'We All Come from Somewhere'
Cultural Diversity at
Sydney Children's Hospital

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Acknowledgments

Executive summary

We all come from somewhere was based on an innovative pilot project undertaken in collaboration with the Multicultural Health Unit (South East Health), the Centre for Cultural Research (University of Western Sydney) and the Sydney Children's Hospital (Randwick). The report examines how staff at Sydney Children's Hospital work with the notion of cultural diversity on a daily basis. We also ask whether the hospital, with its own set of cultural constructs, including professional and institutional cultures, manages or engages with issues of cultural diversity.

This report takes a cultural approach to health care. A cultural approach emphasises how our understandings of the everyday are formed within a broad cultural framework, one that is influenced by multiple factors such as gender, ethnicity, 'race', class, age and sexuality. In so doing, we present a more multi-faceted and complex understanding of the interface between multiple levels of health service provision and the needs and expectations of diverse individuals and communities.

The project documents through qualitative and quantitative research methods how different stakeholders who inhabit the hospital – staff and clients – perceived their own and each other's positions. Our first aim was to find out what, if any, were the major issues that clients from culturally diverse backgrounds faced when accessing a large, and often overwhelming, Western health care facility. And second, what were the major issues and strategies identified by hospital staff in their daily practices of offering health provision to a heterogenous population.

The detailed recommendations are intended to guide Sydney Children's Hospital toward a more inclusive and integrated approach to engaging with cultural diversity in health care provision. They cover four main areas including: interpreter and language issues; training and education; policy and guideline initiatives and joint initiatives (Sydney Children's Hospital and the Multicultural Health Unit).

1. Introduction

1.1 Background to the project

'We all come from somewhere' is a pilot research project jointly conceived by the Multicultural Health Unit (MCH Unit), South East Health (SEH) and the Centre for Cultural Research (CCR), University of Western Sydney (UWS). The project was further developed into a partnership research project with Sydney Children's Hospital (SCH), Randwick. It was conducted between November 2001 and April 2002.

1.2 Brief history of multicultural health care

Australia is one of the most culturally and linguistically diverse countries in the world. Two million people are from non-English speaking backgrounds and 13.9 per cent of the population speak a language other than English. In NSW, the figures are even higher, with 23 per cent of the population born overseas and 16.8 per cent who speak a language other than English.

The NSW Health Service has a statutory requirement to serve the population of the state in all its diversity. It is obliged by government policy and legislation to provide full and equal access to services, appropriate care, and interpreters when necessary. But who ensures that this occurs? Are health services meeting a fundamental obligation to guarantee that cultural diversity is reflected in the day-to-day operations of public health institutions, or do they merely pay lip-service to this concept?

NSW health services have made significant changes in their efforts to deliver culturally competent health care to a range of populations, for example, the increase, professionalisation and specific training of translators and interpreters working in the health sector.[1] These changes notwithstanding, anecdotal evidence suggests outstanding issues, often subtle, in the way cultural diversity is currently negotiated and practised across health care organisations and institutions.

1.3 Sydney Children's Hospital meets the challenge

Sydney Children's Hospital (SCH), Randwick is one of the two major Sydney children's hospitals, the other being the Children's Hospital at Westmead. The SCH is part of South East Health. Both hospitals specifically cater to the needs of child and adolescent health in NSW. They are also streamlined in terms of their expertise and offer services to clients from both within and outside of their respective area health service locales, including from intra- and inter-state as well as overseas clients.

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[1] According to the interpreter service, translation refers to written work while interpretation is oral.

According to 1996 Census data, almost one-third of residents in the South Eastern Area were born overseas and a quarter are from a non-English speaking background. This is a substantial growth compared with 1991 data. As such, cultural and linguistic diversity can no longer simply be seen as a 'minority issue' but rather as an integral part of the social and economic life of the Area. The task for South East Health – as for many other Area Health Services in NSW– is to adapt to this cultural change by developing practices of health care provision which are adequate and responsive to the diversity of its constituency.

While there is a growing body of literature on the relationship between health and cultural diversity its analysis is limited by methodology that tends to rely primarily on quantitative studies based on epidemiological and clinical trials around specific illnesses. Alternatively, research findings are predicated on evidence collected outside of the Australian context and applied without thought for its suitability. Given that Australia has very specific migration, settlement and indigenous histories, these overseas studies, mainly conducted in the US, have limited applicability. This has resulted in a general paucity of empirical or evidence-based research on how multicultural health initiatives in Australia are actually experienced in specific, concrete settings.

Sydney Children's Hospital has met this challenge by opening up its doors to allow an analysis of its structure and initiatives around cultural diversity training, education and practice. The staff has been overwhelmingly forthcoming and honest in their responses, and the clients (parents and carers of the ill children) have graciously given their time to participate in the project. Furthermore, the researchers found that overall the SCH staff show an openness to listen to and value the input of clients. It is also obvious from the experiences and stories that staff shared with the researchers, that they are more than prepared to reflect on their personal and work experiences in order to gain more detailed knowledge of the issues involved.

Increasing knowledge for health professionals, particularly in a hospital setting, is a challenge in itself for they must do this within the parameters of a health system that must already respond to demanding external political, bureaucratic and most significantly economic constraints. In addition, health workers are under considerable pressure to stay abreast of ever-changing research developments both in terms of utilising new technologies within clinical procedures while simultaneously keeping up with the 'cultural dimensions' of how these changes potentially impact on staff and clients alike. While notions of culture (see below) remain added on as one more skill to acquire rather than being automatically integrated in all guideline, policy and training considerations, staff cannot help but be daunted, indeed ambivalent about what is presented as an 'added burden' to their already stretched and busy work lives.

1.4 The aims of the project

- To find out what people from culturally diverse backgrounds think about the access and quality of health care at SCH;
- To discuss with hospital staff their ideas and opinions about 'cultural diversity' and how they might apply to their work practices;
- To ascertain how a range of hospital staff understand, negotiate and subsequently offer health services to a wide range of culturally diverse consumers;
- To collect Australian-based evidence from which to analyse specific concerns and develop recommendations for SCH that may be (partially) adapted to other hospital/health settings;
- To make recommendations to improve access and delivery of care to a heterogeneous public that uses SCH.

1.5 Something in the air: A cultural shift

There is a perceived need for greater understanding and assessment of the effectiveness of existing multicultural health policy initiatives and the ways cultural diversity is currently negotiated and practised within health care organisations.

This pilot project has been developed in response to questions about how cultural diversity initiatives operate on-the-ground. That is, to examine the interface at which culturally diverse clients (parents, carers and young patients) and the range of hospital staff/services meet.

1.5.1 From minority to mainstream

Until recently, multicultural, or 'ethnic' health policy and service development issues were in the main located at the margins of general health policy (Garrett & Lin 1990). Specific health needs were regarded as special measures required to address the disadvantages and so-called 'problems' faced by minority ethnic groups, particularly newly-arrived immigrants from non-English speaking backgrounds. This perspective can be summed up as a *problem-centred* approach, predominantly focusing on the difficult predicaments that individuals face and re-present as a result of their cultural background or 'migrant' status.

Subsequently, there has been a tendency to view and explain the behaviours of particular groups as associated with unique characteristics, risk-factors or 'pathologies'. This often results in a 'checklist' account of diversity where it is assumed that any member of an 'ethnic' or 'indigenous' community will behave in a fixed and static culturally determined manner. This perspective gives rise to one-dimensional stereotypes, or essentialism. Ethnic or indigenous identity is often essentialised when it is assumed that all people of a particular background will behave in a specific way across time and place, i.e. historically and geographically.

The 'problem-centred' approach also presupposes that 'culture' only applies to 'others', i.e. ethnic and indigenous traditions that differ from the dominant Anglo-Celtic 'white' culture. In other words, 'culture' is seen as something that 'other' people have and as a result is 'exoticised' as different from 'the norm'.

The norm is a taken-for-granted concept, one which by implication is universal and assumed to be outside of, or beyond, its own set of ideological practices and representations. The term 'ethnic identity' also conceals and homogenises the complexities of differentiated personal experiences. 'Ethnic identities,' while including cultural identity(s) are always enacted – more or less – in combination with other factors such as gender, sexuality, age, educational background and socio-economic circumstances. Moreover, while the terms 'culture' and 'ethnicity' are closely related, they are not equivalent. Ethnicity does not simply map directly onto culture, nor does shared ethnicity necessarily mean shared cultural practices. Similarly, the same country of origin does not necessarily mean the same cultural background, the same religion, or indeed, the same language.

> *Just because you can have five families who all come from the same cultural background, it doesn't mean all five are going to respond the same way from a cultural identity perspective to their child's illness. And we need to be aware of that. You can't assume that because one family responded to some things in this manner that all families from that cultural background are going to respond in that manner, because they don't.* (Social Worker)

Nevertheless, initially, ethno-specific programs such as language support and ethnic community liaison officers to overcome individual problems became the dominant themes in multicultural health. Concern focused around the obstacles that arose when people from diverse cultural backgrounds attempted to access a largely inflexible health system where generally language was identified as the major barrier to overcome.

Despite the importance of these responses to language barriers, which, according to our findings, still remain under-resourced, it became evident that these strategies were having a limited influence on mainstream health organisational policy and planning. For SEH, along with other providers, it became clear that different approaches were needed. Rather than focusing on the cultural backgrounds and languages of the clients as the source of the difficulties, more attention needed to be directed to the development of strategies around structural inequalities such as access and equity issues and practitioner competency skills. The disadvantages and inequities that particular culturally diverse groups – especially new migrants – face when seeking health care, are not the *result* or *consequence* of ethnicity but rather are part of a socio-cultural relationship *between* diverse groups of consumers and the various health systems in place, including hospitals.

You've got a society that we are serving as a public institution, and the society has certain characteristics, diversity is part and parcel of it, there's no such thing as minority/majority. If we all have equal rights, then the whole argument of ethnic minorities and Anglo majorities becomes a totally redundant concept. And what we need to look at is that the entire society needs to understand each other in the context of health care. (Multicultural Health Unit)

The Service's explicit commitment to multicultural health as a mainstream, not a marginal concern, is an important step in ensuring that cultural diversity is taken as a fundamental aspect of today's society. This requires a significant cultural shift in the mindset of all stakeholders – both in relation to health service provision and what clients can expect. Nor is this shift simply about increasing resources, rather it is equally important to effectively utilise and focus on the 'social capital' and knowledge base that exists. But as this report will illustrate this tends to be based on individual good-will and is thus ad-hoc at best. To achieve its goal, cultural diversity needs to be seen as a naturalised principle or philosophy – in policy as well as in the day-to-day practice of health care delivery.

The mainstreaming of multicultural health issues means that diversity is taken as the norm – a fact of (everybody's) life and daily interactions – whether that be in the work-place, as a consumer, in sports, recreation and so forth.

Unfortunately, these lived realities notwithstanding, the push for such a philosophical shift is often antithetical in the present political climate to populist decision-making that still takes the white, middle-class, Anglo-Celtic nuclear family as the norm by which all others are measured. Nevertheless, an open-window does exist for this shift and it is a critical one if health services are serious about engaging with difference rather than simply 'managing problems' with in-difference.

1.6 Cultural research in health care

1.6.1 What is a cultural approach?

Cultural research defines culture as a broad process whereby social meanings are created, and where our sense of who we are, how we want to be perceived and how others perceive us (identities and subjectivities) are produced. This is through complex social, economic, political, material and psycho-social actions, representations and interventions which are intimately linked to a diversity of factors such as class, ethnicity, race, gender, sexuality and age. How any of these sets of inter-relationships occur need to be explored within specific historical contexts.

Cultural research adopts a definition of culture as something that is multi-faceted, fluid and changing. In the words of John Frow and Meaghan Morris,

'culture' is a term that can designate, … the 'whole way of life' of a social group, as it is structured by representations and by power … It is a network of representations – texts, images, talk, codes of behaviour, and the narrative structures organising these – which shapes every aspect of social life. (1993)

As a particular research method, cultural research is committed to active interventions to make cultural life more democratic or at least to open up conversations with multiple voices and realities. Cultural research uses an interdisciplinary approach to analyse and interpret how culture works by studying the complex relationships between social structures and individual lived experiences. This approach acknowledges, as one hospital staff member stated, that 'we all come from somewhere' and that whether we are health consumers, service providers or cultural researchers our daily experiences are porous and provisional, constantly re-negotiated by ourselves and others in everyday contexts (Featherstone 1995).

1.6.2 A cultural approach to health care

The literature reviewed has shown a paucity of research and analysis on the cultural dimensions of on-the-ground health care policy implementation. However, this research will not focus on the epidemiological or psychological makeup of specific illnesses in relation to particular culturally diverse groups, for example, the impact of smoking or drinking among one cultural group or another. And, it also represents a significant departure from previous studies in that it is not based on a statistical or demographic analysis. Rather, this project aims to document and understand how cultural diversity actually affects the relationships between hospital-based health care professionals and clients, specifically in the context of providing health care to children from a wide variety of cultural, linguistic and religious backgrounds. By emphasising the cultural dimensions of the interactions between staff and clients, we mean to explore the range of values and belief systems, practices and understandings about health, illness, the body and well-being that exist in Australia's multicultural society.

In short, this report investigates how
- cultural diversity operates 'on the ground' within a specific hospital culture and,
- how this impacts on health care provision.

The importance of this cultural dimension is stated specifically in the Introduction of the SEH Service's 1998 EAPS document:

> *Not withstanding the progress made to date in Multicultural Health, health services may **unknowingly** produce barriers for people of culturally and linguistically diverse backgrounds.* (emphasis added)

Therefore, within the field of health, there seems a need for a more complicated view of culture, and a better understanding of how terms such as 'ethnicity' and 'identity' are played out on the micro-level. As Gui-Young Hong argues, 'despite the rhetoric promoting sensitivity and cultural competence in managing culturally diverse clients, the concept of "culture" has largely been excluded' from much health services research. Hong's conclusion is that health services have been paying 'insufficient attention to culture.'

If the primary goal of services research is to provide useful and effective information for service providers, clients, and policy makers, it is not enough to simply examine the set of cultural values and beliefs shared by the majority of members of a racial, ethnic, or linguistic group. It is not sufficient to show whether racial, ethnic, or linguistic matching of providers and clients is better than non-matching. Services research needs to expand extant conceptions of culture by explicitly delineating whether and how the clients' personal cultures and their collective cultures differ (or are similar) in their perspectives on health, illness, and care. It also needs to elaborate on how service provision contexts – where multiple cultures and multiple system levels intersect – impact the accessibility, affordability, continuity of care, treatment, as well as treatment outcomes for both groups and individuals. (Hong 2001: 3)

It is imperative that research addresses both professional and organisational cultures and not just the interpersonal, intercultural interactions between providers and clients. This broader *cultural* perspective enables a consideration of the interfaces between multiple personal, professional, and organisational cultures found within the health system. Furthermore, qualitative methods afford researchers better opportunities to describe these multiple cultures and the interfaces between them.

1.6.3 The ambivalence of cultural identity

Identity is a fluid and shifting term. It refers to the subjective ways we think about ourselves as well as the ways we define our shared understandings of belonging to particular groups, for example, cultural background. However, identity is also dependent on others' conceptions and representations. Therefore, cultural identity can produce both positive forms of self-identification as well as generate negative stereotypes as seen with the recent demonisation of particular cultural groups.

We adopt the approach that cultural identity is constantly 'under construction' or always in the process of 'becoming'. That is, identities are neither natural nor fixed, neither unified nor singular across time or place. Indeed, identities can be read as taking on strategic qualities. For example, it may be beneficial or empowering to identify with one group of people in one context while unnecessary or disabling at other times. In other words, identities are constituted by multiple factors that take on different meanings in particular contexts.

1.6.4 A conceptual shift

This report will argue that:
1. If we accept that culture is *embodied* and central to the ways we understand concepts of well-being, health and illness, it follows that culture should also be significant in all areas of health care provision.

2. We need to be wary of attempts to reify culture, that is, to see it as a unified or unchanging 'thing'; rather it may be more useful to conceptualise it as an open-ended process. Therefore, one of the major shifts is thinking beyond essentialist or reductionist models of 'culture' as fixed and static entities shared by all people from the same cultural background.

3. An organisational openness to diversity, in all its forms, means a qualitative change in the *culture* of health care. This involves a reconsideration and critical reflection of the values, beliefs and experiences that all stakeholders – including professional and institutional – bring to the practice of health care provision. This will be a slow and long-term process. However, it is a fundamental step if health services are going to *engage with* rather than simply *manage* the needs of their hospital clients, which will hopefully have other positive flow-on effects for both staff and clients.

4. The theoretical concepts and a stronger emphasis on qualitative methodologies that cultural research draws on to explain the complexity of contemporary socio-cultural experiences may assist movement beyond the limitations of much previous work in the area of multicultural health.

1.7 Methodology

The research employed both a quantitative and qualitative component. It included:

1. An oral, tape-recorded survey/questionnaire with parents/carers of the children (both in-patients and out-patients). (50)

2. A written survey/questionnaire with a range of hospital health workers: nurses (RNs [registered nurses], NUMs [nurse unit managers] and CNCs [clinical nurse consultants]), doctors (junior and senior), physiotherapists, occupational therapists, social workers, dietitians, pain management specialists, interpreters, Multicultural Health Unit staff, child protection workers, social workers, ward clerks, senior management staff, Access and Equity Committee members and hospital clergy. (78 returned)

3. Semi-structured informal in-depth interviews with a cross-section of hospital and SEH staff. (30)

1.7.1 Client survey/questionnaire interviews (taped)

Initially the researchers approached the Nurse Unit Managers (NUM) to identify patients and their families from culturally diverse backgrounds. While most nurses were obliging, they often weren't sure of what the researchers meant by 'culturally diverse' and tended to draw our attention to the most obvious families, i.e. those who did not speak English at all. On the advice of a ward clerk we changed strategies and went straight to Admissions where we were able to access daily records, which listed language spoken at home and religion. With this information in hand we went to the wards and checked with nursing staff if those families were available and, if so, if it was appropriate for us to approach them.

All of the parents/carers, except for one, agreed to take part in the research. Indeed, in general the people we spoke with were almost glad to be distracted from their child's illness and/or have an opportunity to articulate their feelings whether they be simply expressing their emotions at having a sick child, or in some cases voicing their appreciation or dissatisfaction about the level of health services offered.

To some extent we were limited in talking to parents by the logistics of the hospital setting. In most cases the researchers undertook the oral questionnaires with the parent at the child's bedside. Naturally, most did not want to leave their sick child alone, although a few who had other children or visitors present sometimes suggested going into the parents' room for more privacy. However, most oral questionnaire/surveys took place in the hospital ward. Often other children were crying. Sometimes the fact that attention was taken away from the child and focused on the parent we were talking with caused a child to demand more attention and sometimes they or other siblings present became restless or started crying.

Noise from the ward was at times distracting while in other situations, because children had to go to other parts of the hospital for tests, interviews were either interrupted or concluded prematurely. The result was that despite all the good will, parents/carers did not have the opportunity to think about and reflect on their experiences in the same way that staff did. Nevertheless, parents were usually very happy to take part in the interviews and under difficult circumstances graciously gave up their time and energy to the research project.

In general the oral (taped) survey/questionnaires carried out with clients were on average 20 minutes long and after completing several of these, the researchers felt there was enough information gathered to understand a number of significant issues dealt with by the clients without undertaking longer interviews. While some staff drew attention to the potential power differentials in place for clients if interviewed in the hospital, for example, would what they tell us affect their child's health care – and we acknowledge that this is an issue – time was also a constraint. In addition, given the relatively short stays of the children at SCH, it would have been quite difficult, within the time frame of the research project, to access and gain approval from clients to interview them outside of the hospital setting. Therefore, the client's views need to be understood and interpreted within this limiting context. (See Appendix 1: Survey/questionnaire for clients)

1.7.2 Staff survey/questionnaire interviews (written)

Once the client survey/questionnaires were near completion we moved on to the second stage, which was to canvass the general views of a range of hospital staff. Initially we hoped to attract staff to come to us to fill in the survey/questionnaires – but given the workload of staff, in hindsight, this was an unrealistic expectation. Therefore, we changed strategy and visited all wards (covering morning and afternoon shifts), explained the research and requested anonymous participation.

We placed a box in each ward where completed surveys were to be left and we collected these weekly over three weeks. In addition, with the assistance of the Diversity Health Coordinator, we arranged to address as many professional team meetings as possible where we also gave out the surveys. Out of 130 surveys distributed, we received 78 back, a 60 per cent return rate. Issues raised from the staff survey/questionnaires will be discussed in detail below but the general responses to participating were fairly predictable ranging from enthusiasm to complete disinterest. (See Appendix 2: Hospital staff survey/questionnaire)

1.7.3 Staff in-depth interviews (taped)

Over a four-week period, from the beginning of February to mid-March 2002 we carried out 30 in-depth semi-structured open-ended interviews. From looking through both the client and staff survey/questionnaires we identified the major issues raised and used these as a guide for the interviews. As mentioned above, the interviews were undertaken with a range of health professionals at the hospital and also included workers from South East Health Services who worked with the hospital on cultural diversity, access and equity issues.

In contrast to the client surveys-cum-mini-interviews, the in-depth interviews all took place in private offices for confidentiality. Interruptions did occasionally occur but were mostly minimised through staff effort. The interviews were approximately 45 minutes long and they were taped.

1.7.4 Methodological considerations

Undertaking a qualitative approach drew attention to a number of specific factors that large quantitative studies can obscure. These included:

1. *SCH is extremely busy.* Staff are on the go constantly and there are often staff shortages. Children and parents are often going to different places around the hospital to have various tests, both are often distraught or feeling vulnerable, so there are times when it was not appropriate to talk with them. The researchers had to gauge each situation and we often checked with staff to find out specific circumstances and respond accordingly.

2. *Undertaking research on cultural diversity in a children's hospital* in contrast to an adult hospital presented its own set of unique characteristics. These were both observed by the researchers and commented on by both clients and staff:

- Hospital staff are empathetic to and displayed overt physical affection, particularly to very young children, as part of their daily work practices. It was not unusual to walk into a ward and see staff cuddling and soothing children when they were upset, lonely or bored. This is obviously a very different relationship to that of working with adult patients.
- Children are extremely vulnerable and are generally dependent on adults for decisions about treatment.

- Parents felt vulnerable as it is usually they who have control over their children's lives and in a hospital this control is to a large extent taken away often leaving family, especially parents, feeling extremely helpless. This is made more difficult by the fact that the children turn to parents for explanations and emotional reinforcement in situations when parents/carers themselves are struggling to understand what is going on and they (parents) cannot always adequately respond. These feelings are further exacerbated by other communication barriers.

- As a result of the latter, parents are more likely to try and regain some control and are reasonably assertive in expressing their views. While the issue of being seen as a 'troublemaker' when being assertive did surface, staff seemed to be more willing to listen to parents/carers concerns than if it was a family member of an adult patient.

3. *Timing of the research.* The empirical research component was primarily undertaken from the beginning of December 2001 to mid-March 2002. This was the Christmas/New Year Period and as such the combination of working with children, the partial and full closure of some wards for 2-3 weeks, the fact that staff were looking forward to taking some time off after a busy and demanding year along with the festive holiday atmosphere of the wards all worked towards creating a more relaxed environment than would have been found in the middle of winter or in a general adult ward.

4. *Accessing interpreters.* Initially there were some problems with accessing interpreters for the project, which resulted in occasions when we could not speak with clients who did not speak English. After discussing the situation with the head of the interpreter service, we were able to resolve these problems. Nevertheless, if as researchers we were having problems with access, we wondered how staff and clients who did not have the same institutional connections fared.

5. *The quantitative component* was used with the specific objective of collecting information fairly quickly in order to identify the issues in health service delivery to culturally diverse clients (parents, carers and patients). As this was a pilot project we were cognisant of the fact that time was of the essence and that we needed to initially at least employ an expedient method to canvass a range of issues. The oral survey/questionnaires were then to be followed up with longer semi-structured interviews with both clients and staff. As noted earlier, however, in-depth interviews were only carried out with hospital staff, which once begun, increased from the original planned 15 to a total of 30 staff interviews.

2. Interviews with Parents and Carers

2.1 Making cultural diversity visible

In this section we explore first, the ways in which clients (parents/carers) conceived of and expressed their cultural identities and second, how they felt hospital staff responded to them. In so doing we examine to what extent clients were free to express a range of cultural identities. We were also interested to find out if some expressions of cultural diversity were seen as legitimate while others were not, for it has been noted that during times of illness cultural traditions may be drawn upon as an important resource for identity and self-definition (O'Callaghan 1998). And finally, by talking with parents/carers directly we were able to identify significant issues from their perspective which served a dual purpose. First, it recognises and validates the experiences of health consumers and their ability to articulate their opinions and concerns. And, second, by acknowledging this expertise and listening to their responses, our discussions with hospital staff were better informed.

The interviews with parents/carers were conducted from December 2001 into January 2002 at a time when Christmas and (Christian) New Year festivities were in full swing. For one Jewish parent, the most obvious and problematic site for the lack of religious diversity was the hospital school, which her adolescent daughter attended:

> *Because the teachers are ethnically, are culturally Christian-oriented the assumption at this time of the year is that everyone has Christmas. They cannot believe, they think there is something fundamentally wrong if you say that Christmas is not the least bit relevant at all … so they don't understand that Christmas is totally irrelevant to our family.* (Jewish parent)

This parent then recounted how her daughter introduced Jewish practices and educational activities into the school, in effect, 'transforming the activities from a Christmas programme to a multicultural programme':

> *There have been a number of Jewish kids enrolled with [my daughter] in the school where she's been able to change it from a Christmas programme to a multicultural programme … so, my daughter had [done] a whole lot of things like word searches, and taught the other kids about Chanukah … But if [my daughter] hadn't been there doing it, it wouldn't have been done, and these kids would have been extremely isolated.* (Jewish parent)

For this parent and her daughter, the mono-cultural character of the hospital led to an active assertion of their [Jewish] cultural practices and made them visible. This, in turn, also had positive consequences for other patients and their families.

Another Jewish parent told us how her son had attended the school and how she was pleasantly surprised to find activities relevant to his religious practices:

> *When the other kids were doing Christmas craft, [my son] has been doing Chanukah things. There was an older girl there who's a Jewish girl but who's in the hospital, and she's been helping out, and so I think she's tried to do some Jewish craft for [my son], so that was really nice. I was actually surprised. I didn't expect to find that.* (Jewish parent)

In this case it was the patient, the teenage girl, rather than the teaching staff, who initiated a supportive religious/cultural atmosphere for the other Jewish children attending the school. Whether the teachers learn from this experience and open up a space for children to practice and learn about a variety of cultural and spiritual traditions will be interesting to follow up on.

Other parents/carers also told us that on admission to the hospital they were asked about their religious background, and that 'a box was ticked', but that this didn't lead to any further discussion about possible requirements. Yet, as one Jewish mother explained, for her, questions about religion and cultural background are inextricably entwined:

> *But we, I would say, when you ask a question about cultural background – it's the same thing. Judaism's both religion and culture. So it's both ethnic and religious, if that makes sense.* (Jewish parent)

Another orthodox Jewish parent explained that rituals, such as Shabbat, seemed to be difficult to negotiate within the hospital wards:

> *The first two weeks he was here, we were here on Shabbes for three weekends, and what happens is that the adolescent ward closes at Shabbes … So, anyway, it was a problem because, first of all, I mean, obviously, [the patient] couldn't watch television … there were lots of other things he couldn't do, painting and drawing and things like that, at Shabbes. None of our family were able to come and visit us, so we were really on our own all day, and there was no school that day. It was like a very long day! And all the other kids had their televisions on, so we had to keep the curtains closed for most of the day which was awful.* (Jewish parent)

A number of clients also commented that they would like to have seen a religious or spiritual adviser, but that they did not know about the Chaplaincy Service nor had they been offered the service. In contrast to the parents above who were native English speakers, there were other parents who had only rudimentary English language skills and expressed their discomfort about asking for such services, at times feeling somewhat overwhelmed by the hospital system. They also suggested that they did not want to appear demanding or to be seen as causing 'trouble'. As one parent from a Korean background explained:

For example, in our country, in hospital there are people from most religions, most Ministers of religion, they have Ministers in hospital so they can come and pray and visit and help and talk to our family, and sometimes we can go to the services and meet with Minister, and they also look after and pray for our family. That kind of system would be good. (Korean parent)

The Hospital's Chaplaincy Service offers religious guidance across Jewish and most Christian denominations, yet this parent was not made aware of the service. Although we interviewed two Chaplains, it is still unclear exactly how spiritual advisers make contact with patients and their carers, and how this communication is organised. While the Chaplaincy Service is extremely committed to providing pastoral care through visiting the wards, perhaps better communication channels need to be established between hospital admissions, the wards and the Chaplaincy Service. There is also an obvious gap in that religious/spiritual advisers outside of Judaism and Christianity are not readily accessible. This issue is addressed in more detail in the hospital staff section.

2.2 'I'm not really into this "culture" thing'

While some parent/carers felt that their cultural background was extremely significant and needed to be considered in relation to their health care, others strongly asserted that their cultural practices and background were irrelevant. In fact, several parents/carers commented that staff did not need to know about their cultural practices, religion or cultural background because their children were *patients* now. For these parents being a 'patient' meant relinquishing the rights of cultural expression and individuality, and conforming to the assumed 'level playing field' or so-called neutral culture of the hospital.

For example, when asking a Chinese-Indonesian family, whose child had been in the hospital for a three-month stay for Leukaemia treatment, whether the hospital staff had asked them if cultural issues needed to be considered, they adamantly responded:

No. Some of the doctors ask, but in general they don't really. They don't relate anything to our background ... No. No, it's not important. We're just like the other patients. It doesn't make any difference if we're Indonesian or not. They treat us the same. So, we don't really need to discuss or talk about or think about our background ... (Chinese-Indonesian parent)

It is interesting here that cultural difference is seen as an attribute that is 'special', and that 'special' equates with some kind of 'problem'. There is also an insistence on being or appearing to be the same and a reluctance to be identified as 'different' in any way; '*we do things the same way like you*'. This 'norm', this 'you', is often referred to as 'the Australian way' and is implicitly measured in terms of difference from the Western Anglo-European status quo.

> *My children are raised the Australian way, so a lot of things the Australians do we do. So when I come here, it's no different to an Australian person coming here.* (Macedonian Orthodox parent)

One parent from a Lebanese background (and whose partner and parents are also Lebanese) was eager to stress her 'Australianness':

> *Like, basically I'm Australian … Like, I've been brought up here. Not in Lebanon or anywhere … There's no custom or anything. Even my parents … you eat the same food, you know you're not different to anyone.* (Lebanese parent)

This was similar to comments made by a parent from a Bangladeshi background:

> *Actually I am not interested in cultural background. I am not particularly concerned with background. Because in Australia, everything is possible here … I believe in diversity. We are [all] from diverse backgrounds, diverse culture, background. But we need to be flexible.* (Bangladeshi parent)

In the above narratives there are obvious contradictions between wanting to appear 'Australian' and a fusion of diverse cultural practices. Cultural practices and identities are always under negotiation and contestation whether that is in the home space, community settings or a hospital, and in daily life these contradictions are more often the norm than the exception. As such, it was not unusual to come across situations where families, while strongly asserting their successful assimilation into an 'Australian way of life', were, for instance, sharing a variety of food among a large group of family members while explaining particular cultural practices and customs in a mixture of Lebanese and English. Yet, this reservation to focus on 'culture' by clients pervaded many of the interviews. On asking a Lebanese family whether they saw any value in staff raising particular issues about their cultural background, the uncle, who acted as interpreter for the family responded:

> *They're more than welcome to ask about anything they like, about Australia – how we are in Australia, where we come from, why we left Lebanon … Our life in Lebanon … it's the same for us.* (Lebanese carer)

Yet, as the interview continued the importance of the everyday role of the extended family as a common Lebanese familial structure was revealed.

> *But our culture, the Lebanese people – especially the Lebanese – we have, in the family, too much love. We take care of ourselves in the family – like, she's my sister. I am her brother. We all connect as one. If one of us sick, we come all to the hospital. We all care for each other.* (Lebanese carer)

During this conversation, some food was passed around the room,

> *Take one, they're very nice. Take one … This is part of our culture. If you don't take one that mean you're no good! (laughter)* (Lebanese carer)

However, not everyone felt as comfortable about having large numbers of family and friends around at once.

> *I don't really like it myself, when I've got a whole ten visitors. I feel embarrassed. I don't feel comfortable with a whole heap of visitors myself.* (Lebanese parent)

Overt declarations of cultural background were also read as an invasion of privacy which only served to construct, label or potentially stigmatise the family as 'different'.

> *I mean, if you look different, you shouldn't be asked where you come from. If you have green eyes, blond hair, that means maybe you wouldn't be asked a question like that because they assume you're from English background, whatever … Some people they ask questions just as a matter of interest, or just to know, like you said, if you want some special food or something. You can tell from the way they ask (the reason) why they ask.* (Palestinian parent)

An Assyrian family expressed similar feelings but also conceded that knowing about different cultural practices might be useful for hospital staff. In this case, the parent placed the responsibility on the hospital to develop their own cultural 'check-list' rather than asking questions of individual families.

Finally, for one parent from Croatia, questions about her 'cultural background' were both confronting and intimidating and she did not want to discuss where she came from. In this case, just the mention of Yugoslavia was synonymous with war, devastation and abuse, memories she would rather forget.

These narratives highlight that understandings and the importance placed on cultural background by the parents themselves are as complex as they are diverse. Moreover, while some basic information may be useful as a general guide for staff we would caution against over-relying on such an approach. In employing the 'check-list' method, there can be a tendency to slip into vague cultural stereotypes. These are often inadequate when dealing with the complex combination of socio-historical factors and personal experiences that frame individual notions of 'cultural identity' and 'belonging'.

2.3 Communication issues

2.3.1 Interpreters and language services

It is official hospital policy that staff are not to use family members as interpreters, yet this practice is commonplace. We were told that regular memos are sent around the hospital to remind staff of this fact and likewise they are regularly ignored. The general opinion, and here we are in particular

talking about nurses and doctors, is that this policy is seen as both 'idealistic' and 'unrealistic'. The hospital policy does not take into consideration the time constraints that staff are under, often due to staff shortages.

It also underestimates the difficulties of arranging interpreters (see staff section below) nor does it allow for flexibility in the range of issues that need to be discussed, from simple daily requirements through to pain management and medical diagnoses. While all staff acknowledge the importance of using interpreters, the guidelines to direct staff on when to call on them, outside of 'medical' explanations, needs to be addressed. At present these decisions are left up to individual staff to use their common sense and experience. It also, of course, depends on interpreter availability.

A second concern that surfaced was when and who initiated the use of interpreters. Some parents/carers were offered interpreters, others were not. Patients and their families are supposed to be offered an interpreter when they go through the Admissions process. However, explanation and clarification of why and in what situations an interpreter may be required needs to be clearly conveyed to the family from the moment they enter the hospital system.

For a Korean father caring for his baby daughter, there was a sense of frustration about not being able to communicate with the hospital staff, especially the specialists looking after his daughter. He also mentioned the difficulties staff encountered in trying to organise an interpreter when needed.

> *I think if the interpreter stays in hospital, more helpful for me. But I think it is impossible. I mean, maybe if the interpreters stay always in hospital, so I can contact easily and they can come easily, maybe that kind of assistance is better. Usually I can understand the doctor's instructions … but sometimes I need more detailed information!* (Korean parent)

This parent also mentioned that he would appreciate being provided with written information in Korean about his daughter's condition and treatment, especially clear and accurate instructions for when he took her home.

Similarly, a mother caring for her daughter who has Cystic Fibrosis, did not know or understand how to explain her daughter's condition to her parents, the child's Macedonian grandparents. This inability to accurately communicate with her parents also has implications for finding out any family history of the disease.

This was a source of considerable frustration for the woman, and also for the grandparents, who would like to help and understand but cannot comprehend what they are dealing with. When we asked whether it would be useful if written information was provided in her own language explaining in simple terms the disease, its effects and treatment, she responded enthusiastically to the suggestion.

Parents and staff alike described several situations where family members were called upon to act as interpreters. This was despite the fact that these de facto interpreters had varying levels of English language proficiency themselves. Not surprisingly many experienced difficulties when attempting to translate complex medical terminology and procedures. However, despite ethical and practical problems – including disruption to their personal and work lives – some family members still felt that it was their duty and responsibility to act as interpreters.

For example, the 23-year-old sister of one patient had taken a good part of three months leave from her University course to interpret for her sister and mother, both of whom spoke little English. She told us that she spends nearly every day at the hospital and, along with her brother, takes on the role of interpreter between hospital staff and the rest of the family:

> *I like to be here when they talk about important things, when they talk about [her] treatment and what they are going to do … Operation and stuff I don't really understand, I don't understand difficult medical stuff … but still it's important for me to be here … doing the translating for my sister.* (Indonesian carer)

This is similar to the experience of a Lebanese family. Members of the extended family were called upon in various ways to assist in the communication process between staff and the child's mother. For example, nursing staff liaised with the extended family to arrange for times when they could be used to act as interpreters. When the family was asked if they felt that communication was satisfactory and adequate, the uncle of the child, who is also one of the principal carers, responded:

> *Well, they did ask if we need it (interpreter), but we say no, because we're all right … But, I mean, they tried to get somebody to explain everything to my sister, but my sister said it's not necessary because we're always here. If I'm not here, my wife is here. If my wife not here, my other brother's here. We all speak English … the doctors, they're very nice, they speak easy language to make her understand…even one of the nurses, when she was filling the form, she asked, 'What language do you speak?' and I asked her why they ask that question, and she said, 'In case you're not here and we have to get an interpreter for your sister.'* (Lebanese carer)

As in this case, some families prefer to 'make do' without a professional interpreter. Often these families come from countries where welfare or allied health care is traditionally provided by the family or community network rather than government or external organisations. Consequently, they express reservations about using support services, insisting that it is the family's responsibility. In contrast, one mother, originally from Poland, read the fact that she hadn't been offered an interpreter as a compliment.

> *No, nobody asked … I am happy that nobody asked. If someone asks if I need an interpreter, I feel 'Oh my goodness, they think I can't speak*

English.' If people don't ask me, I am so happy! … Before, in hospital, I need interpreter. I was happy that somebody ask me for interpreter.

But now, I know my English not perfect yet, never will be perfect, but I feel like embarrassed if somebody asks me … Still, sometimes, if I have problems understand some things, I go to ask, to make sure I understand everything. I will check. But if the staff don't ask me, I didn't feel like they are lazy, I feel like, 'Oh that's good! My English is OK!'
(Polish parent)

One of the main reasons why this parent was so pleased at not being offered an interpreter is that it saved her embarrassment. Therefore, it is not surprising that her mother, who is also a primary care-giver but who does not speak English, said she felt a great sense of shame whenever an interpreter had been suggested.

2.3.2 Cultural communication: More than just language

Effective communication was a recurrent theme with parents/carers and not just in terms of English language competency. While the latter is obviously an important issue a number of parents also expressed feelings of frustration, intimidation and loss of control within the hospital system.

Communication was identified by one parent from a Jewish background as the most important determining factor in the quality of health care her daughter received:

I think we've had a very mixed experience in terms of nursing care … Nothing to do with culture (laughs) but, you know, it's just…as a result of communication breakdown … there's been lots of fantastic stuff going on and I would never want to deny it, but if they won't hear the other side, if they're not open to hear the other side, then that mars the good things.
(Jewish parent)

Hospitals can be overwhelming and at times intimidating environments where there are often quite apparent hierarchical distinctions both among health professionals and between service providers and clients. Yet, it should be noted that SCH does try to create a non-threatening, at times fun and festive atmosphere for the children. Despite this, parents/carers can feel extremely vulnerable and isolated, after all they are in a strange, impersonal environment removed from their everyday lives, family routines and the familiar setting of the home. They are also frequently faced with a 'foreign' medical language, a language that requires an understanding of test results, body parts and functions, technology, medicines, procedures and treatment. The terminology encountered is difficult enough for proficient speakers of English, let alone for those who are required to work in English as a second or third language.

One Tongan parent we talked with recounted a number of incidents where she felt both patronised and ignored.

> *No, it was just the first day, you know, that the nurse was showing me the room for the kids, if they want something to eat. And while she was showing me, this lady was doing toast in the room, and she looked around at her and said, 'It's for patients only!' And she gave this funny look, you know! It's like – but the nurse already tell me it's for patients. And I said to her, 'I understand that. I know English!'…but I'm glad I wasn't angry with her, you know? I just thought, oh, no. Don't get too upset, maybe she didn't have a good day.* (Tongan parent)

This parent, who had six other children and travelled long distances to the hospital three times a day, would try and coordinate her visits when the clinicians did their rounds or when her son had tests. However this does not seem to have been fully appreciated by staff, and she spent long periods of time waiting for specialists or missing them altogether. The level of communication when she was present was equally problematic.

> *[The clinician] just came in and looked at him [her son], She didn't even say anything to me! No! Nothing! Nothing (laughs. She just went and looked at this, didn't tell me what's happening … You know, I thought that's just the way they're supposed to be. Like, I have to ask [another clinician], when she left, you know, and then I said to him … 'Can you explain to me what she was talking about?' and then he said, 'Oh, it's shingles,' you know, telling me the word, and then I said, 'Can you explain to me what's that?' and then he said, 'Oh, it's just nearly the same as chicken pox, you know' … and I said, 'Is he all right? Is he going to be fine?' You know, and he said, 'Oh, yeah, he's all right. We're just going to send up blood, and then we'll know what we're treating, you know.'* (Tongan parent)

This parent did not feel confident or comfortable at all asking questions or discussing her child's treatment with staff. She felt as if she should just 'stay out of the way and be quiet':

> *Yeah, yeah. I just feel like that – I've been feeling like that since I was here in Australia, you know? I never ask questions! … but my husband do it for me. He usually do it for me … I just don't know [why I get this feeling] – I just feel like I don't have to upset them, ask too many things, you know? It's just like – I just feel – I don't want to upset anyone! (laughs) Yeah!* (Tongan Parent)

This parent felt that any active participation or engagement might make her appear as demanding, which then might affect the quality of care for her child. In so doing, parental control and responsibility was to a large extent relinquished and she was forced to defer to the authority of others. To be fair, within a hospital context, some loss of control is inevitable, however, parents, particularly mothers, repeatedly mentioned this feeling of impotence:

> *The whole part of being a parent is feeling like you've got some control over your child – and you get to a hospital, you don't have any control.*

They tell you what he's supposed to eat, when he's sleeping, when he's doing this, when he's doing that, they weigh his food, they weigh his wees, you know, you just think, what am I here? Like a puppet on a string! And then you try and ask if you can have some control, some people are nice in letting you do it … and you're just caught in that. A big hospital, big system. (Indian-Australian family)

Health professionals are the designated 'authority figures' within this 'big system.' They consequently tend to possess both social and linguistic power and as a consequence their authority can override the quality of the interaction, or what is referred to as 'speech without communication' (Bourdieu cited in Kllinken & Noble 2000).

I mean, he (the doctor) doesn't come across as being a rude person, it's just in that situation he wasn't very good at communicating or listening. (laughs) (Jewish parent)

*And sometimes you feel like, you know, you keep saying things and you feel like you're not really being listened to, because, you know, hospital protocol and this has to be done, and this has to be done, and sometimes I think nobody's listening to me. (*Indian-Australian family*)*

A number of parents commented that this loss of control was particularly difficult to deal with when they spent so much of their day sitting next to their child, watching their reactions and are in continual contact with the different nurses and doctors caring for the child. Yet, some found that their opinions were simply not acknowledged.

I think some doctors can be, like, that's their specialty and they won't listen to you, whereas as a mother you're here all day, I'm here 16 hours a day, every day, and sometimes when you speak to the doctors they tend to ignore some points that you might have, when [my son's] having a problem, or something … (South African parent)

I think the hospital, in some cases, where the parents do have a little bit of experience, need to trust the parents a bit more! (laughs.) (Serbian parent)

As the above narratives illustrate, and there were a number of other examples, some hospital staff do sometimes find it difficult to listen to parents' concerns and when women in particular assert their views it is often in response to staff not listening and refusing to acknowledge their parental and life experiences. As one social worker remarked, the culture of the hospital is one in which the client is supposed to hand over their body and relinquish their mind to the experts. While this may be a little extreme, we did find that there were many parents who felt that they could regain some control without undermining staff expertise or impacting negatively on their child's ability to recover.

2.3.3 Diet and food

Many patients need special meals and dietary requirements. This is for both cultural/religious reasons – for example, kosher or halal meals – and/or for medical reasons due to allergies such as lactose intolerance or skin conditions.

On the whole we found that staff are prepared to accommodate these special needs but the problem keeps arising that the degree of accommodation is more often than not left up to the individual staff member. While one parent, whose son suffers from debilitating eczema was recounting a list of appropriate foods, she was stopped by a staff member stating there was a limit on the amount of information that could be recorded on the computer dietary system:

> *One nurse, actually, I think she'd done enough typing with regards to him on the computer, and his food menu, and she just told me that there's not enough room in the computer to put anything else in! Things like that. And they've actually been sending some stuff that's not – that he can't have. Yeah. But that's OK, we've sort of worked our way around that. (laughs)* (Australian-born Chinese parent)

For two Jewish families we spoke with, both Kosher meals and special dietary needs were required. Although the hospital caters for Kosher diets, the actual organisation and provision of this system did not always meet their religious requirements. As a result, female parents often had to supplement their child's diet with home-prepared foods.

> *That's been a problem for me, and [my son] is on a special diet – we eat kosher food, and we only eat kosher food [and] he's on a restricted diet, and for the last week he's only been able to eat certain foods, and I've had to actually bring in a lot of food myself, because it takes a couple of days to organise special meals … So, the food has been a problem.* (Jewish parent)

One Lebanese parent was very emphatic that if you come to an Australian hospital then you should eat 'Australian' food:

> *I mean, it's a hospital not a hotel. If I'm Lebanese, then I like Lebanese food. If he's Chinese, he wants Chinese food. How many chefs they got here? How many kinds of food they going to cook? That's not fair for the hospital, no.*

Yet another parent who came from Korea was reluctant to eat Korean food because he was worried about the strong aromas and the possibility that others in the ward may be offended. While it is not possible to cater for individual cultural tastes, given contemporary Australia's culinary diversity, it might be possible to offer a range or a fusion of foods.

2.3.4 Conflicting values: Negotiating practices

In the parents section we concentrated on three main areas of concern. The first dealt with language and the use of interpreters. Some parents felt that interpreters were under-utilised and they would have liked better access while others were quick to justify why they didn't need them.

When discussing the interpreter service, it became apparent that unless a parent really did not speak English at all, there was a feeling that one ought to 'make do' or draw on other family members to facilitate communication. In both cases, this reticence seems to be based on not wanting to appear different from other Australians, with difference defined as requiring special needs, which can be perceived as negative.

The second issue concerned cross-cultural communication in terms of staff understanding and negotiating client values and beliefs across a range of factors including cultural diversity, race, gender and socio-economic status. It is also cross-cultural in that it relates to clients' ability to access health care for their children within a specific professional and institutional culture.

Finally, we touched on the significance of food and diet and how different cultural beliefs become points of conflict if they are not understood in a wider context of cultural and/or religious values.

3. Interviews with Staff

3.1 What is cultural diversity?

3.1.1 Hospital staff definitions

In this section we shift our focus onto SCH staff and explore their responses to how they work with cultural diversity as front-line service providers in a complex hospital setting. We began by asking staff 'what does "cultural diversity" mean to you?' In posing this question we were interested to explore how staff understood the rhetoric of 'cultural diversity' compared to their lived experiences of diversity within the workplace.

The responses were overwhelmingly positive, inclusive, indeed, celebratory. Moreover, implicit in all the responses was the associated assumption of an easy coexistence among different cultures.

3.2 Cultural diversity in the workplace

How did staff perceive cultural diversity working within the hospital?

> *In general I think that cultural differences are not systematically managed.* (Senior Management)

> *It [cultural diversity] is recognised, but it can be counter-productive, leading to discrimination and generalisations about cultural groups.* (Social worker)

> *Cultural differences are recognised by [having] Hospital Admission handouts in other languages, but some patients don't help themselves and don't bring an English-speaking person with them.* (Ward clerk)

> *I think the SCH do a fabulous job in recognising the many cultural differences.* (Nurse)

> *I feel sometimes we find people that don't speak English too hard to deal with. You are pushed for time to see patients and waiting for an interpreter makes it so hard – you just can't 'hit the wards' when you feel like it.* (Dietitian)

> *I don't think it's an important issue other than for language as all patients receive the same treatment according to their needs and not their culture.* (Nurse)

3.2.1 The distinction between popular rhetoric and lived social practices

The ways in which skilled staff, the majority of who are Anglo-Europeans 'worked' the concept of 'cultural diversity' covered a full continuum of views. In general, as the explanations above illustrate, the playing out of diversity within this hospital setting does not fit neatly into the former romanticised version of all Australians living together in a multicultural society.

At the same time, the views reflected both a sophistication of contemporary attitudes along with an uneasy apprehensiveness in relation to the extent to which 'cultural diversity' should or can be accommodated within existing systems.

> *I think we've got a long way to go, but I also think we are becoming more conscious of it [cultural diversity] and aware of it, and are willing to go that way … It's just that we're coming from our own cultural perspective which we find very safe and secure … So when we come across other situations, what we need to do is let go of some of our own, and that's not easy to do. To let go of some of our own cultural identity and our own cultural security to accommodate other people.* (Minister of religion)

> *I think 'diversity' is actually not a bad word because it includes white Anglo-Saxon Protestants and anyone else, so it's good in that it doesn't have a negative connotation. It can mean everyone and everything that has a difference, if you like. You can have a diverse range of views on something.* (Senior Management)

3.2.2 Ambivalence about cultural diversity

Despite a growing awareness, the ambivalence expressed in some comments highlights a number of concerns:
- Cultural diversity is seen as something that needs to be 'fitted into' the existing system.
- There are extremely limited guidelines to direct staff to resources.
- There is a lack of understanding by staff of the definitions of 'culture.'

Culture tends to be interpreted as something static and unmediated, premised on individual personal behaviours that exist outside of social arrangements, and there is a lack of recognition, particularly by Anglo-European staff, of the cultural context in which they themselves exist.

> *There's a lot of ignorance. I mean, people misrepresent their religion. People have views which are based on who knows what, which are not sustainable. They say 'this is for religious reasons' but if you get an expert in religion, they can't sustain it, it's a personal interpretation, and it's a good excuse … So, I think it's not cultural diversity that's the problem. I think that's part of life. The problem is people's interpretation of the way they use cultural diversity to interface their own views with what's going on. So that's where the problem lies.* (Doctor)

3.3 Language communication

Communication is a crucial aspect of cross-cultural interaction and exchange. When asking staff about ways in which working with a culturally diverse population impact on their daily work practices, the use of interpreters was the predominant issue raised.

3.3.1 Background to Health Care Interpreter Service

The Health Care Interpreter Service used by SCH is based at Royal Prince Alfred Hospital and provides service to both Central Sydney and South East Health Services. There are between 55 and 60 interpreters on staff who work full-time plus about 180 contract interpreters. The former group covers the languages that are in most demand (about 27 languages) and when the latter group is included approximately 70 languages are covered.

The role of interpreters has changed significantly over the last 15 years. Previously interpreters took on a more combined role of interpreting and consumer advocacy/support. In many cases it was the only communication path between patients, their families and hospital staff. The shift to a more professionalised service began around the time interpreting became a university-credited course. This has resulted in a more narrow definition of the role and the associated skills and requirements around issues of ethics and specific translating expertise. A state-wide professional development committee has also been formed and is made up of the managers of all the health care interpreter services in NSW.

There is on-going training that includes development of interpreting skills, for specific situations involving a group or family conference. Interpreters must also keep up with the rapidly changing health issues and terminology, for instance in the area of HIV/AIDS. In the near future the professional development committee will introduce competency-based training of interpreters. As there is an increasing acknowledgement within health care services that people's health requirements are not simply limited to their specific illness, the demands on interpreters also increase to include a wider-range of health knowledges. Interpreters not only undertake a medical terminology course but also need to be able to work with, for example, issues around mental illness and sexual health.

3.3.2 When and how are interpreters used?

In theory there is universal acceptance that interpreters must be used in the case of medical instructions, information, explanations and consent forms, yet the reality can often be different. It was a small minority of staff that said they were happy with access to the interpreter service. Indeed, it was generally acknowledged that you only called an interpreter when it was absolutely necessary and that was more often than not when the doctor(s) was present.

The main frustration that staff expressed was trying to access the interpreter service when needed. Our discussions also indicated that social workers, with some exceptions, seem able to book interpreters more easily than nursing staff.

There was some suggestion by interpreters that health professionals tend to leave families who do not speak English until last on their rounds because interpreting is more time-consuming. There was also an associated assumption that the process of interpreting is somewhat burdensome.

> *For instance, you may have a patient in hospital, an inpatient, for a week. And then all of a sudden you get the call to send an interpreter for a dietitian. Normally, that patient has been in the ward for a week and they have managed one way or another, and it's only when a very concerned dietitian comes along, and she is used to using an interpreter and she wants to make sure that the message is passed on correctly to this patient.* (Interpreter)

One of the major issues seems to be that it takes time to work with an interpreter and that the system – both in terms of the schedules of the interpreters and the busy hospital routines – often places a great deal of pressure on all those involved.

> *And it's very hard – especially when you have a busy clinic. You want to go through and see as many patients as possible. Working with an interpreter does slow us down significantly. And you really have to keep reminding yourself of the importance of what you're doing and take the proper time. And it's always very difficult in a hospital environment. So you have to make a conscious effort to address that. Otherwise it's very easy to overlook it. And it's not because we're not caring enough. It's just the reality, the pressure of work.* (Doctor)

Several staff indicated that accessing an interpreter was often left until the middle or end of a patient's stay. This is to a large extent a resourcing issue but one that significantly affects the culture of dealing with linguistic diversity. Problems raised included:

- If a language group is small, interpreters can be difficult to find;
- Because of the high demand of interpreters among large communities, interpreters can be difficult to access. In one instance we were present when an interpreter booking clerk told a doctor that a Mandarin-Chinese interpreter would not be available for up to 2 weeks.
- Booking an interpreter can be extremely time-consuming and hospital staff often wait for long periods on the phone.
- There is a lack of clarity about whose responsibility it is to book interpreters.

Interpreters are not easy to access. If you want an interpreter, you've got to ring up, you've got to spend 20 minutes on the phone trying to get the booking, and they might book you one for the day after tomorrow, if you're lucky … although there are still people here who think if you talk more slowly and more loudly you will eventually get through. (Social Worker)

I can tell you that at X-hospital I rang and got it [an interpreter]. And now it's like, when I ring now, I remember sitting on the phone service on hold for 45 minutes one day and I'm not prepared to wait, so it puts people off. So it's not necessarily a hospital thing, it's a central thing that has failed. Not failed miserably, but stretched and I don't think it's been evaluated. (Senior Nurse)

It's left to the nurse to organise the interpreter, or it's left to the nurse to suggest the interpreter … in the meantime what I think happens is people just try to get by with snippets of information, and often they are misinterpreted. It's just not accurate!

3.3.3 Reactive rather than proactive

When these difficulties repeatedly occur, staff become less pro-active and more re-active in initiating interpreter use and try to make do in other ways. For example, when an interpreter is not available, the ill child, or sometimes a sibling, having attended school in Australia, is used to interpret for the adults.

The interpreters are brilliant, but we can't access them all the time. There are three predominant languages which we always need that are the most booked out interpreters in Sydney. So that creates a lot of stress as well. So then you're starting to rely on family members or the children themselves in interpreting with their parents, or just somehow trying to get by. (Social Worker)

While it is acknowledged by most staff that this is not a satisfactory situation, they are often left with no alternatives when simple questions, answers or procedures need to be explained to the parents. While care is taken, the result can be that too much responsibility and active involvement can be placed on the child or sibling. It also has the indirect effect of excluding or alienating the parents from gaining accurate knowledge, asking questions and giving opinions. Indeed, sometimes the parents are completely cut out of the loop and instead 'experts', such as counsellors or psychologists, are called in. However, parents/carers if given access to complete information are often in a better position to work through explanations, shock and/or grief with their child, or at least be an active participant in the process.

It has also been noted by other staff members that cleaners on wards have on occasion been asked to translate. Although this practice is generally acknowledged to be inappropriate, it still occurs. As one staff member pointed out, because the majority of cleaners come from non-English speaking backgrounds and are often in junior and insecure job positions, there is the

real possibility that they may feel pressured to comply with requests to interpret even if they don't feel comfortable when asked.

The obvious pitfalls such as misunderstandings, inaccurate translations and a range of ethical considerations are similar to those of allowing family members to act as interpreters, particularly when translating medical terminology or instructions.

3.3.4 Interpreting language and culture: The role of the interpreter

Cultural diversity is rarely, if ever, the sole issue and misunderstandings due to language are often only one part of a more complex range of issues. From the perspective of the interpreters this can place them in complicated situations where both hospital staff and parents/carers rely on their expertise to enable communication and understanding of what is usually a multifaceted situation.

> *[A child] with leukaemia had come down to Sydney from another state and the mother had very limited English. There wasn't the usual family support and so there wasn't anybody here to give her support… The doctor was going through an explanation of blood cells and she seemed to be in a daze … She didn't seem to respond. She seemed to be in shock. But later on … it occurred to me that she had very limited education, she hadn't gone to high school.*
>
> *So, that whole explanation, simply didn't mean anything to her … that was a good lesson for me, because I remembered in the future, if I felt that the patient really needed some more background information before they start to understand about a procedure then I feel comfortable in asking a professional to go back and explain … You need to exert a lot of flexibility, it's your role [as an interpreter] to facilitate communication.*
> (Interpreter)

This account clearly illustrates the complexity of interpreting. In this case it wasn't simply language that separated the parent from understanding her child's medical condition. It was also her educational background, the general non-understanding of medical terminology, the fear and vulnerability involved in having a very sick child, as well as social and geographic isolation that in combination created an incomprehensible situation in which the parent found herself. In this case it was the interpreter recognising the relationship between the mother's response and her own education within a particular cultural context and her adeptness as an experienced interpreter that allowed her to cotton-on to the reasons behind this woman's lack of response. It also succinctly highlights the way culture plays itself out on a number of levels that initially appear to be determined by a 'problem' with language but end up being so much more.

3.3.5 A shift in approach?

On the one hand, there is a general understanding that interpreters cannot be available 24 hours a day, and so at some level common sense and possible alternative strategies need to be implemented to fill in the gaps. On the other hand, there seems to be an unwritten quota system in place: 'Well, you've

seen the interpreter once, you don't need to see them again for a while' mentality.

One of the negative effects of this one-off approach is that parents are under a lot of pressure both to immediately understand an often complex situation while also being very aware of the time constraints of staff and interpreter. Furthermore, follow-up explanations and consolidation of information, usually carried out by nursing staff after the doctor has left, does not take place. This is often instrumental to parents' understandings for it allows them time to process explanations and to raise further concerns or ask questions. However, even if this were possible in terms of extra resources, as one senior nurse pointed out,

> *The nursing staff needs to know how to utilise the interpreters more effectively, and know to ask the right questions.* (Senior Nurse)

Indeed, another staff member expanded on this need for change by suggesting that a complete conceptual shift in the role of interpreters was necessary and that the interpreter be further integrated into *the whole process* of the client's stay:

> *In a hospital setting, where you have complex technical information, where you have lots of unfamiliar procedures and settings and positions and roles, where people are already under stress from coming into hospital or having family in here, and we all know that interferes with comprehension anyway, to then not have interpreters at the front end of admission to work out what the expressive and comprehensive language is of people, to me is a worry, and I've seen it at other hospitals as well.* (Child Protection Unit)

3.3.6 Resistance by clients to using interpreters

There is some resistance by some clients to using interpreters. Some of the reasons for their reticence include:

1. They may come from a small community where many people know each other and there is the fear that either confidential information may filter back to the community or that they might know the interpreter personally and not feel comfortable. One example given was working with people who are HIV+ and the implications of this information getting back to their families and communities.

2. There is also a level of embarrassment in others finding out that they are not able to 'work' in English – whether they be hospital staff, interpreters or family, friends and community members.

3. If clients have come from a police state, they may be reticent for others to know their personal backgrounds and so wish to appear to 'fit in' and to some extent deny any problems or special needs they may have, including language assistance.

4. As discussed in detail in the 'parents/carers' section many clients expressed a strong desire to function in English along with an underlying political imperative that if you live in Australia you should be able to

communicate in English. Thus, to be asked whether one needs an interpreter is seen to be a criticism of one's ability to 'integrate' into Australian society. This position is associated with feelings of national belonging in which being seen not to need or not being asked whether you need an interpreter validates and works to define one as 'being an Aussie' or 'fitting in'. This is in contradistinction to the 'celebrating difference' rhetoric. Rather, there is a reinstatement and validation of wanting to be the same as everyone else – everyone else being white Anglo-Australian – not by, as one would think, staff, but ironically, by clients themselves.

3.3.7 Phone interpreter service

Staff are generally satisfied with access to the phone interpreter service. Some staff did point out that while they understood that it was not always possible to have face-to-face interpreters, there were some obvious disadvantages with using phone interpreters. Disadvantages included: when a conference phone are not available there is a constant handing on of the phone from various staff to the client; the de-personal nature of using telephones and the inability by interpreters to be able to translate non-verbal messages. It was also suggested that when telephone interpreting takes place between a medical team, interpreters and parents, that the room used be private, where nobody can see or listen in to the conversations, a situation we were told is presently not always the case.

3.4 Working with cultural diversity

3.4.1 Accommodating differences

Most staff, while happy to try and accommodate individual needs where possible, are left to deal with cultural diversity on an individual, ad-hoc basis. As a result, responses elicited from staff tend to be framed in terms of just another work responsibility that does not necessarily fit into the pre-existing hospital system.

> *There was a woman who had given birth to a child – and I'm not sure if she was Vietnamese or Chinese – but she didn't come in with baby, the grandmother did. And people were talking about making DOCS notifications … they thought the mother was neglecting the child … I had a chat with a friend of mine who is a psych nurse, and I just said, it's kind of weird, because when you talk to this mother, everything sounds very normal, and she's actually at home getting stuff ready for the baby, but she's actually not taking care of it', and she said, 'Oh, no, that's right. She won't for six weeks. The grandmother will do that.' … What normally happens is the grandmother shows the mother how to handle the newborn … and we accommodated the two of them in hospital, so it actually worked out OK. But it was only in response to something that was perceived as a problem.* (Senior Management)

The pre-existing framework is constituted by both the Anglo-European well-educated consumer and the Western bio-medical model. It is not surprising

that on asking one doctor how multicultural health fitted into the overall health care of consumers within the hospital, the term 'problem' repeatedly surfaced.

There are problems, particularly because we've got such a multicultural society, so there are problems, if you like, at the direct workplace level …you've got people who don't speak English, you've all the problems of families with sick children who can't communicate with the carers, it's obviously a big problem . . . I mean, you've got a person who has a congenital heart defect and has an operation, that's a process that occurs, it's not culturally relevant. What's relevant is the communication process. The recognition that people may have different perceptions of what's going on because of their cultural background. We can't change the treatment, as it were, because people have different perceptions. What we have to do is try and help them understand what we're doing . . . So, I think I have to say, it's not cultural diversity that's the problem. I think that's part of life. The problem is people's interpretation of the way they use cultural diversity to interface their own views with what's going on. (Doctor)

In this instance, the onus is on the consumer to 'fit into' the existing professional and organisational system that functions in the hospital, as well as the assumption of already knowing how 'cultural diversity' is expressed by different individuals.

We need to be looking at the more general ways in which people are culturally aware of their own cultural backgrounds and what's significant for them … You've got a whole spectrum here. You can't talk about Islamic people are always this, or Muslim people are always this. There's a difference with Turkish Muslim people, Lebanese Muslim people, Indonesian Muslim people. (Minister of Religion)

Having said this, it is also obvious from the following examples[2] of 'cultural accommodation' that dealing with cultural diversity is already a constant factor in hospital staff members' work lives by both working in a culturally diverse workforce as well as dealing with diverse clients on a daily basis.

People are ready for more complex ways of dealing with culture and different ways of thinking about it, they just haven't had access to resources. (Multicultural Health Unit)

3.4.2 Parents' sleeping accommodation

One of the most common situations that staff face is the issue of orthodox Jewish or Muslim women who cannot sleep in the same room as a male adult other than their husband. This has created two dilemmas for staff:

1. These women, and hitherto it has overwhelmingly been women staying overnight with their children, are left to sit by their children's bedside because

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[2] The examples of 'cultural accommodation' that are presented here are a small selection that was addressed in the questionnaire/surveys and interviews. See Appendix 3 for a more comprehensive list of concerns and issues raised.

either there is a man sleeping in the parent's room or one might come in while they are asleep.
Instead, they sit up all night in chairs next to their children in the ward. This results in exhaustion and in the case of one woman who had diabetes, placed her own health at risk.

2. Staff pointed out that for years male parents have been excluded from staying overnight with their children and that they were trying to encourage men to take a more active role as carers. As a result, staff do not want to discourage this practice. In this situation there appears to be an organisational response to issues of gender equity but not to cultural diversity, or more precisely, how cultural diversity intersects with gendered practices.

3.4.3 Cultural diversity and gender

A repeated area of concern mentioned by hospital staff was that of their ability to understand how gender is expressed among diverse groups, and of course, among any one cultural group there will be variations of both extreme and liberal views. The most common situation that we heard about was when it is evident that the mother is the primary care giver but the husband or the patriarch of the family makes the decisions.

> *You feel a bit sorry sometimes – you see a woman who's got a babe in arms and a child crying, and the father's just sitting there because it's not his job to do any of the comforting, or do anything, and some cultures are very different. It's obviously a very personal thing as well … Sometimes the father will drop them off here in the morning and say, 'I'll be back after work', and that, for me, is quite hard to understand.* (Nurse)

This situation can be further complicated if the father/male family head understands more English and may decide it is not necessary to use an interpreter. The result is the mother can be excluded from both knowing and deciding issues for the child, but in either case, the staff are unaware of how they should respect cultural difference but still uphold their ethic of delivering information to primary caregivers.

> *The father will say, 'I'm there, I can interpret for my wife.' There's nothing you can do about that. How can you? … because in some of the cultures, the husband has the last say, and there's domination in the relationships, and the woman just accepts what goes on. And often I feel that they (women) miss out, they don't exactly know what's going on with their child because the father will only give her what he wants her to know, and they don't want outsiders. And if the father says, 'no, I don't want an interpreter', you can't . . . it's an invasion of his privacy. It's very, very, very difficult.'* (Senior Nurse)

To have a healthy child is what all parents hope for no matter what one's cultural background. In some cultures, for instance, the birth of a male in particular is said to bring both luck and is a moral reflection on both the parents and the extended family.

There was this child, they were an Asian couple, both came from Hong Kong. It was their first baby. And the baby was born with ambiguous genitalia. Initially, the father and mother were told that the baby was born a boy. You need to have a boy for the first baby . . . then they were told that it wasn't a boy, it was a girl. And the father was beside himself. And I actually sat and talked to him and he said, 'They don't realise the shame on the family. I have to now ring back to Hong Kong and say, 'I don't have a son, I have a female … It's like I've got a curse on my family and I married the wrong woman.' And this poor woman, this girl, she was beside herself, and she said to me, 'You have no idea of the implications of this… I can't even produce a normal child.' (Senior Nurse)

This child eventually died and the hospital social worker did give a great deal of support to the family. Nevertheless, according to the nurse who relayed this story the incredible distress of the family was seen as secondary and the implications, including the mental health of the parents, was added on, or seen as an extra complication.

Many female staff members be they nurses, doctors or allied health workers also commented on the issue of women health workers not being taken seriously or even having treatment refused by some families on the basis of gender.

Sometimes it's hard when you're talking to someone who [you] *can see is not used to being told what to do by a woman, and hates it. It can get your back up a bit.* (Nurse)

The more obvious issues seem to be commonly understood and responded to appropriately, for example, issues around the inappropriateness of male doctors and nurses treating female patients, or, male patients being treated by female doctors. However, some concerns, for example, Muslim women who can only remove their *hijab* (face veils) if they are with their children, husband, or with other women are less understood.

One woman I can think of, a while ago, she wore a veil. And in the wards, around each bed, there's the possibility of drawing curtains around the bed, but it's pretty much discouraged by staff because it means that they can't see the child … and it was also very hot and this woman, she'd like to be able to take her veil off, but she could only do that in privacy … so this was a major conflict. She kept pulling the curtain around and taking her veil off to be more comfortable, but people just did not understand that. Men [nurses and doctors] would pull the curtain aside and come in. (Social Worker)

This situation simply required cultural sensitivity to specific gender norms, which in practical terms meant an understanding of cultural safety and comfort for the woman involved, particularly by male doctors and nursing staff.

3.4.4 Illness, death and mourning

There is vast diversity around the rituals of illness, death and mourning. For example, in some South American cultures it is usual to visit someone ill in hospital even if they are not a close family member or friend. Among Lebanese Muslim families it is not only important to visit a sick relative but to feed them and so often a ward can be full of visitors and food. In contrast, among Anglo-European families, if it is not a crisis, visitors are generally far less regular.

Issues around religious laws on when one can travel, use basic technology such as lights, touch money, to different understandings of when a body is considered dead, how to prepare bodies and appropriate behaviour around sick or dead children vary considerably.

On the one hand, it can be difficult for other people in the ward if a family is very emotional and wailing over a child. On the other hand, the opposite can apply as when some nurses found it very upsetting that a Jehovah's Witness family didn't appear to grieve at all. Interestingly, in both cases, it is the effect that the family has on others, rather than what is happening to the family itself that appears to be of concern.

Of course one can't assume that staff are aware of all situations and religious information but it is possible to call on hospital staff members' individual personal and work experiences as a collective resource that other staff can access rather than leaving it up to individuals to work their way through what are often similar or repeated situations.

The same diversity of approaches applies to how people react to death and mourning. For some, it is important to verbalise their anguish through loud weeping and wailing, rocking, and throwing oneself on the bed, while other cultures appear much more austere, either not showing emotion, keeping it within the confines of their home-space or crying quietly in a corner. The following narrative told by a social worker contrasts the range of cultural situations that hospital workers meet on a daily basis.

> *An Anglo-Saxon family [arrived] with a disabled child who had stopped breathing … and when they came the child was already dead. They were both just totally overwhelmed, and unlike the stereotypes, the father sobbed as much as the mother. And they were both comforting each other and really able to make use of all the services. No problem at all. I mean, it was terrible for them but they were able to make uses of the services quite easily.*
>
> *Compare that to the Lebanese Muslim family … the child was not dead … it was a fall, nobody's fault … the mother was hysterically sobbing on the floor of the resuscitation room. The father was in the room, the interview room that we set aside for families, with a number of men who had been with them when it happened … I went and got her a pillow or something and then the next minute I know, the whole troop was there! (laughs)*

All the friends! … then I watched this amazing process where the men will gather at one end and the women – they go to her as if the mother is about to pass out, and it's the most amazing thing I'd seen. And so the women were all physically touching this mother, stroking her, wiping her brow, I mean it was like half a dozen women around this one mother, and they're variously praying or consoling her, and the men are praying to Allah, having their conversation, more prayers, and it's quite segregated. And he [the father] says 'I hope you don't mind, this is our way' and I say 'You need to do whatever you need to do, and let me know if there's anything [I can do]'. (Social Worker)

Whatever the situation, there seems to be a general understanding, particularly by nursing staff and social workers, that time and space take on different meanings in various cultures.

3.4.5 Extended family issues

Situations occur where there is disagreement between medical, nursing, immediate and extended family. There have been cases where the extended family for a variety of reasons is in conflict with Western medical opinion. The most common example offered was when the child is on life support and the medical and nursing staff counsel that treatment should be withdrawn. In some instances there can be multiple conflicts occurring between hierarchies in Western medicine and specific cultural values of the families.

For example, in one situation, the parents were holding off making their decision because the extended family, who were overseas, did not agree with the medical team's evaluation and the parents felt compelled to get their approval before agreeing with the plan.

While hospital staff are aware that extended families do play an important role in various cultures there is still a lack of awareness about the extent to which roles may differ from the general culture of an Anglo-European family. For example, in the case of a Chinese family, it is not unusual for the grandparents to be primary carers but generally they are not taken into consideration when medical explanations and interpreters are organised.

It is often the Chinese grandmothers who are there looking after the child, if the kid comes in to have their tonsils out. Grandma's there to look after them while they're in hospital. And I guess you only really come to know that when you've done it for a fair while. (Nurse)

I have to say that I tend to be quite selective when there's a huge extended family. I acknowledge the rest of them, but I always make my main focus the parents. Because I think, sometimes for them as well, probably more so if they grew up in Australian society, they're a little more understanding of the needs and the ways of the here and now. Whereas, with the older generation, they don't always have an appreciation of that and they pressurise the parents. But equally, they're there and supportive in their own way too. And in a situation of a critically ill child, you can't have a whole extended family there – it can be a

hindrance to us as workers – but I think they are obviously an assistance most of the time. (Nurse)

Extended families seem to be easily accommodated if there are no demands being made by them or when they agree with medical advice, for example, when interpreters are not available and family members are used in their place or when they can take on roles as carers. In contrast, when clarification or explanations by the family are called on, the extended family becomes a 'hindrance' at times appearing obstructionist to staff.

3.4.6 Religion/Spirituality

There are a number of Jewish and Christian chaplains available to the Sydney Children's Hospital. There was a good understanding of cultural diversity issues among the clergy we talked with, partly due to a number of them having spent time overseas, working in a range of cultural contexts. Having done so means that they are aware of the different expressions that one religion may take on depending on the socio-historical context from which it emerged.

> *When there's a clear overlay of original, spiritual, religious beliefs of their community that's being melded with an imported Catholic culture, it results in a very distinctive way of living and believing, and practising the Catholic faith. It's particular to their culture and that comes through clearly. And as a person working with them, I have to be really sensitive to their cultural expression of this particular way of expressing the Catholic faith.* (Minister of Religion)

While the clergy are more than happy to accommodate clients' religious needs, they first have to know about them and if language is a problem, it may be that this part of the clients' wellbeing is simply overlooked or considered a periphery issue to their health. Apparently there have been some attempts by the present clergy to try and attract a range of spiritual advisors to their unit but with little success. As the following anecdote illustrates the difference a culturally diverse clergy makes to some client's ability to communicate their concerns and needs cannot be underestimated.

> *Bringing a Vietnamese priest into our Ministry here was a deliberate thing, because we are coming across more and more people from a Vietnamese cultural Catholic background. And I can see the difference … The whole perspective of the encounter changes. Because there's someone there who speaks the language and is aware of their culture. And, it's helpful for me, because I can ask, 'What's happening here?' or 'What should I do in this situation?' … it makes a world of difference.* (Minister of Religion)

This story also exemplifies the importance of actively pursuing culturally diverse employment policies at SCH.

3.4.7 Hospital signage

Signage was one of the first practical issues raised by staff and that we observed standing outside the Intensive Care Unit (ICU) in our first week. There was a sign posted in English with various instructions on how to enter this particular ward. Naturally, the first question that came to mind was 'why aren't these instructions posted in more than one language?'

What emerged was a tale of repeated requests from the MCH unit to put in requisition forms and gather quotes from sign-writers. After 3-4 months this was achieved.

> *I've encountered barriers at every level of bureaucracy in terms of getting money approved, figuring out whose budget it's going to come out of, getting translations done, finding a quote that's acceptable to the hospital. The fact is that there's no sign up there at the moment, even for anybody who speaks English about how to get into that unit (ICU), let alone anyone who doesn't speak English.* (MCH Unit)

> *I was in a meeting the other day and I was saying, 'Our signs are all in English, and I've had parents come up to me and show me a piece of paper, and they need to find the Admissions desk.' So firstly, they can't speak the language, and secondly, they are just totally disoriented. Now, people who come from the country are disoriented in this hospital and they can, well most of them can read English, but it's that much harder for someone if English isn't their predominant language.* (Social Worker)

Staff frequently commented on the lack of signage and how it affects people's insecurity and confusion in trying to negotiate their way round the hospital.

3.4.8 Non-compliancy

Reports of non-compliancy to treatment after children are taken home can be due to either failure to understand the medical treatment or perhaps through simple misunderstandings of instructions. The following narrative clearly articulates how important it is for staff to explore the cultural context in which procedures are implemented while at the same time it also points to the fact that once identified as a cultural issue, alternative treatments can be initiated.

> *I've found with doing nasogastric feeding, the children go home with a nasogastric tube in their nose. And I've found that some of the cultures, they've found that very hard to take … one father said to me, 'my child will be seen with a tube in the nose, it seems like there's a bad spirit on us'. Not that the child is unwell, but that the family has done something and it's put shame on the family. A lot of them wouldn't like the tube, so they would pull the tube out, and so I'd say, 'We need to look at a gastrostomy. How about if you had a gastrostomy tube? No-one could see it, it's covered up', and they'd be much more happy. We don't look beyond, we just make rash decisions. Some of the doctors say, 'Oh, there's non-compliancy here, let's contact DOCS.'* (Senior Nurse)

Thus what on the surface appeared as non-compliance with the potential of DOCS being called in was in this situation avoided because of an individual response and cultural competence of a particular staff member.

3.4.9 Resistance to and misunderstandings of Western medical practices

I've had a number of patients of Muslim background. They've not wanted to do what you thought was best treatment for them. Despite the fact there's no rationale as to why they would not want to do what you suggest. These have been issues of medication, taking away life support, and so on…(Doctor)

It appears more time and understanding needs to take place around why some people appear to be or indeed are resistant to Western medical practices. The reasons or 'rationales' behind these attitudes are varied and need to be understood in their specific cultural contexts. For example, the racial stereotyped use of the word 'witchdoctor' (see below) based on its Western associations with mysticism, superstition and being uncivilised needs to be examined given the ways in which staff accept or dismiss particular health practices. While overt resistance can be seen as ineffective and even obstructionist it generally arises out of particular cultural or religious observances.

We had a Samoan family who said that before we try chemotherapy we want to go and see a 'witchdoctor' and ask the witchdoctor to massage the child and that was really really hard because we – say the medical team – know that that's just not going to do a thing for the tumour and as long as you leave the tumour, the harder it's going to be to treat. But the flip side was that they needed to do that. Psychologically they needed to do that before they tried chemotherapy, because if they were whisked straight into chemotherapy they would have been struggling with that the whole time. So it was about them finding that balance of what was OK. (Social Worker)

Alternatively, resistance or non-compliance can emerge from trauma experienced by family members, at times, under the guise of a health setting.

So, if you're from a country where you have social workers and other health care professionals who are part of a police state, for example, how does that translate into people's understanding and engagement with us? (Child Protection Unit)

Whatever the case, as one doctor noted, it is extremely important to empower parents and carers within the treatment process because the Western hospital system takes away a lot of power from the parents in terms of decision-making and treatment and this can be extremely frightening. Indeed, the process of losing control of one's child's health can be the catalyst for the act of resistance.

If I know whatever they're suggesting is not going to harm the child, I have no objection to that. You know, sometimes you see people from Asian backgrounds rub flannel, like soft clothes around the chest of the child who's got a cold or pneumonia. Now, that's not going to harm the child, so I don't really make an issue of it, … and it makes them feel that they're helping the child. And I can't underestimate that, either. How people need to have some power in the medical system … Even if you're a middle-class, well-educated person, as a health consumer you are disempowered. And I'm the first to admit it. (Doctor)

Another issue of potential conflict was the correct way to control high temperatures. The current interpretation derived from the Western medical model recommends cooling the patient. However, in Chinese cultures for instance, the belief is that a patient should be heated until the temperature rises and then dissipates. While there were some misunderstandings over this, after some explanations, most clients understood the reasoning behind the Western bio-medical model and agreed to the treatment.

Variations in the way individual people react or deal with a range of situations differ markedly and as argued elsewhere are mediated through a combination of factors such as cultural diversity, gender, nuclear and extended family, community structures and socio-economic circumstances.

3.5 Cultural diversity and Aboriginality

3.5.1 Why the indifference?

Compared to the complex understandings expressed in the notion of multicultural Australia there was minimal knowledge around access and equity issues for Aboriginal clients, with the exception of some social workers. This was reflected in a sharp contrast or distinction made between the way Aboriginal culture/behaviour was discussed and the celebratory multi-cultural rhetoric, even when it was framed within statements of cultural understanding.

In my experience here, I've learnt a lot about Aboriginal people, the way it's quite common for them to leave their children with Aunty or Grandma and go off. And that's their culture. It doesn't mean they don't care. It's just what they do. (Nurse)

The above statement reflects a number of assumptions that are held by hospital staff and there are still major stereotypes and obstacles that Aboriginal clients face when accessing the hospital. This is despite on-going reports that point to extremely poor health conditions and outcomes for indigenous Australians. These include:

1. Aboriginal people tend to access medical and hospital care as a last resort. There is a general lack of understanding about why Aboriginal people might fear both the physical structure and the staff in the hospital. At the most basic level the architectural design of a multi-storied building can be unsettling in terms of feelings of insecurity and fear in being separated from the 'ground' or land.

2. Aboriginal people have a long history in which their Aboriginality has determined the quality and access of their health care. As a result, it was widely reported by hospital staff that some people tend to be reticent about disclosing their Aboriginality. These feelings do not exist in a cultural vacuum but rather we found that negative stereotypes around language and class were often inadvertently perpetuated and reinforced by a number of SCH staff.

> *They're (Aboriginal people) very reluctant to acknowledge their Aboriginality … I guess reports on Aboriginals are never very favourable, let's face it! … and a lot of them think that if they admit that they're Aboriginal they'll be looked down upon. I think they're insecure. And it's got nothing to do with the organisation … I think we need to have an Aboriginal health worker involved, and they're looking at getting one here … a lot of them have issues like when the child comes into the hospital, and I guess back then, when the children were taken away from them, they've got to deal with that as well, and they get really upset when they lose control.* (Senior Nurse)

3. Due to this reticence, the figures collected on how many Aboriginal and Torres Strait Islander peoples access the hospital are not accurate. Consequently, this under-representation in the statistics de-emphasises Aboriginal health concerns within both the hospital and the region. It also affects funding and obscures questions about how hospital staff might respond to such issues. Furthermore, there is little attempt to understand or tease out how the institutional and professional culture of the hospital itself might be complicit in reinforcing what are overwhelmingly negative stereotypes about Aboriginal clients.

4. The mind-set of correlating Aboriginality with neglect was found to be common and one that social workers and child protection officers often commented on in terms of Aboriginal people not feeling safe in accessing the hospital. Inferences were commonly made about parenting skills where, for example, parents' reluctance to stay with their children were on occasion linked to neglect or not caring.

It does not take much for this cycle of misinformation to be broken. As one staff member explained, a little in-service training can make a real difference in attitudes:

> *I went to an education day on how Aboriginal people feel about coming to hospitals and it was just so interesting and then we understood why sometimes they don't turn up, why they come late, and that was interesting, it was helpful to understand, … to be more understanding, instead of 'Oh, they didn't show up! … it was interesting because Aboriginal people were giving us the in-service, so it was from their perspective. That made a huge difference*! (Ward Clerk)

5. All health consumers lose some control when entering a hospital setting. For those people who have a history of child removal and recurrent

dislocation, feelings around loss of control are considerably magnified. Some staff commented that these fears can translate into either expressions of neediness or frustration at often incomprehensible cultural systems. For hospital staff, these responses can be both extremely confronting and demanding.

> *It's very much education, so that staff can understand their needs … so staff can understand it's not just greedy, grasping behaviour, [but rather] that the family is under enormous stresses and there are major reasons for that – and you've got to be aware of confidentiality factors as well, so you're not going to tell all their background – but as much as you can, just to raise awareness of individual difference.* (Social Worker)

As stated at the beginning of this section, the term 'cultural diversity' was read as a celebratory notion – albeit at the rhetorical level – where difference is embraced. However, Aboriginal Australian 'success' stories don't seem to be heard or to take on the same triumphant tone, perhaps because of white Australia's uncomfortable and tenuous relationship with its recent past. This story is, of course, much more complicated, but we did find that there were significant differences in how other culturally diverse and indigenous communities were represented, discussed and accommodated within the hospital system.

3.6 The role of the Multicultural Health Unit

The MHU has a role to provide staff with resources, contact support as well as harnessing outside expertise in the areas of research, education, training and service evaluation. Yet hospital staff are far more attracted to issues that emphasise skill-based practical learning than theoretical discussions.

There has been a concerted effort to build up support from those in senior positions over the long-term. However many staff are unaware of these moves and remain sceptical of senior management's commitment to practical change.

There is the perception that training and education around cultural competence is seen as merely something extra or an added burden that staff need to be seen to engage with. In order to make changes the MCH Unit needs to examine and collaboratively navigate the hospital system and its constraints, including how the organisational and professional hierarchies impact on work undertaken across a range of occupations.

While many senior staff know and understand the role of the MCH unit, the lines of communication between front-line service providers and the Unit remain less clear. Hospital staff should be regularly informed about languages covered by the Health Care Interpreter Service and shifting demographics of those who access the hospital, as well as material and knowledge-based resources available from the Unit.

Further attention needs to be paid to recognising the advantages of a multi-directional flow of information and resources across the hospital and between the hospital, MCH unit and the interpreter service.

> *If I have a family come in here, how can the MCH unit help me? And also, vice-versa. As a nurse working here, what sort of stuff am I learning that would be beneficial for the MCH unit to know about that they might be able to address? So, it works both ways … It's not just, 'What can I get from somebody else?', it's also, 'What can I give back?'* (Senior Nurse)

While the MCH Unit's main function is to act as a knowledge base and resource centre that all staff have open and equal access to, hospital staff themselves need to be listened to and utilised as a resource reservoir. To achieve this, the MCH Unit and hospital management need to know what staff are thinking about, how they are responding to different situations and what they are struggling with.

3.6.1 The Diversity Health Coordinator

For those who had worked with the Diversity Health Coordinator there was overwhelming support and appreciation of the work so far undertaken. This is an essential position that it needs to be expanded and develop a high profile around diversity issues within the Access and Equity Committee. The Diversity Health Coordinator can play an indispensable role as a communicator and promoter of Cultural Diversity as part of the Hospital's underlying philosophy. This may alter the current cynicism amongst staff who consider the stance of senior management towards Cultural Diversity to be "top-down, politically correct" and lacks sophistication in both approach and implications for all stake holders.

4. Conclusion and Recommendations: Cultural diversity – the need for an organisational response

Traditional management and training structures operating on Western models of care present significant challenges to the incorporation of cultural diversity considerations in decision making processes and health care provision. The casualisation of nursing present an added factor to human relations within the hospital environment.

The issue of cultural diversity is not one that can be isolated from other cultural practices within the hospital. Therefore, specific practical changes at the ward and management level, as well as conceptual shifts in staff training and education are necessary in the longer term. This will affect the way staff think, work and probably most importantly, engage with the parents and children from culturally and linguistically diverse backgrounds.

The following outlines a series of recommendations that address a number of issues that have been raised by parents/carers and hospital staff throughout this report and have been corroborated in many of the interviews and completed questionnaires.

1. Interpreter and language issues:
1.1 Implement and make widely available information and guidelines on interpreter standards practices.
1.2 Provide "plain English" multilingual brochures on illnesses that are relevant to certain population groups
1.3 Install "Interpreter Boards" in all wards where they are plainly visible to both staff and clients.
1.4 Prepare a multilingual parent's /carer's rights and responsibilities booklet.
1.5 Develop and prepare Hospital-wide "ward word" cards in priority languages for daily use by ward staff.
1.6 Install telephone conferencing facilities
1.7 Supply books, videos and toys from a range of cultural, religious and linguistic backgrounds for parents to use with children on the wards
1.8 Install multilingual and universal signage directions throughout the Hospital Translate "Handy Hints" brochure in Arabic, Chinese and Vietnamese

2. Training and education

2.1 From frontline staff through to management encourage all health professionals to participate in cultural diversity education and training.

2.2 Integrate cultural diversity issues in Staff Orientation.

2.3 Give emphasis on cross-cultural perspectives in relation to parenting practices in research and training initiatives

2.4 Facilitate Hospital staff to share their own varied cultural experiences and backgrounds and how these affect their ability to work and offer best practice within the hospital workplace.

3. Policy and guideline initiatives

3.1 Include a former parent/care spokesperson from a culturally diverse background on the SCH Access and Equity Committee.

3.2 Integrate diversity issues into the Hospitals Strategic Plan.

4. Joint initiatives (Sydney Children's Hospital and Multicultural Health Unit)

4.1 Examine options for establishing a network of cultural volunteers from a wide range of backgrounds.

4.2 Provide training on the interface between cultural and bio-ethical concerns. For instance situations occur when particular staff members cannot understand cultural differences – such as dying, conflict over treatment or delays.

4.3 Consult periodically with a range of culturally diverse community groups on issues of access, quality and partnerships.

Appendices

1. Client (parent/carer) survey questions

General information:

Age:

Cultural Background:

Parents' cultural background:

Do you identify with a religion? If so, which one?

Sex:

What has brought you to the hospital?

How many times have you been to the Children's Hospital in the past year?

Survey questions:

1. What do you think about this hospital? What do you like or dislike about it?

2. Are you able to talk with doctors/nurses/other staff at this hospital about your children's health problems?

3. Hospitals can be overwhelming and sometimes scary places. Does your child talk to you about their visits to this hospital? Do they like their doctors, nurses, physio-therapists etc?

4. Do you feel that your doctors and nurses listen to you and your child when you ask them questions or tell them about what you think?

5. When doctors and nurses are taking your child's medical history are there issues about your cultural background that you think should be talked about?

2. Hospital staff questionnaire/survey

General information:

Age:

Sex:

Cultural Background:

Parents' cultural background:

Do you identify with a religion? If so, which one?

Which department/ward do you work in?

How long have you been working at the Children's Hospital?

Survey questions:

1. In your opinion, what does 'cultural diversity' mean?

2. In your daily work experience, what are the most significant practical issues you have come across when dealing with cultural differences?

3. Can you describe one experience/situation when you think cultural difference has influenced the way you have carried out a particular job (this may have been a positive or negative experience)?

4. Do you feel that cultural differences are recognised as important in your workplace? If so, in what ways? If not, why do you think they are not? Can you give an example? (This could relate to situations either amongst staff or between staff and patients).

5. Your ability to carry out your work is not only limited to your relationship with your patient but is also affected by wider networks (for example, family, friends, other health professionals, community groups etc). Can you describe a situation in which this wider network has presented you with a specific 'problem' when you think about cultural difference?

3. Significant issues identified in staff questionnaire/surveys

• Organising interpreters, providing adequate access
• Making recommendations re: home modifications
• Organising treatment sessions that don't conflict with religious holidays
• Communicating with people with little English/language barriers
• Clients struggle with understanding the medical system
• Clients find it hard to communicate with health care professionals
• Rights of the patient/parent are not evident
• Difficulty in finding government and non-government agencies to help
• Parents' difficulty in filling in written documentation including consent forms
• Problems created by using family members as interpreters. Sometimes the patient   takes on this role
• Food habits, diets, nutrition beliefs/problems
• Raising, feeding children, different parenting and family roles
• Sleeping arrangements
• Death protocols and support, different expressions of grief
• Social/acceptable norms/behaviours/cultural barriers
• Religious beliefs, customs, barriers
• Involvement of religious practitioners
• Cultural dress codes of both patients and parents
• Cultural gender issues among families and between families & staff
• Refusal or questioning of treatment by parents
• Number of relatives that visit
• Domineering nature of eastern-European patients/parents
• Level of patience needed
• Daily interpreting issues without interpreters
• Modifying assessment and treatment procedures/ resistance to Western medical practices, different understandings of illness & care, compliance issues
• Attitudes of some fathers to their child's disability
• Explaining pre- and post-operative information
• Aggressive behaviour towards female staff
• Children being carers for siblings
• Hygiene
• Responses to male nurses by parents/patients
• Racism to and from staff
• Emotions
• Expectations by parents of nurses
• Parents don't have access to usual food
• Attracting ethnic media to SCH
• Prejudices & fears can be hard to reverse – empathising & understanding is difficult when there are pre-existing boundaries

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