked to cultural factors that led to misunderstandings and were more often than not based on a lack of knowledge about the hospital 'rules' or 'culture of care' operating within the Australian health care system.

9.4 Expressing dissatisfaction and resistance

Some staff members were quite aware of the tenuous position parents/carers felt about expressing dissatisfaction with their child's care or treatment. This can be made even more difficult in the case of chronic illness when the young person and family are regularly attending the hospital.

And the other thing is that in this unit because it is so constant and they have got to come back, they can't always complain when they have a complaint because they've got to come back and I worry that they worry about repercussions. There aren't any, but do you know what I mean? (Nurse)



Indeed, It has been noted both in Australia and overseas, that clients from CALD backgrounds navigating institutional health settings do not want to be recognised or stigmatised as acting or embodying difference (Airhihenbuwa, 1995; Chalmers, 2003; O'Callaghan, 2000; Pinderhughes, 1989). This is based on the fear of negative consequences premised on the inherent power imbalance (Pugliese, 1995) bound up with one's sense of rights and belonging. In contrast, it has been found that people feel more empowered within their own home where they possess a greater sense of self which can be reflected in expressing pride in their cultural background (O'Callaghan, 2000).

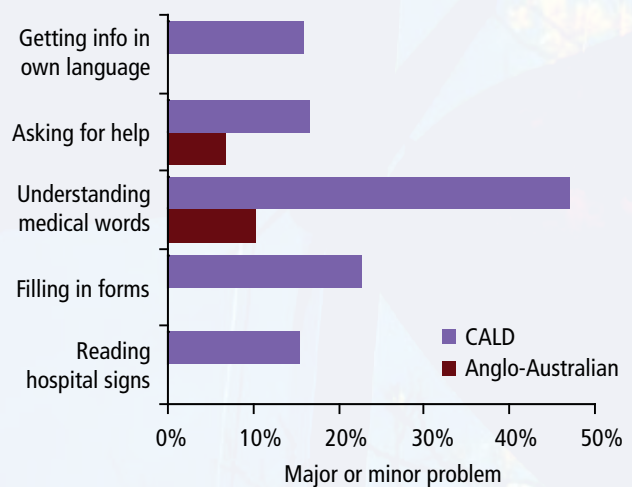
While the statistical results did not suggest any significant differences in satisfaction between the Anglo-Australian and CALD groups, the open comments portrayed the former parents/carers as more ready to demonstrate their dissatisfaction.

Generally people who are not from an English [speaking] background will very rarely complain because they're not aware that they can. (Senior Manager)

The largest number of complaints by the CALD group referred to sleeping arrangements in the wards whereas the Anglo-Australian group complained about a greater range of issues. These included grievances about food, sleeping arrangements, courtesy, communication with health staff, staff shortages and waiting times.

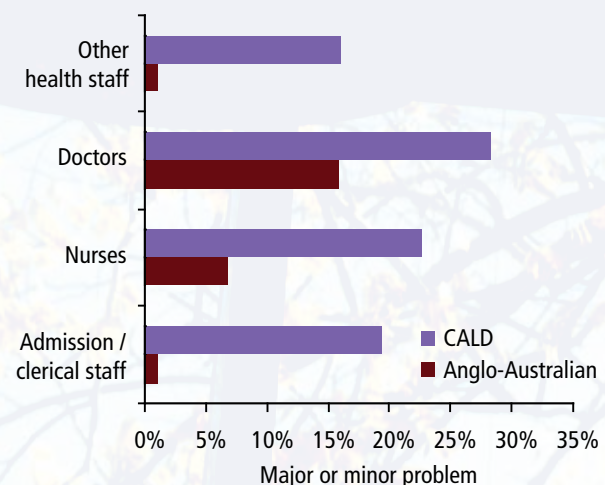
Not surprisingly, however, written and oral communication issues did figure significantly in the survey results. The responses by parents/carers who expressed difficulties in communicating across a range of service providers in the hospital were as follows:

During your child's stay in hospital, did you have (minor or major) problems with any of the following?



- 16% of the CALD group found difficulty in gaining information in their own language. In addition, only 1 in 5 from the CALD group received written information in their own language about their child's operation.
- 6.8% of the Anglo-Australian group and 16.5% of the CALD group had a problem asking for assistance.
- 10.2% of the Anglo-Australian group and 46.9% of the CALD group had a problem understanding medical words.
- 22.6% of the CALD group had a problem filling in admission forms or other documents.
- 15.5 % of the CALD group stated they had problems reading the hospital signs.

During your child's stay in hospital, how was communication with people from these groups?



- 16% of the CALD group and 1.1% of the Anglo-Australian group had problems communicating with other health staff.
- 28.2% of the CALD group and 15.9% of the Anglo-Australian group had problems communicating with doctors.
- 22.6% of the CALD group and 6.8% of the Anglo-Australian group had problems communicating with nurses.
- 19.4% of the CALD group and 1.1% of the Anglo-Australian group found communication with admission or clerical staff a problem.

Through our observations and interviews, we found that responses by staff to CALD families' dissatisfaction included having parents' concerns minimised especially when the complaint was directed at staff. At times, staff attempted to reassert their professional authority by then identifying these families as either problematic or difficult. This was often achieved by way of conflating particular responses, living arrangements and/or behaviours into preconceived stereotypes often based on isolated experiences and subsequently extrapolated onto several undifferentiated communities.

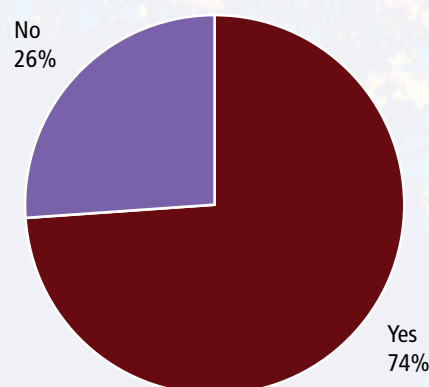
Middle Eastern groups have got more recent and challenging cultural issues that include how the Hospital looks, how the diets are made available, how modesty and individual habits or clothing is acknowledged, how the hierarchy within families and gender relationships are acknowledged. They're new challenges I think. (Senior Manager)

Middle-Eastern families don't want to talk to me, they want to talk to the 'real doctor', or ask, 'can you get the doctor in charge?', and I say I am the doctor in charge. (Female Senior Doctor)

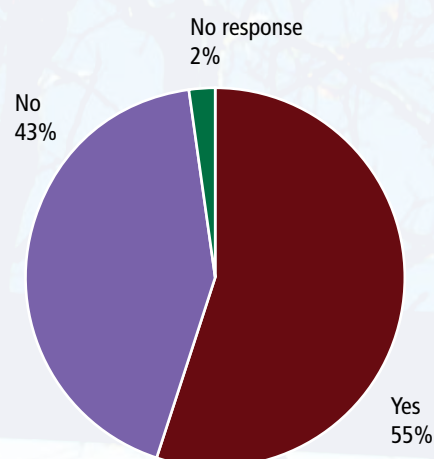
Staff from both hospitals also employed the category of ethnicity when commenting on the misuse by families from CALD backgrounds' of the tertiary hospitals themselves. There is a common assumption that these families are more likely to present at a tertiary children's hospital rather than visit their GPs when their child first becomes ill (acute emergencies excluded).

This was emphatically contradicted by previous qualitative research (Chalmers, 2006) and the multilingual survey findings which established that in fact 73.9% of the Anglo-Australian group compared to 54.7% of CALD families used the children's hospitals as their first port of call.

Was the children's hospital the first place you went when your child needed medical treatment on this occasion? (n=88 Anglo-Australian speakers)



Was the children's hospital the first place you went when your child needed medical treatment on this occasion? (n=181 CALD group)



Indeed, it is common sense that if linguistic communication is a necessity within a health interaction, then accessing a medical practitioner that is fluent in one's first language will be the preferred option.

Usually we see a Chinese doctor. It's easier for us to explain a symptom. And when the doctor explains to us, it's easier to communicate. (Mr Yeung, father)

Other findings revealed that in contrast to staff perceptions, if there were problems when 'certain cultural groups' tended to visit in large numbers, the statistics showed that from the families' perspective, they were unaware of staff concerns. Further, when asking staff what were the major issues they encountered around cultural diversity, the responses revealed language and religious differences dominated their answers.

The significance of and/or obstacles to religious observance, however, was not reflected in the survey results with only 2.8% of respondents from CALD backgrounds reporting minor problems. Stated differently, when asked 'do you identify with a religion' it was in fact the Anglo-Australian group (84.1%) that rated higher than the CALD group (76.8%). This is not to suggest that religion is not significant among the 7 families with whom we talked. There was a range of religious/spiritual diversity among the families which included Buddhist, Christian, Muslim, and Hindu. Indeed, several expressed the relationship between their religious faith and the concept of hope, although this was not always articulated in terms of attending formal places of worship.



What it does indicate, however, is that while staff feel accommodating religious difference in the hospital is a significant issue of concern, particularly among CALD parents/carers, this was not reflected in the findings.

9.5 Transitioning from child to adult services

The development of the transition model is something relatively new within several areas of young people's health care. In the not-too-distant past, for example, the prognosis for children/young people who contracted HIV/AIDS would have been extremely poor. Moreover, there is now a much greater awareness of the consequences in the gaps and mismatches that young people experience moving from child to adult services. As a relatively new addition to paediatric health care, not only do the young people have to navigate the transition period but so do staff. Previously, once a young person reached a certain age, their health category status automatically changed and so did their care.

Adolescence within a Western neo-liberal discourse is inherently about the transition towards an individual identity; moving from a state of dependence to independence in relation to the rest of one's family, dealing with state bureaucracies, institutional supports as well as managing one's own on-going care. Thus, even for families who have been socialised within this cultural model, the move away from having long-term consistency in health providers, a shift away from a family-centred care ethic and taking on their own decision making can be quite confronting.

Moreover, the definition and assumptions about caring responsibilities within a 'family' continue to be premised on a Christian Western nuclear structure. Consequently, diverse values and practices in relation to family composition, decision-making, familial relationships, notions of independence, dependence and caring become measured as different from or the same as this familial norm. While most staff do try and accommodate some of these variations, the model itself works on a recipe of 'add difference and stir' rather than an inclusive model of difference in which a range of options are offered. This was openly acknowledged by some staff as an issue to be addressed.

There's so much to learn about other cultures, what it means for them to be hospitalised, how much families expect to participate is different in different cultures. Sometimes we have an expectation that is not congruent with what the family expects. (Senior Manager)

In fact, these differences are becoming more common than the so-called 'norm' whether that be among Anglo-Australian or CALD families. Differences such as who takes on the primary caring of the patient in hospital to the role of family members in the long-term care of children once they reach the transition period. By marginalising other kinds of family structures staff can inadvertently exclude and/or isolate other adult, sibling and extended family members.

[In our area] the whole transition programme towards going on to adult clinics start at about 12 years or thereabouts. We try to get them to become independent of their parents because the parents are very much the centrepiece of the management programme until then. And a lot of them won't let go either, they want to keep doing it. (Doctor)

While this movement from child to adult services is critical for continued quality of health outcomes, too much emphasis can be placed on future needs at the expense of the every day challenges that all adolescents face.

This focus on making the leap from adolescent to adult at a specific age is both arbitrary and Eurocentric. The various roles that both children and adults take on are culturally and historically specific. The very notion of transition from childhood as dependence to adulthood as independence is seen as non-sensical or an anathema in many cultures. Indeed even in the area of adolescent care, there is a growing consensus which suggests that a family-centred model of care for all young people has legitimacy beyond paediatric care.

9.6 Rules of engagement

Besides questions around familial relationships, other issues of concern included the role and value of large health team/family meetings. While these meetings may be appropriate for some, possibly even the majority of families, individual families are not consulted in deciding whether this model will produce the most positive outcomes for them. That is, part of the model of a family-centred approach is a philosophy that presumes that an open and consultative approach is the common desire for all those involved. However, many newly arrived families, while in the long term may become used to and even embrace such a system, there needs to be some caution in assuming this is the optimal approach.

Similarly, the dominant positions of 'expert' service providers, particularly when they tend to both outnumber and monopolise the discussion, also needs to be evaluated in terms of how useful the meetings are for the families who may simply feel overwhelmed and at times even intimidated.

I spoke to Mr Yeung about the home modifications many times. And the time when he actually gave me permission to put the referral in was in a family meeting situation. And afterwards I was a bit worried. I think I said to you [fellow health worker], 'I feel like we bullied him into it a little bit.' (Occupational Therapist)

This power imbalance, despite sincere good will, can be potentially counter-productive and can create a situation in which families feel unable to articulate any concerns for fear of appearing ungrateful. Added to this milieu is the role of interpreters who similarly can become overwhelmed by the cross-talking, long technical monologues as well as translating the range of professional voices that need to be represented.

In one such meeting the researchers attended, there were approximately 13 hospital and external health providers present. The parents of the child entered half way through the meeting, the interpreter exasperated, eventually gave up interpreting and the parents at the end of the session were asked 'Do you have any questions?' which they quickly responded with 'No, everything is fine.' This may well have been the case but given that the interpreter was unable to follow the discussion, the parents were hardly in a position to know whether they needed to ask a question or not.

From the perspective of staff these meetings also involve professional hierarchies that can not only influence the communication process between staff and the family but also affect the ability of families to deal with the transition from hospital to home. Despite a devolution of medical authority through the development of multidisciplinary health teams some doctors acknowledged the difficulties in letting go of their dominant positions within hospital hierarchies. In general the health teams described themselves as 'working well as a team together', yet on further questioning, the power differentials between the discipline hierarchies became apparent.

The most obvious power imbalances among health professionals were those between senior medical and allied health workers and were evident in the decision-making processes.

The authority of surgical teams, senior managers who deal with moving patients in and out of hospital beds and senior medical consultants outweighed those of social workers, physio and occupational therapists, and other allied health providers. Often these tensions occurred behind the scenes, the family being unaware of the pressure some teams were under:

They [senior management] want to get the long stay patients out of here. Yeah. They're on a mission. ... Individually I can understand where they're coming from – it's about access block, we're going to have to have single rooms ... But I feel quite distressed that there is a lack of appreciation of this particular individual family's circumstances and the child's needs ... So personally I find it an affront to our clinical work. (Doctor)

In another situation the power relations had the potential to affect the long-term relationship between the allied health worker and the patient and family. A family/health team meeting was arranged to discuss Zac's present health condition which had deteriorated over the preceding few weeks. On requesting Zac to attend this meeting he stated that he did not want to be present. This was accepted and when the physician asked where he was, his message was conveyed along with the explanation that it was his choice. Nevertheless, the doctor insisted that he be present. This resulted in undermining the authority and ability of the allied health worker to not only make autonomous and informed decisions but also dismissed Zac's agency in the process. While seemingly trivial, it also undercut the trust and respect built up between Zac and this particular health professional.

The culture of adolescence is a challenging time although, as young people get older, it is assumed they will take a greater role in making their own decisions. Most teenagers comply with treatment but offer forms of resistance as a way of reclaiming some kind of control while at the same time, still wanting not to appear different.

A lot of that control is about normalising their condition within their lives and part of that normalising is resisting long-term treatment. However, we noticed that bad behaviour was the only way children/young people could demonstrate control as in the example with Zac. In the above example, once Zac had been summoned, he made it clear he did not want to be there by not responding to questions, and finally demonstrating his resistance by turning away from the senior physician.

The doctor framed her discussion in the often-used invocation of war metaphors around HIV such as 'alien invasions' and 'shooting blank bullets' in an attempt to draw Zac's attention to the seriousness of his condition. Her attempts were ultimately counter-productive and his mother's final comment after observing this stand-off was, 'Has anyone asked Zac how he feels?'

Doctors, nurses and allied health professionals often need to impart difficult medical, therapeutic and technical information to families. However, the health providers' lexicon tends to be constructed within a set of hierarchical relationships that relies on, indeed gains its dominance and legitimacy from the use of complex language. This then tends to be reinforced by the traditional uni-directional process of 'handing down' information. In this way, the recipients (young people and their families) are always seen to be the beneficiaries of knowledge while health professionals remain the sole custodians of knowledge.

Ms Allam and Rabiah would be included in decisions such as what time she comes, whether she comes in the morning or in the afternoon. [But] if she has to go on a different medication, I think they would be told rather than asked if they wanted to think about trying it. I think those sorts of medical decisions would probably be made in a fairly paternalistic way. (Social Worker)

This hierarchical relationship also has significant implications for the role, use and training of interpreters. On several occasions during the clinical observations, responsibility was placed on the interpreters to decipher and translate complex medical terms across a range of specialties. Not surprisingly these interactions were more often than not flawed.

9.7 Compliance: a moral dilemma

In the long-term chronic care of children/young people, the notion of 'compliance'⁴ was an ever-present term. This term was used in multiple situations referring to either the young patient or various members of the family. 'Compliance' came to represent: the good patient or family, whether they were easy or difficult to communicate with, took their medications or not, were on time or late for appointments, understood the condition and the prognosis, responded and accepted assistance appropriately, well-mannered, meek or vocal, and spent time with their children.

The mother did ask me relevant questions. At first she fired questions at me in a sort of really bossy way. She's a bossy woman, did I tell you? (Nurse)

Several nurses in particular commented on families being non-compliant by not turning up on time and by not keeping to appointment times despite the fact that clinics usually run late. Some staff responded to transgressions with what one could describe as old-fashioned parental authority:

I find it very rushed [in the mornings]. Now, since the staff have scolded me a few times I don't dare go inside the hospital school anymore. So, I just send my grandson to the entrance and then I come back here to his room and tidy up. (Ms Chiu, grandmother)

4. While there has been a recent shift in terminology from 'compliance' to 'adherence' in the health literature, the term compliance was constantly used.

I'd come on a home visit to talk to her about certain things and she left the interpreter and I sitting in the lounge room. 'Ms Allam?' I called. 'I just have to do this! I just have to do this!', she replied. So she was running around and cleaning up the house. When she came and sat down it was time for us to go! ... She had no concept of how to use the home visiting service. It just didn't work, so I used to make her come and see me. (Social Worker)

Often the combination of ways of being and responding to what are often the 'unwritten rules' or institutional and professional expectations often consciously and unconsciously translated and fed into moral judgements from which the concept of the 'good (normal) family', the 'good (normal) parent/carer' and the 'good (normal) patient' were measured. Needless to say, there were differences in responses across and within the health teams, yet the hierarchical nature of the teams and their adherence to medical dominance or not, did to some degree reflect how effective the long-term communication with the respective families developed.

Mr Yeung is such an amenable fellow to work with. ... He's still been very good to work with. Easy, I don't know whether 'easy' is the right word, but we feel that we've been able to engage quite effectively with him. (Staff focus group participant)

They're a very kind of compliant family, particularly the father who would not ... you get the feeling he wouldn't want to do anything to upset the apple cart. (Doctor)

These unwritten hospital rules supported a moral discourse that delineated the boundaries of normative behaviour based on a standard Anglo-Celtic middle-class family structure. This related to the type and level of compliance in terms of understanding the logic behind the treatment as well as the family and young person's behaviour throughout the treatment.

These judgements led to responses that set some young patients and families up as compliant or non-compliant without any reflection on how the health system itself functioned. There were instances where staff, without realising it, conflated different parenting, cultural expressions and behaviours into negative stereotypes.

There is a general expectation by staff that parents should be actively involved in the care of their child and to fit in with the hospital regime. While staff understood parents' limitations they also expected a certain level of behaviour from the children/young people so that they could get through their work schedules.

Omar's family had just arrived in Australia as refugees and he was in hospital for months, did not speak English and was confined to his bed, yet his 'annoying' behaviour, constantly ringing his bed buzzer tended to be put down to a cultural 'parenting' issue. This was despite Omar's claim that 'I'm not the only one who buzzes. All the others [children] in the ward buzz them [nurses] too.' Nevertheless, factors such as having always had things done for him and being the eldest son in a 'Middle-Eastern' family were cited by staff as contributing to his bad behaviour even though staff also acknowledged that this behaviour was in part due to his condition.

My nurses are not your friends who can spend social time with you. You need your friends and family to come in. (Nurse)

Yet there was very little communication between his family and the nursing staff because of the language barriers. While some of the nurses knew this family had recently arrived in Australia, their work routines could not accommodate Omar's demands for attention. The above reprimand by the nurse occurred in front of several staff and his parents. This was despite knowing that some of the reasons that the family couldn't always be at the hospital were that his mother was in her last stages of pregnancy, was caring for three other children, caught public transport and it was summer.



Nursing staff also criticised his siblings running around the ward when they came to visit. Given that Omar was confined to his bed for the majority of the day, had very little English and had limited visits it is not surprising that he was yearning for human contact, those most nearby being the nurses. As one senior manager succinctly explains:

While the large majority of hospital admissions are very brief, there are children who stay in hospital for weeks and even months or years in some cases. So you can have situations where the family is actually resident within the hospital. For the brothers and sisters, this is their home and their backyard. (Senior Manager)

Several medical, nursing and allied health staff in both hospitals acknowledged that those who worked in a children's hospital do 'go the extra mile' and that 'it's the child and the family which are the centre of care.' This philosophy was repeatedly cited as at the heart of children's health care and we saw this being implemented at many levels. The presence of siblings, however, did cause some tensions and as was noted above, the invocation of hospital 'rules' were often used as a justification for dismissing a more flexible approach.

The attitude of the ward's nursing staff was sometimes inflexible. (Vietnamese parent/carer, survey respondent)

Ms Das, who had recently arrived in Australia by herself with her children, was advised that she would be unable to keep her younger child with her while her daughter spent a few days as an in-patient. The worry over how her child would cope staying with relatives he hardly knew increased her stress. Although staff were sympathetic, guidelines were brought into play.

Ms Das didn't want to leave the four-year old sibling out with their extended family because she worried he wouldn't settle there, and that he'd be scared. ... Ms Das really did not want to follow hospital policy in regards to not having her little child stay here. ... So that was very difficult for me to try and enforce the hospital policy on someone who was so vulnerable. (Social Worker)

In a different context, during a family/staff meeting one family had comments made by the doctor about how Mum couldn't concentrate on the discussion because her young children were climbing all over her. Yet no provisions for child care were made to allow her to focus on her sick child's needs.

His mother does work hard to pay attention, but it's just, almost at every meeting the kids (younger siblings) are always there, so it makes it very difficult to maintain the flow of the conversation. (Doctor)

Maintaining close relationships with siblings is important during long stays in hospital. For example, Zac's younger sisters spent many hours on his bed playing with him and even having naps during the day. It was also obvious how close and protective Zac felt towards them.

Zac and his mother were ostracised by their family in Samoa primarily due to their HIV status. Ms Dixon had had previous partners and other children both prior to and after her relationship with Zac's father. Ms Dixon felt she was blamed as the 'site of contamination' by the family although Zac's father had been infected through a blood transfusion while in hospital.



These feelings of isolation were somewhat offset by the extended family support of her sister's family who encouraged them to move to Australia. Their decision to move was also motivated by more advanced information and treatment options for people living with HIV, particularly during the 1990s. Despite this, his family as well as some members of the health team made constant references to her mothering and the size of her family with the implicit linking of Zac's HIV status with her sexual history.

[H]e's going to need an adult to help him, and we're not confident there's any stable adult person in the household who he can rely on to help him with his medication. Our experience in the past has shown us that his mother doesn't consistently exercise enough responsibility to be relied upon. Now, that may have changed, because the ante has been upped. Also, her life is obviously pretty chaotic in that she has a child from a different father every – I think she's actually had two children by the same father, so that's a cause of celebration. (Doctor)

This moral injunction that assumes that because she has had multiple partners she is more prone to risky behaviour, instability, irresponsibility and linking this all to bad mothering constantly surfaced in our interviews and observations.

She is inconsistent in her care of the children ... and I think Zac can't expect to get from her the sort of attention that he would have had three or four years ago. She had, even then, relied on other members of the family to take a lot of the brunt of his care. (Doctor)

As discussed, this family did not function as a White, male-headed, Anglo-Celtic nuclear family unit and extended family was integral to its functioning. The family members, especially the children, moved across households supporting each other whenever and however they could. This resourcefulness was often confused with chaos as it differed from what the hospital staff usually associated within 'normative' family dynamics.

While the treatment for Zac was requested and appreciated, the constant worry of losing Zac and the strain of travelling to and from the hospital inevitably took its toll.

Even so, the only situation in which the researchers saw Ms Dixon lose her temper was in relation to what she described as unrealistic demands by a system that expected her to be flexible but had labelled both herself and her family. This led to a breakdown in communications with Ms Dixon misunderstanding why the team couldn't attend to more than one of the problems at one time that Zac was experiencing.

I told them I'm not going to come backwards and forwards to this hospital. And it made me feel bad because you know; it was like I was an irresponsible mother. That's how I felt. (Ms Dixon, mother)

The term 'chaos' became a short-hand term that several of the health team used when describing the family's living arrangements and lifestyle.

I get the feeling with Zac's mother that life is chaos and chaos is life in the family. (Doctor)

Arguably what was considered chaotic perhaps could be more accurately described as the total unpredictability of the HIV condition itself and the limited responses to working with the range of family types that are affected. Indeed, Ms Dixon's ability to run a household on an extremely limited income; a family that relied totally on her emotionally and physically to survive, including keeping herself well enough to take care of others, was far from disorganised. Yet, the health team did not make much effort to engage with the extended family and integrate them into a whole-of-family approach.

9.8 Interpreters and interpreting services

Language service provision is an intrinsic part of health care delivery for CALD communities in NSW hospitals. Through area health services, the NSW Health Care Interpreter Service (HCIS) provides both face-to-face, telephone interpreting services and less commonly, on-site videoconferencing to facilitate effective

communication between patients, their families and health care providers at a time when clear communication between all parties within the health encounter is essential. This is supplemented by a 7 days a week telephone service, The Commonwealth Translation and Interpreting Service (TIS). Survey results indicated that, out of the parents/carers who had had a child hospitalised at least overnight within the past three years (2003-2006), the majority of interpreting was conducted face-to-face and staff overwhelmingly preferred to use this rather than the TIS service.

As discussed, children are now living with some illnesses that used to carry higher mortality rates, which has resulted in their having ongoing clinical intervention in children's hospitals and eventual transitions to adult services. For children and their families from CALD backgrounds who require interpreters, while their long-term clinical needs might fluctuate, their requirements for language service provision may remain constant.

9.9 Policy

The policy on using interpreters with CALD communities is mandated by NSW Health (NSW Health, 2006). Staff at all levels – from nurses through to hospital managers – consistently reported that they were aware of the service, and that it was accessed and well utilised. One senior manager observed that the importance of using interpreters was often reinforced by stories about what happened when interpreters weren't effectively used.

The aim of interpreter services is to facilitate communication such that consultations between health care providers and families occur as if there were no language differences. This is based on the assumption expressed by a number of staff members that effective communication is based on literal translation. However, even with the use of the interpreting services, we found that families from CALD backgrounds continue to experience difficulties within the health service:

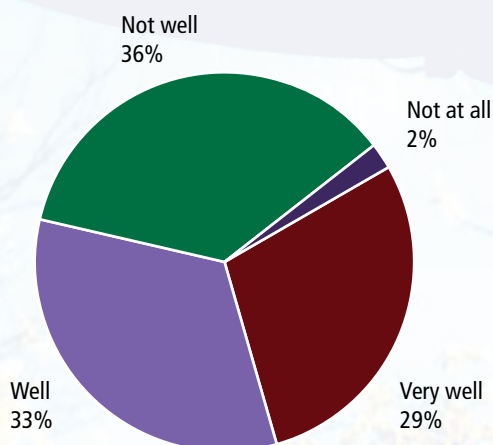
I think the parents whose first language is not English, or [if] they don't have a good command of English are perhaps not as well engaged in the partnership and care arrangements as they might otherwise be. (Senior Manager)

Effective communication between health teams and families may not only be premised on English language proficiency, but also relate to issues of health literacy. Survey results illustrated associated issues surrounding communication and language that were of concern for families. While 10.2% of English families had problems understanding medical words, 46.9% of parents/carers from the group whose primary language was other than English (CALD) indicated that this was a problem during their child's hospitalisation. These parents/carers had trouble understanding medical jargon, medical conditions and treatments, even with the use of interpreters.

I was a bit worried that because of my lack of English and poor understanding of [medical] terminology I couldn't communicate effectively with the doctor. (Chinese parent/carer, survey respondent)

Interpreters provided services for families with varying levels of English proficiency. Survey statistics indicated that among the CALD group slightly more than one third (37%) identified as poor English speakers who spoke English not well or not at all.

How well do you speak English? (n=181 CALD respondents)



Even those families who spoke English well could find their English language proficiency was compromised during times of stress. Having interpreters available helped to facilitate communication for all these families in their interactions with staff, especially within the context of large meetings (Karliner et al., 2007).

[For] most of the formal, family meetings I ask [the staff] if it's possible to arrange an interpreter because some of the medical terms and explanations I feel I'd better get clear ... I don't want to misunderstand all these things. (Mr Yeung, father)

Thus, it was clear that families whose first language was not English benefited from the services of professional interpreters during consultations and family meetings (Johnstone & Kanitsaki, 2008).

Families often struggle for words to describe what they're worried about for their child ... or what they're worried about for themselves. (Senior Manager)

This was echoed by survey responses where a number of parents/carers also identified difficulties expressing themselves in English. For other families, the problem sometimes lay with understanding Australian English; as one father observed, 'we can't understand accents and sometimes we miss important words; we can't understand the spoken English' (Mr Das). These difficulties in understanding due to accents and pronunciation may be partly overcome by families having access to written material, although the survey indicated that this information was overwhelmingly in English only. Despite this, respondents indicated that when they did have the opportunity to read written information, it was easier to understand the doctor's subsequent explanations.

9.10 Informal interpreting

Staff acknowledged that informal interpreting occurred between staff and families even though it was common knowledge that this was an inappropriate practice when communicating medical information. Health staff also expressed mixed understandings about the appropriate use of bilingual staff as interpreters within clinical contexts. The NSW Health policy directive explicitly states that while these staff can communicate directly with patients/families in the course of their own work they are not to be used as interpreters (Interpreters – Standard Procedure for Working with Health Care Interpreters, 2006).

While staff reported that the use of interpreters was 'ingrained into practice', policy requirements were sometimes 'pushed aside' – both in the case of emergencies where immediate communication was urgently required, as well as in longer-term care. Qualitative and quantitative findings identified continued use of family members as informal interpreters. This included partners as well as children:

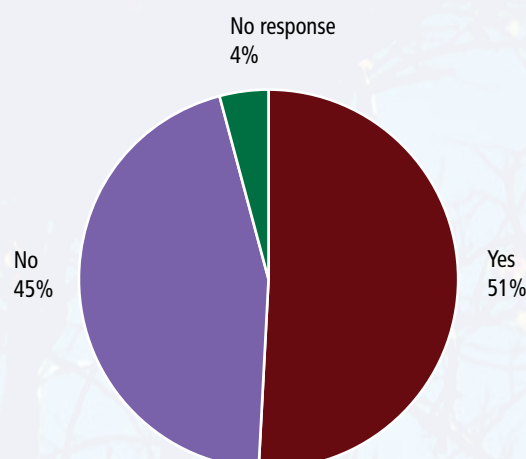
I can only speak limited English unless accompanied by my husband. (Vietnamese parent/carer, survey respondent)

My child was 15 when he fell ill, so most of the communication was done by my child who in turn translated it back to us [parents]. (Vietnamese parent/carer, survey respondent)

This was corroborated by survey findings where, out of half of those who had used an interpreter, 51% also had family or friends interpret medical information for them.



Have family or friends ever interpreted medical information for you in children's health services? (n=49 who had used a professional interpreter)



Within the children's hospitals, emergency departments were seen as 'high users' of interpreter services. Nevertheless, staff and/or other family members were reportedly often called upon to interpret, a consistent finding within similar research (Kazzi & Cooper, 2003). This can partly be explained by the fact that the parent/carer who comes to Emergency may be the primary carer who stays home and whose English is least competent. This was born out in our research and included the use of siblings:

Quite often, the younger members of the family are more fluent in English for emergency situations [but] we're not supposed to do it. (Senior Manager)

As acknowledged, this was despite knowing that using siblings was not a desirable practice as it adds to the sense of disempowerment and disequilibrium already being experienced by families in these situations. From a staff perspective, there is an element of expediency attached to using family as informal interpreters, while on the other side, some families do not necessarily identify their language as a problem, 'filling in the linguistic blanks' by using other family members (Chalmers & Allon, 2002).

There was not too much of a problem since my elder son was interpreting for me ... My child filled out the form with the doctor. (Korean parent/carer, survey respondent)

Previous research (Cohen et al., 1999; Heaney & Moreham, 2002) identified the potential dangers in the use of informal interpreters in hospitals, whether staff or families. It also contributes to an underestimation of the need for interpreter services. That is, informal interpreting is obviously not included in hospital figures which clearly identify the occasions of service and language delivery.

- For the 2006/2007 period at The Children's Hospital at Westmead, there were 18,495 occasions of service utilising the Health Care Interpreter Service (The Children's Hospital at Westmead, 2006). Of these, 2,285 (12.35%) were for inpatients, while 16,210 (87.65%) were for outpatient services. By far the majority of consultations were face-to-face 18,016 (97.41%). Figures given for unmet requests appear to relate to appointments that were unable to be met by the HCIS which numbered 33 (4.96%).

- For the 2006/2007 period at Sydney Children's Hospital, 2,291 occasions of service were recorded for health care interpreters, with 703 (30.68%) of those for inpatients and 1,141 (49.80%) recorded for outpatient consultations (Sydney Children's Hospital, 2007). Out of the total number, only 26 (1.13%) were recorded as using the HCIS by phone, while a further 300 utilised the Translation and Interpreting Service.
- The most common languages accessed across both hospitals were Arabic, Chinese (Mandarin and Cantonese) and Vietnamese, followed by Indonesian, Korean, Farsi, Tamil, Tagalog and Bengali. These languages correspond to those translated for the multi-lingual survey.

While there was no limit for families accessing interpreter services some staff were aware that the HCIS was 'expensive'. A senior manager remarked that it was policy for interpreter sessions to be offered at least daily to CALD families. However, the families of children who had extended hospital stays faced further language and communication barriers. Despite regular interpreting sessions which may occur daily, parents and carers could be present at their child's bedside for several hours every day.

In the case of Edmund's grandmother, she was a constant in his care for over one year. Yet both family and staff commented that there were limited opportunities for her to have meaningful communication because of language barriers, and that misunderstandings and miscommunication about the child's treatment had occurred. Staff and carers reported using non-verbal forms of communication including hand gestures, for example, pointing to a nappy when needed.

Even when interpreters are regularly used there are long periods during the day where CALD parents/carers such as Ms Chiu only had the odd chance exchanges with other Chinese speakers.

These encounters were extremely rare such as handover with Edmund's father in the afternoon and occasionally running into Chinese-speaking staff members. This linguistic isolation extends to CALD young people who may be hospitalised for lengthy periods.

Being in my room on my own for long periods could happen almost any time: morning, afternoon and at night ... When I was in my room I would feel I was alone, by myself, and so I would start to cry. (Omar)

Omar had poor English skills coupled with developmental issues which affected his ability to communicate effectively. Confined to his bed, as previously mentioned, he exhibited challenging behaviours to nursing staff and was accommodated in a single room, the door of which was reported to be frequently closed. Like many children he attended the hospital leisure centre, programmes and the school. Every evening he looked forward to ringing home, possibly the only communication that he experienced during the day in his own language. Thus, access to language services for socially isolated children and young people outside of formal health-related encounters is rare.

In some families it was reported that interpreter services were extensively used at the start of a child's hospitalisation or treatment, but these were reduced after a period of time.



The complex needs of hospitalised children may have initially required frequent team meetings with families, often on a weekly basis where interpreters were present. One staff member noted:

Very early on I spoke with Grandma with an interpreter and I said, 'At any time, if you would like us to speak with you with an interpreter, if you could point to a telephone and that would be the signal for us to contact a telephone interpreter [to] help [us] communicate. (Social Worker)

Towards the end of her grandson's extended hospital admission, staff continued to offer Ms Chiu interpreter services, but she declined. This may partly be due to difficulties with access to the service, or in this case, where a carer expressed a preference for another family member to interpret on her behalf. Sometimes parents/carers attempted to 'make do' with their own English skills. This was the case for Ms Allam, whose daughter had been coming in for renal treatment for nearly ten years, 'If the doctor speaks with me slowly, I will be able to understand, otherwise, no, I would need an interpreter' (Ms Allam, mother). However, while English language proficiency may have improved for some parents/carers – who may feel that they can communicate well – this view may not be shared by health staff who complained that they still faced difficulties:

And then Ms Allam got to the point where she basically refused to use the interpreter. She didn't need them anymore because she believed that she'd been to all these classes and she knows good English. (Social Worker)

While this mother attempted to communicate in English, the staff complained that they were often unable to comprehend what she was saying. This highlights the sensitivities attached to the use of interpreters where people do not want to appear to be needy or do not want to be seen to be asking for something extra (Chalmers & Allon, 2002).

Furthermore, interpreter services may not be part of a system to which some CALD families are accustomed. The system is based on providing equity within health provision that may be outside some CALD families' experiences and therefore they may feel being seen as 'different' may in fact disadvantage them.



9.11 The role of interpreters

The NSW Health policy states that interpreters work as members of the multidisciplinary health team. However, within the context of a clinical consultation, the role of the interpreter is somewhat ambiguous and is often represented as marginal to the communication process because they are part of an external service and represented as outside of the primary health interaction. Furthermore, with the often complex medical and socio-cultural backgrounds of the families we interviewed, simply acting as a 'voice-box' was inadequate to bridge the connections between cultural and linguistic barriers. Indeed, at times, the information and responses the interpreters translate have a substantial emotional impact and these situations in particular exemplify their inherent involvement in the communication process. For some, however, their access to debriefing, especially those on contract work, is limited.

Sometimes the interpreter breaks down and starts sobbing, because they're so caught up by the drama and the poignancy, or the sadness [of children's medical situations] ... or they identify with something some way ... I offer the person a little bit of sympathy and understanding, but that only makes them cry all the more! So they dry their eyes and blow their nose, and just about gallop out of the place! (Doctor)

We encountered interpreters with varying levels of experience, expertise and interpreting styles. According to the NSW Health policy, interpreters need to complete approved courses in medical terminology. However, staff recognised that interpreters may only have a limited knowledge of different conditions. In one case, a father complained that the interpreters were unable to provide accurate interpretations:

One or two times at the meetings the interpreter has tried to explain some of the words and I know they didn't get the real meaning because from a lot of the time I stayed with my son in ICU I have learned a lot of the terms. (Mr Yeung, father)

It is the role of health professionals, not interpreters, to communicate in a language that can be easily understood by both interpreters and families about diagnoses, treatment and care. However, in our observations of several interpreter/staff/family meetings the onus of deciphering and translating specialised medical knowledge was in fact placed on to the interpreter.

The experience of having people talk in another language together can be disempowering for those who do not share that language.

While some staff successfully engaged with interpreters to communicate, other staff complained that interpreters would sometimes speak at length with parents/carers and only interpret briefly in English. This led to suspicion on the part of some staff that not everything was being translated back to them, placing them at a disadvantage, with the associated feeling of disempowerment. This was articulated by a few staff members who felt that interpreters may be acting as 'amateur doctors' providing unwanted, extra information to families (Chalmers & Rosso-Buckton, 2007).



9.12 Access to interpreter services

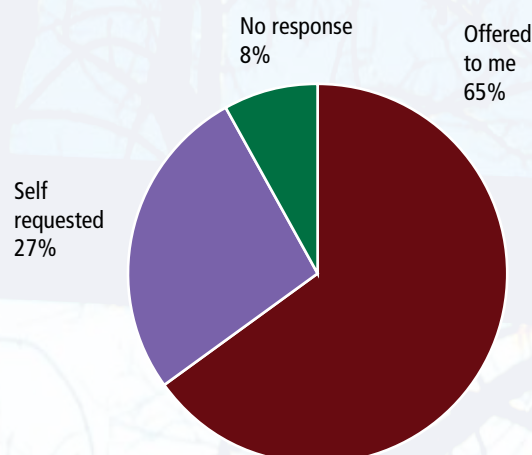
The consensus among staff was that the NSW HCIS provided an excellent service. However, staff expressed frustration around the service being 'too busy'. These access issues were also echoed by parents/carers:

English was a problem for me. When I used to ask for an interpreter, they weren't available at the required time. (Arabic parent/carer, survey respondent)

Findings from this study support earlier research in NSW children's hospitals which identified substantial concerns surrounding access and use of interpreters (Chalmers & Allon, 2002; Chalmers & Rosso-Buckton, 2007). This earlier research identified the following access barriers, for example inadequate advertising of interpreter services, appointment times that were inconvenient for staff or families, a high demand on certain language groups, insufficient interpreters for new and emerging community groups, issues of confidentiality with interpreters who were known within small communities, interpreters having recently migrated, and practical issues such as the use of speaker phones and the resulting lack of privacy for families.

The NSW Health policy directive states that people from CALD backgrounds must be offered the services of the HCIS at the initial point of contact. The survey indicated that 24.3% of parents/carers reported having used a professional health interpreter in a health setting. Most of these were poor English speakers. Out of these, 27% requested an interpreter while 65% had the service offered to them.

Was the interpreter service offered to you, or did you request the interpreter yourself? (n=49 who had used a professional interpreter)



Health workers and families also experienced time constraints on interpreting sessions because the session content was halved by the requirements of the interpreting process:

I don't have any longer appointments with [CALD families], and sometimes we have a shorter time because the interpreters are not booked for the same time that I see the family. (Doctor)

Appointments may start late or finish early for a number of reasons, including being booked elsewhere and the need to travel between appointments. These constraints led to practitioners prioritising the content and length of their communication and resulted in less time to closely acquaint themselves with families from CALD backgrounds.

One practitioner observed that, when working with children from English speaking families, she would offer more detailed clinical explanations. However, when using interpreters, due to time limits, this did not occur for CALD families:

I don't want to bombard [CALD families] with too much – with just words. And by the time you've said what you're going to say to the family and then it's been interpreted you want to get on to the next thing. You're conscious you've only got the interpreter for so long and you've only got so much time yourself. So, yes, you probably don't get the detail and hope that you're covering the broad concepts. (Occupational Therapist)

Interpreters were often called for sessions which involved multiple health practitioners utilising their services, either concurrently in team meetings or sequentially:

It's usually a special occasion when you get an interpreter, and everybody comes to see them and everything's all done at once because that's the only time you can get an interpreter. (Doctor)

While this practice may conform to HCIS policy (SWAHS Health Care Interpreter Service, 2006), the process has the potential to cause confusion and overload the young people and families with information. Furthermore, interpreters provide language services during such sessions, however there is a lot of information about clinical care that is supported and reinforced by other staff involved in a child's care outside of these clinical language 'intensives'. For English-speaking families, this information may easily be repeated by other staff and queries may be answered; families may be given further information or informal advice on how to administer care, and these are often times when health care messages are consolidated.

9.13 Interpreter service usage

Staff reported that interpreters were used in hospital with school-aged children but mostly with parents and carers. Nurses reportedly accessed telephone interpreters to communicate with parents on wards over practical issues associated with the daily care and treatment of children. In contrast, face-to-face interpreters were more commonly associated with consultations involving medical practitioners, clinics and health team/family meetings.

There were difficulties when interpreters worked with children who were compromised in their ability to communicate, for example through being developmentally delayed. Or, with adults who are either illiterate in their own language and/or unfamiliar with the conceptual basis of their child's illness and the functions and structures of Western health systems. The transmission and interpretation of complex medical knowledge may well be interpreted but may still not be understood:

I find that communicating with [Ms Allam] is almost impossible even when I have an interpreter there ... And I don't think that I've ever felt that I've actually ever communicated anything satisfactorily to her. (Doctor)

Understandings of illness and the body are culturally specific, learnt and picked up through everyday popular culture, formal education and experiences with health providers and health institutions. Interpreters were used by staff over a period of weeks to educate Omar's family about Western concepts of biology, physiology, disease and treatment – something the family had not encountered in their limited access to health care for their son. And, an understanding of these concepts had serious implications for Omar's physical condition and care. A range of staff spent many sessions instructing the family and repeating information in order for the family to understand, and interpreters were the lynchpin to them attaining and being able to use this knowledge.

The basis underlying Western medical history-taking, for which interpreter services are utilised, is also embedded in Western constructs and understandings about the self and communication. Discussing one's inner feelings, experiences of pain and discomfort (Lovering, 2006; Morris, 2001), likes and dislikes and needs for care may not come easily for those who may be more accustomed to describing their experiences less directly, or for those people who have recently experienced trauma. This is acknowledged indirectly within the policy which states that interpreting requires:

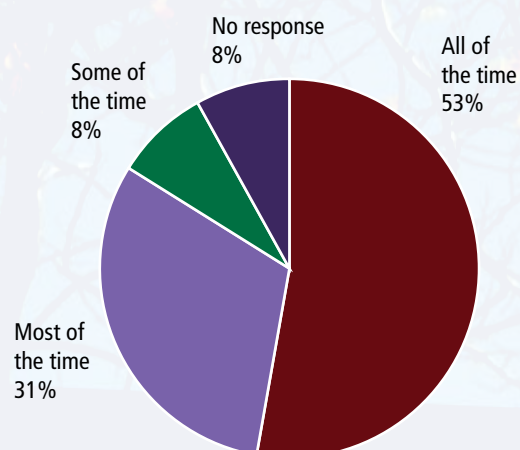
... a thorough knowledge of cultural differences, values and belief systems expressed through the use of language, as well as an understanding of the cultural contexts within which the health care provider and the patient/client interact. Accordingly, interpreters may be asked to provide specific culturally related information that is relevant to the clinical and social needs of patient care. (NSW Health, 2006)

One staff member described interpreting sessions as seamless when working with specific interpreters saying that it was like, 'talking to [the family] without somebody else being in the room [because] the interpreters are so good' (Doctor).

In contrast, several staff acknowledged that using interpreters was 'hard work', while still others stated that it was sometimes tempting to just talk to the interpreter instead of the family. Cross-talk by various health professionals in large family meetings meant that it was impossible for interpreters to communicate what was being said effectively.

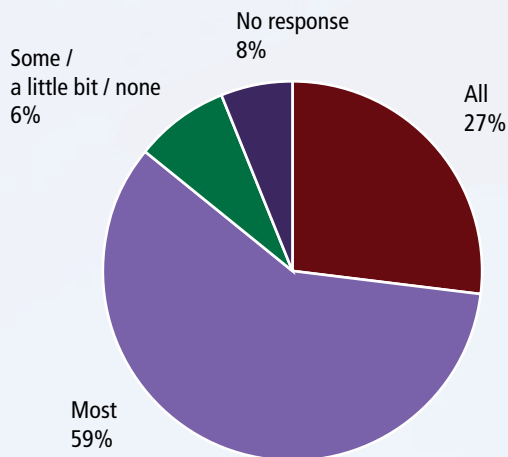
We found that health staff who spoke for long periods overwhelmed interpreters who then had to translate large chunks of medical information from hurriedly made notes or from memory, often unsuccessfully. Thus, the success or failure of an interpreted health encounter resides equally with the interpreter and health service provider. These concerns over the accuracy of interpreting is also reflected in the fact that 39% of survey respondents felt that everything they said was only 'most of the time' or 'some of the time' interpreted correctly.

Did you feel that everything you said was being interpreted correctly? (n=49 who had used a professional interpreter)



The potential implications of poor use of interpreter services are reflected in the results of the survey of parents/carers. Only 27% of respondents were able to recall all of what was said after the interpreter had gone, while 59.2% were able to recall most of what was said.

How much of what the health worker said were you able to recall after the interpreter had gone? (n=49 who had used a professional interpreter)



These figures raise serious concerns about the transmission and understanding of medical and other health information.

9.14 Other language and communication issues

The research highlighted instances where there were problems with linguistic diversity across broad communities. For example, the use of generic 'Arabic' interpreters was not always successful because the Arabic language can be broken down into specific but linguistically variable dialects such as Egyptian-Arabic, Lebanese-Arabic, or Iraqi-Arabic. A family who had been using the interpreter system for a number of years said that they initially had problems understanding and being understood when they used 'Arabic' interpreters but were now accustomed to the regional variations:

Although I had an interpreter, [they] were from Lebanon, and it's a different dialect from the Egyptian and from the Sudanese [which I'm familiar with]. Unfortunately there was some things I couldn't understand. [I couldn't even understand] the way to take the medication and these kinds of things. (Ms Allam, mother)

NSW HCIS staff worked across area health services at hospital and community locations and were not necessarily available to work consistently with specific families. When consistency did occur it was due to coincidence more than planning.

Every time a new interpreter comes in it's hard for me, because I have to explain the same thing [about my daughter's problem] to the [new] interpreter. (Ms Das, mother)

We also found that some young people responded positively and warmly when the interpreter was familiar to them, which enhanced the rapport of the health interaction overall.

Staff at both children's hospitals identified communication as one of the largest issues when dealing with CALD communities, while parents/carers surveyed indicated that understanding medical information was one of the greatest problems that they experienced. Interestingly, this latter concern was the case for both the CALD and the Anglo-Australian groups.

Communication across language barriers presented staff with specific challenges when caring for children and their families, challenges which were partially overcome through the use of interpreters. Problems around access and usage of the interpreter service continue to dominate their effectiveness and these concerns were especially highlighted for children and families from CALD backgrounds who had long-term or ongoing relationships with the hospital.

10. Concluding Comments

Multiculturalism consists of many different policies and practices. Attitudes and responses to each of these will depend on the ways they are experienced in particular contexts. (Ang et al., 2006: 68)

The challenge for senior managers in health organisations is to mediate and negotiate between the demands of the hospital, Area Health Services and the NSW Department of Health. They must provide vision, leadership and direction for staff (Lloyd, 1998) in addition to meeting ever-diminishing funding and staff shortages (Pollard & Metherell, 2007). At the same time, they are also required to achieve the organisational objectives such as ensuring better health of children, and maintaining excellence in child health care (Sydney Children's Hospital, 2007; The Children's Hospital at Westmead, 2004). One senior staff member explained the difficulties managers faced in just providing a basic service which tended to preclude a more concerted focus on diversity issues:

I don't think that people have it [cultural diversity] very high on their agendas. The issues that we're dealing with, particularly at the moment, are much more fundamental. It's like, where do we get the resources to provide the service that we think we should be providing; regardless of to whom we've got to provide it to? (Senior Manager)

Holding cultural diversity 'high on the agenda' suggests that it is an extra issue to be considered – separate from the main concerns of running a large urban tertiary institution.

This conception of both culture and diversity implies it exists as an aberration, needing 'special' consideration, a further burden or problem separated from mainstream health care. Such an approach continues to relegate cultural diversity to the periphery and in so doing disguises the ideological assumptions behind so-called 'mainstream policies' inherent in Western professional and institutional systems. Systems are of course necessary and funding and staff shortages are an enormous concern within the Australian health care system. However, there seems to be a disjuncture between managerial rhetoric and those that work with a multi-cultural clientele on a daily basis. Put simply, while equity across all communities appears to be central to the philosophy of both hospitals, the inclusion of diversity health care policies and practices has not attained the same level of significance within core business.

I am very conscious of the fact that what I say, how it's heard, how it's interpreted, depends not only on linguistic barriers but also cultural barriers in terms of how information is heard and interpreted. And I've long been conscious of the importance of that capacity to communicate across those barriers and how important it is sometimes to the survival of the child, let alone all the other quality aspects of care. (Senior Manager)

Individual champions do make a difference and they exist throughout both hospitals at all levels. The problem is, champions leave and diversity health workers tend to be part-time positions that require the on-going political will of state government funding. The way the hospital management responds to the lived reality of how cultural diversity plays out at the intersection of family and staff interactions significantly influences how seriously other staff take up the challenge. This involves commitment both at the hospital (little 'p' policy) and state (big 'P' policy) levels.

The results of both the quantitative and qualitative work clearly demonstrates that different levels of health literacy – both linguistic and cultural – are fundamental to the safety and quality of long-term health outcomes for all young people and their families, including those from CALD backgrounds. The empirical findings alongside an integrated discussion provides a strong evidence base that supports a philosophical and practical move away from policies that emphasise a dominant Anglo-mainstream perspective by which all ‘others’ are measured. This shift cannot occur or make a difference unless there are a new set of tools to accompany this re-conceptualisation.

The safety and quality of care issues that stimulate the need for this change have been amply demonstrated through the unpacking of the accounts that the families and staff have drawn on to make sense of their daily lives. In doing so, the findings draw attention to the complexity and the provisional nature of terms such as culture, diversity, multiculturalism and ethnicity as exclusive categories of analysis.



11. Recommendations for Policy and Practice

All the findings, evidence and suggested actions below point to the need for a conceptual shift within paediatric hospitals that locates diversity health care within core business. Cultural diversity is already embedded in Australian society and this shift would reflect the reality of the population demographics that this sector of the health care system services.

This change also demands a whole-of-organisation approach that integrates diversity health issues at multiple entry points as outlined below. Implementation of these actions could be linked to the Ethnic Affairs Priority Statement (EAPS), the Evaluation and Quality Improvement Program (EQuIP) as well as other safety and quality reporting mechanisms.

1 FINDING

- ▶ Consistent diversity health care training remains a challenge. Currently its application is uneven and often site-specific. Other than interpreter policies, there is little guidance for health providers in working with such a diverse constituency. This places a large responsibility onto health providers to respond at an individual level.

EVIDENCE

- International evidence (De Souza, 2008; Grant & Letzring, 2003; Johnstone & Kanitsaki, 2006; Mattie & Ben-Chitrit, 2007) has demonstrated that developing cultural competencies is a safety and quality issue that can reduce harm and ultimately save lives.
- The majority of hospital staff surveyed have a narrow understanding of 'ethnicity' as something that belongs to 'others'. Moreover, the notion of 'ethnicity' tends to be limited to non-English speakers and religious diversity.
- Very few staff have taken part in any diversity health training despite acknowledging the benefits this could bring to clinical practice.
- Lack of diversity health care training is an issue for all health service providers from management through to nurses and doctors. At present the focus seems to be on diversity health coordinators and social workers to engage with issues of diversity at the margins of the health care system.
- The existing knowledge about positive responses (and what doesn't work), that is, the collective knowledge of individuals, teams and management is not being retained or passed on to other health professionals.

ACTION

- ▶ Establish mandatory diversity health training at both children's hospitals.
- ▶ In consultation with the Transcultural and Multicultural Health Services, initiate, through joint leadership between the tertiary children's hospitals, the development of a diversity health training curricula that can be integrated into staff's professional development. This could be taken up by not only tertiary children's hospitals but also by paediatric wards within local and regional hospitals.
- ▶ This curricula needs to be tailored to the specificity of diverse professional groups, including those involved in administrative and clinical governance.
- ▶ Institutional knowledge needs to be embedded in and disseminated among all staff. Pilot a mentorship program among staff located within hospital wards/units that reinforce the significance and health implications of diversity health training and cultural competency in relation to safety, quality and equity.

2 FINDING

- ▶ Many children/young people, whether they be 1st, 2nd or 3rd generation CALD, inhabit a range of cultural worlds.

EVIDENCE

- Young people are often the cultural and linguistic conduits for their families, negotiating various systems, including health care. This can place an enormous amount of pressure on them while trying to deal with their own illness.
- Generational change does not equate with cutting off from one's cultural heritage, nor does it signify simply mirroring one's parents' cultural traditions. Rather, it often involves innovative forms of cultural hybridity that create new possibilities of 'belonging'.
- Children and young people generally do not want to appear different. They attempt to 'normalise' their lives within a range of contexts: school, family, peers as well as in relation to their health condition. Inhabiting different cultural spaces can be seen as both, a source of pride while at other times, disempowering. The common denominator to both these positions (and those in-between) is claiming a sense of 'belonging' and this is of course made more difficult because of their chronic conditions.
- The difficulty in collecting and documenting qualitative information from children and young people, especially those living with complex health conditions, cannot be underestimated. This research began to identify some of the issues and implications specific to a small group of 1st and 2nd generation CALD children and adolescents. The findings suggest that, for some of these young people, migration, language and cultural heritage in combination with other variables do have an impact on their long-term health outcomes.

ACTION

- ▶ While we now have a strong quantitative and qualitative evidence base that reflects the issues and concerns of parents/carers and health staff, the voices of young people from CALD backgrounds remain on the margins of health research. This can only be addressed with adequate funding, time to build relationships and specific expertise.

3 FINDING

- ▶ While health consumers are generally satisfied with the quality of health care provided, this does not necessarily indicate effective communication.

EVIDENCE

- The research demonstrated that families from CALD backgrounds were more hesitant to show dissatisfaction than Anglo-Australian families, suggesting they feel more powerless to articulate their concerns.
- The evidence (both quantitative and qualitative) suggested that while the health outcome may have been considered satisfactory, the process often did not allow for, or offer opportunities for expressing dissatisfaction.

ACTION

- ▶ Create culturally appropriate and sensitive feedback mechanisms to open up opportunities for families to express any potential concerns. This may need to occur after the immediacy of the initial diagnosis and may take the form of both formal and informal communication.
- ▶ In terms of informal feedback, the use of bilingual volunteers, work placements and an increased culturally diverse workforce would not only give these families an opportunity to articulate their concerns and daily pressures but also lessen the isolation that many of these children and families face within the hospital system.

- ▶ At a more formal level, brochures explaining children/young peoples and families' rights and obligations should be translated into selected languages. This material should also include reference to an independent arbitrator that can be accessed if a complaint cannot be resolved at the local level. This would be the Health Care Complaints Commission, or, the Ombudsman.
- ▶ There should also be an opportunity for staff to call on interpreters to elicit feedback from a young person or their family. The interpreter's ability to pick up on the nuances of the family's responses and the significance of the health information being imparted places them in a unique position to convey potential problems or concerns that the family may have, back to the staff member.
- ▶ In the case of chronic care, opportunities need to be built into the process of care giving that offers children/young people from CALD backgrounds the same opportunities that their parents have to express their opinions and concerns.
- ▶ All of the above need to be seen as enhancing excellence in the patient/family care process.

4 FINDING

- ▶ There are a number of false assumptions that circulate about the use of health care facilities by CALD families when accessing paediatric hospitals.

EVIDENCE

- Data revealed common myths such as CALD communities over-using tertiary paediatric hospitals, being late for appointments and/or exhibiting particular behaviours. These misconceptions tend to be based on a combination of individual experiences and negative media and political representations that are then extrapolated onto whole communities or ethno-specific groups.

ACTION

- ▶ There is a need for staff to be presented with evidence that shows that these generalisations are ill-informed. This misinformation can be countered through a training curriculum that demonstrates the reality based on population demographics. This information can also be disseminated through professional development initiatives such as the mentoring system.

5 FINDING

- ▶ The interpreter service is well-utilised and greatly appreciated by staff and families alike. However, issues concerning access, availability, use and quality of interpreters are compromising safety and quality of care. Furthermore, interpreters themselves are often confused about the extent of their roles.

EVIDENCE

- Comments on the availability of interpreters was evenly divided by those who were able to access interpreters regularly when needed and those who complained about waiting for days or weeks to access an interpreter. The former group however, did still have issues around the allocation of time even when they could gain access to an interpreter.
- There is substantial evidence that shows that there is some confusion and ambiguity, by interpreters and staff alike, about the role of interpreters in the communication process. Part of this confusion is staff's lack of training in how to use interpreters to gain optimal communication results.
- Reports of informal interpreting within medical contexts by family, friends and by the young patients themselves are still forthcoming.
- An unfair burden is placed on interpreters to decipher complicated medical terms into a form of English that they then need to convey to the young people and families in another language.

- Length of medical consultations with interpreters substantially reduced the depth and content of the interaction. This was due to the limited time that interpreters could participate in the consultation. In addition, the often inadequate allocation of time for interpreters also impacted on the lack of follow up consolidation of information.
- There were several occasions where different health professionals, for example, doctors and allied health workers, all vied for the interpreter's time, resulting in mixed outcomes.

ACTION

- ▶ NSW Health needs to re-examine the role of health interpreters and how effectively the interpreter service is operating specifically in relation to paediatric hospital health services in the current environment. Part of this evaluation needs to acknowledge and address the under-resourcing of this service. Both the role of and access to interpreters needs to be understood as integral parts of the quality assurance process within health care services and funded appropriately.
- ▶ As part of this re-examination the following are identified as possible options:
 - To increase availability of on-site interpreters to enhance accessibility in these hospitals.
 - To include interpreter training for all hospital staff in diversity health care curricula development, particularly in relation to children/young people's health conditions.
 - When not involved in formal interpreting sessions, interpreters could be employed to reinforce information given within the more formal 'medical' consultations. This is an area where most CALD families miss out.
- As noted earlier, interpreters' roles could be broadened to include their participation in quality assessment by facilitating an informal space for staff to communicate more openly with young people and their families. This may also work towards lessening some families' social and linguistic isolation.
- ▶ Staff need to book interpreters appropriately so that the aim of the session is clear for all those involved, including the interpreter. This means for example, family-health team meetings need to be planned carefully among staff so that an unfair burden of responsibility is not placed on the interpreter to negotiate among competing interests, all be they well-intentioned.
- ▶ Medical personnel in particular need to use language that interpreters, young people and families can understand in plain English. It is not up to the interpreter to translate twice: from staff into a simplified form and then into the community language.
- ▶ Accreditation of 'language aides', supported through training by the Multicultural Health Services can assist in more informal interactions. The effectiveness of such a system, however, depends on increasing the culturally diverse workforce within the hospital and health sector in general.

6 FINDING

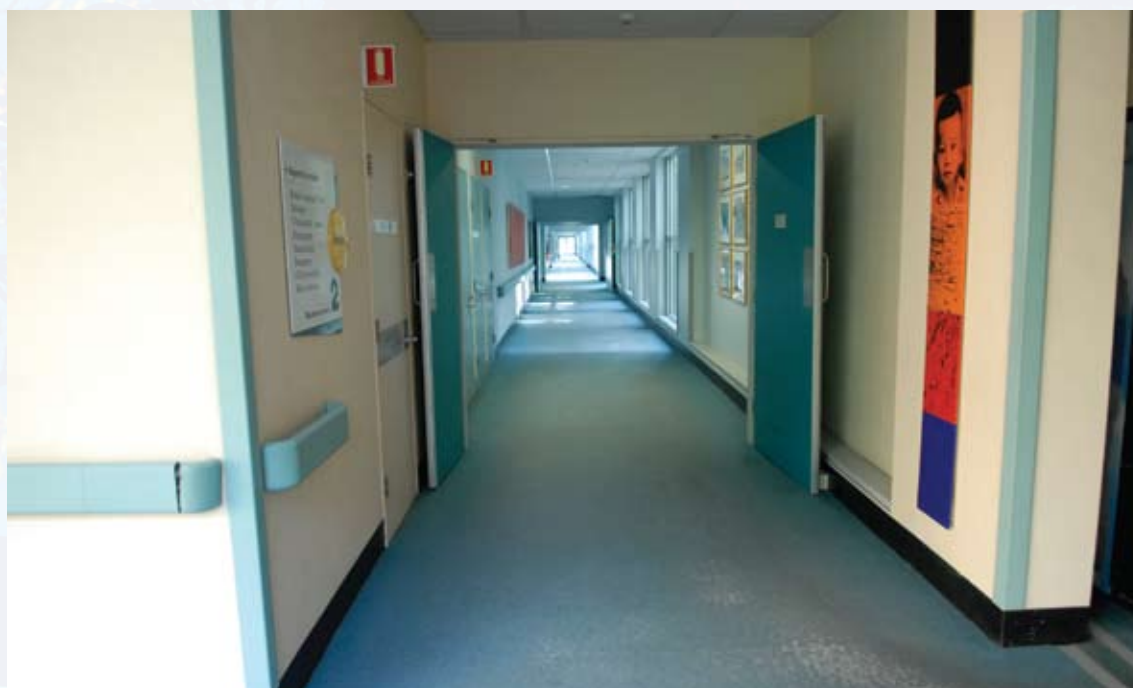
- ▶ Although there has been an increase in multilingual signage, further signs and written information is essential.

EVIDENCE

- Navigating the hospital is difficult not only for those who cannot read English but also for those who are illiterate.
- While there has been an increase in written information about common child-related health conditions, this is still minimal and there were calls for more of this translated material to be made available.

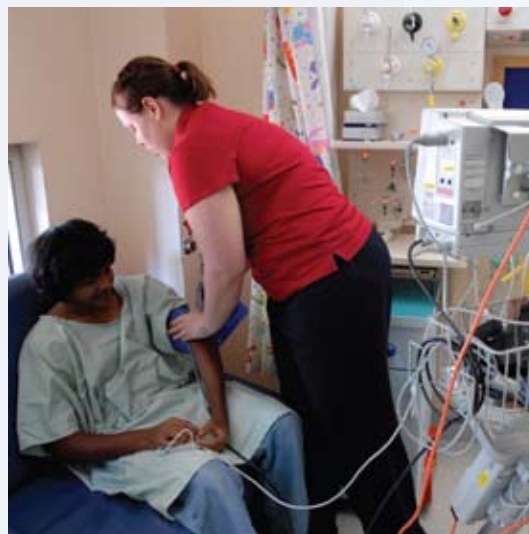
ACTION

- ▶ Providing universal signage, multilingual signs as well as maps in the major language groups. This would assist people in finding their way around in often stressful situations.
- ▶ Further translation of common child-related health conditions. Not only does written information provide a fundamental understanding for the family, but also gives them time to digest the basic information and then follow-up with relevant questions. This can be achieved through a consultative process between the hospitals and the Multicultural Health Communication Service.



7 FINDING

- ▶ The transition process from child to adult services is now recognised as a significant mainstream issue within paediatric health services and research. While there may be similar issues among all families, there also needs to be recognition of the differences among diverse family values and practices. The existing model of transition is premised on Western understandings of childhood, adolescence and adulthood which assume a move from family-centred to individual and independent care.



EVIDENCE

- Health teams placed a lot of emphasis on the transition process but did not seem aware of the potential differences among families. For example, the notion of 'care' is not necessarily based on individual self-management within a family but rather a whole-of-family approach.
- The meanings, values and practices attached to concepts such as 'childhood', 'adolescence', 'adulthood', 'parenting' and 'old age' are somewhat arbitrary as well as historically and culturally specific. For instance, when does childhood end and adulthood begin, or does it? Where does authority reside within the family and how does the process of decision making occur within different family structures? All these issues surfaced as potential impacts on the transition process but it appears little attention has been paid to these differences and the long-term impact on health care outcomes.
- The research also illustrated how young people inhabited and moved between different cultural contexts. The notion of family along with 'fitting in' with their friends was fundamental to their sense of 'belonging'. The above cultural differences notwithstanding, one cannot simply assume inter-generational sameness.

ACTION

- ▶ Hospital services need to provide culturally-relevant options for young people from CALD backgrounds who are undergoing transition to adult services. Rather than assuming the family will fit in with the Western model, models of transitioning may need to expand to take account of different ways of understanding family roles and the role of caring in different familial contexts.
- ▶ Hospitals may find utilising the expertise of Transcultural and/or Multicultural Health Services a valuable starting point from which to develop or draw on existing alternative models.

8 FINDING

- ▶ Children and young people with a chronic illness have more frequent contact with health services as they undergo long term treatment. For some families this created difficulties as they negotiated access to tertiary paediatric health services. This can have a disruptive effect on households who may already be under considerable stress.

EVIDENCE

- The research showed that families invested time, energy and personal resources in caring for their children who were undergoing long-term treatment. Parents/carers accompanied children to the hospital, often along with other siblings. Staff cited families being late for appointments as a problem, while families often complained of transport costs and travel times as issues of concern in meeting appointments.

ACTION

- ▶ Hospitals can assist families by providing flexible appointment systems that take into account the distances and frequency of travel involved.
- ▶ Shuttle services could be provided at bus/train interchanges to assist families with travel to the hospital.
- ▶ Where possible look for local solutions to accessing the tertiary hospitals. Alternatives might involve stronger communication and partnership arrangements between the hospitals and local general practitioners.

9 FINDING

- ▶ While not overt, some criticisms implied specific ethnic groups were associated with particular behaviours.

EVIDENCE

- Most health teams did their utmost to accommodate the pressures that families were under, yet there were still instances where staff slipped into moral/ethno-specific judgements about the involvement and kind of parenting that occurred. Judgemental remarks about adherence to medical advice and treatment plans, parenting practices including the kind and level of involvement in their child's care as well as visiting issues emerged.

ACTION

- ▶ As part of the diversity health training curricula, self-reflection on the different world-views individual staff bring to the workplace as well as the broader cultural implications of the system in which they work need to be unpacked. While staff may hold a range of divergent views, it is incumbent on health professionals to be non-judgemental in relation to young people and their family's life circumstances.

10 FINDING

- ▶ Culturally diverse populations are not accurately reflected in the data collected by children's hospitals which impacts on the demographic profile of users of the hospitals as well as affecting reliable estimates of interpreter need and utilisation.

EVIDENCE

- The research revealed that data collected on admission identifies the child's country of birth and as stated in 98-99% of cases this was Australia. The parents' country of birth is not always recorded hence, the child's cultural heritage and their family's cultural background may only be indirectly determined, for example, through interpreter use.
- There were further problems in accurately identifying culturally diverse parents/carers in the quantitative component because of the multiple indicators used to identify ethnicity.
- Even with the inclusion of 'parents' country of birth' there was evidence that this field would not necessarily reflect cultural heritage/background or language spoken at home. There are infinite examples of familial, linguistic and religious differences based on regional variation within one country let alone the increased transnational movement of people re-locating several times before settling in Australia.
- There is inconsistent documentation and auditing of data collected by admission staff.

ACTION

- ▶ This is a significant issue that needs to be addressed by NSW Health in the first instance and followed up by the hospitals to maintain more reliable documentation of hospital demographics.
- ▶ NSW Health needs to develop admission forms for tertiary paediatric hospitals and paediatric wards within local and regional hospitals to better reflect the cultural diversity of the populations they service. Admission forms should include: each parent's country of birth, child's country of birth, preferred language spoken at the hospital, and an ancestry field.
- ▶ The paediatric hospitals and other paediatric wards need to train in-take staff to collect this information and regular collection audits need to be implemented. This process can only occur with support and reinforcement by senior management.
- ▶ It is also recommended that this strategy be urgently considered and taken up by The Child and Youth Priority Improvement Taskforce.



11 FINDING

- ▶ Children/young people with chronic illness often have complex needs. This can be compounded for recent arrivals, particularly refugee families, or for those people who find themselves socially and economically isolated.

EVIDENCE

- Health staff tend to go to great lengths to coordinate services both within and outside the health sector. However, the speed and efficiency of providing relevant services is often dependent on finding 'the right' or 'helpful' person in another service.
- With the increase of refugees from emerging African and Middle-Eastern communities, it is probable that more children with chronic illness/injuries will present themselves at tertiary paediatric hospitals.

ACTION

- ▶ More effective coordination of health and associated services. A service directory could be compiled that included relevant government and non-government immigrant, refugee and social service providers and their specific roles.
- ▶ Establish a refugee children's network within the hospital that draws on the expertise and knowledge that already exists. This creates a focal point within the respective hospitals from which staff can access information that can enhance their understanding of how different refugee experiences may impact on young people and their families' health outcomes. Mentors could be actively involved in this program and be the link between the network and dissemination of refugee health information and resources throughout the wards/units.

12 FINDING

- ▶ It was reported that there were some problems which emerged from the hospitals' recruitment practices of filling shortfalls in medical and nursing positions with staff from overseas.

EVIDENCE

- Junior medical officers at SCH (50%) and at the CHW (30%) and nurses at SCH (60%) and at the CHW (4%) have been recruited from overseas to fill training and clinical positions.
- While overseas recruitment solved staff vacancies, there were issues emerging about some conflicts among staff in relation to settling into the Australian health care system, workplace issues, English language proficiency, racism towards staff recruited from non-English speaking backgrounds (NESB) as well as racism from Anglo-Australian families towards CALD health staff.
- There is a belief that there is great cultural diversity among hospital employees. However, it was observed that while diversity exists in certain employment categories such as junior medical officers and domestic services, this diversity was not necessarily reflected across other professional groups, especially management.
- The above finding was further reinforced by the interviews undertaken with both the health teams and the Executive members of the respective hospitals. Out of 41 individual staff interviews, only 5 people came from a non-English speaking background, and two of these were from a European background.

ACTION

- ▶ Provide supports for new overseas recruits and existing staff to integrate.
- ▶ Both hospitals need to pro-actively promote the benefits of a diverse workforce across all health professions and this needs to take place within a child and family-centred environment.
- ▶ In consultation with NSW Health and the Multicultural Health Services Managers Network the hospital leadership needs to actively develop policies that promote careers within the health professions among CALD communities and schools with high numbers of CALD pupils.



Glossary of terms

ARC	Australian Research Council
CALD	Culturally and Linguistically Diverse
CCR	Centre for Cultural Research
CHW	The Children's Hospital at Westmead
CSAHS	Central Sydney Area Health Service
DoCS	Department of Community Services
EAPS	Ethnic Affairs Priority Statement
EQulP	The Evaluation and Quality Improvement Program
GESCHN	Greater Eastern and Southern Child Health Network
GWS	Greater Western Sydney
HCIS	Health Care Interpreter Service
JMO	Junior Medical Officers
MHS	Multicultural Health Service
NESB	Non-English Speaking Background
SCH	Sydney Children's Hospital (at Randwick)
SESIAHS	South East Sydney and Illawarra Area Health Service
SJSC	Social Justice and Social Chance Research Centre
SPSS	Statistical Package for the Social Sciences
SSWAHS	Sydney South West Area Health Service
TIS	Translation and Interpreting Service (Telephone Interpreting)
UWS	University of Western Sydney
WSCHN	Western Sydney Child Health Network

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