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**Hide and seek: Parents' perspectives on children's
access to health care**

**A thesis presented in partial fulfilment of the
requirements for the degree of**

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Abstract

Children are often referred to as the „hidden“ generation, a powerless group who in infancy and childhood depend on their parents and families/whānau to ensure they receive everything in life required to enable them to grow into healthy young people and adults. Some are more disadvantaged than others due to the socioeconomic circumstances they grow up in. This can have lasting effects on their health in childhood with associated impacts later in life. In New Zealand the populations of children most disadvantaged are those from Māori, Pacific and other low income families/whānau. The disparities that exist between children from these populations and other groups whilst lessening, is still significant.

The purpose of this study was to explore with Māori, Pacific and low income parents and caregivers why they choose to „seek“ health services for their children, or not as the case may be. Patterns of use are established early in life therefore it is important to understand children’s health care use. The literature suggests that children’s access to health care is influenced by predisposing factors such as their socioeconomic status, ethnicity, the availability of services, choice of providers, availability of school-based health services, outreach services, relationships between the community and health service providers and having a regular source of primary health care.

A qualitative exploratory design was the methodology chosen for this research. A modified „community as partner“ model (Anderson, 2008) formed the conceptual framework for the research. Sixteen Māori, Pacific and Pakeha parents and caregivers participated in three focus groups to discuss their perceptions of children’s access to health care. Thematic analysis was used to identify codes, categories, themes and sub themes from the data. The New Zealand Child Health Strategy (Ministry of Health, 1998) was used as a model to inform the discussion. The main themes were: reality of life, visibility, knowing you, knowing me and kids come first. The findings suggest that relationships with primary health care providers, the cost of health care for children over five years, awareness of services and a need to prioritise children’s needs, enable or prevent children’s access to health care. Decisions made regarding further service provision for children will be enhanced by health providers and practitioners having a clearer understanding of the enablers and barriers to access and the factors that influence parental choice of services.

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Chapter 1 - Introduction

Introduction

Infancy, childhood and adolescence are unique periods of rapid growth and development, characterised by dependency on others, vulnerability and unfortunately, for a disproportionate number of children, poverty (Chung & Shuster, 2004; Forrest et al., 2004; Ministry of Social Development (MSD), 2006; New Zealand (NZ) Child and Youth Epidemiology Service, 2007). Children require a health system which is responsive and structured to meet their needs and assists in the prevention of, or at least minimises the likelihood of illness and disability. The United Nations (UN) Convention on the Rights of the Child, adopted in 1989 by the General Assembly of the UN and ratified by New Zealand in 1993, promotes children's rights to survival, protection and development (UN, 1989). The Convention's relevance to child health is reflected in the principles of the 1998 New Zealand Child Health Strategy (Ministry of Health (MoH), 1998). The Child Health Strategy provides a framework to improve the health of all children in New Zealand. It, along with other reports and strategies supports the need to more effectively address the health needs of New Zealand's children (Health Funding Authority (HFA) & Paediatric Society of New Zealand (PSNZ), 1998; Minister of Health, 2000; MoH, 1998; UNICEF, 2007).

Aims

The primary aim of this research was to explore with parents and caregivers what health services they perceived would best address the health care needs of their children and how those services should be delivered. Unless attitudes, beliefs and perceived pressures and barriers are known services cannot respond appropriately to children's needs, and improvements in quality of care will not be fully realised. A further aim of the study was to provide recommendations regarding how health services may assist in reducing disparities and improve the outcomes of the children who reside in that community. The research findings will inform the implementation of the local District Health Board's child health strategy.

This qualitative research project involved parents and caregivers of Māori, Pacific and low income New Zealand children. For the purposes of this research children are defined as being from 0 to 12 years of age (Standards New Zealand, 2004). The terms parent and caregiver describe a child's parent, family member or caregiver sufficiently familiar to the child so as to provide emotional support and comfort (Standards New Zealand, 2004).

Background

The health of children, important in its own right, is a central issue for all communities. Children comprise 25% of New Zealand's population, therefore it is in communities' best interests to ensure that all children grow and develop to achieve their potential (MoH, 2006; Statistics NZ, 2006). The concept of Mokopuna Ora¹, where the care and responsibility of children is a collective one, (NZ Child and Youth Epidemiology Service, 2007) and He Korowai Oranga (Māori Health Strategy) (MoH, 2002a) recognise along with the New Zealand Child Health Strategy (MoH, 1998) that children are our future and need protection and nurturing. Specific investment in the positive development of Māori children will have major benefits for New Zealand's total population in future years, especially given that a third of the Māori population in 2006 was under the age of 15 years and statistics support that on average Māori children as a population group have the poorest health status of any ethnic group in New Zealand (NZ Child and Youth Epidemiology Service, 2007; Statistics NZ, 2006). Investing in the health of our children will also have a positive impact on the future adult population (Forrest & Riley, 2004; Hall & Elliman, 2003; Poulton et al., 2002). Protecting children from socioeconomic disadvantage will partially reduce the burden of disease experienced by adults (Poulton et al., 2002). The time to amend or prevent the development of risk factors for long term health problems is in childhood rather than adulthood when those factors are well established (Dowell & Turner, 2007).

The health system aims to assist families/whānau² to anticipate the needs of their children, monitor problems as they arise and coordinate services delivered to children. An effective system promotes healthy development for all children while reaching out to those most in need (Chung & Schuster, 2004). It is essential to understand where the current New Zealand health system is succeeding in meeting children's needs but also where it could be improved. As reported in the 2007 review of the New Zealand Well Child/Tamariki³ Ora Framework, assessing the effectiveness of services and measurement of any improvements in child health outcomes is currently difficult due to a lack of robust information (MoH, 2007a).

The outstanding feature of the 2007 New Zealand Child and Youth Epidemiology Report was the marked disparities in health outcomes that still exist between children and young people of different socioeconomic and ethnic groups (NZ Child and Youth Epidemiology

¹ Mokopuna - Māori definition for grandchild, descendant; Ora is to be alive, well, safe, cured, recovered, healthy, fit

² Māori definition for extended family, family group

³ Tamariki is the Māori definition for children

Service, 2007; Turner, Hoare & Dowell, 2008). Childhood obesity (see Appendix 1), asthma, diabetes, peri-natal problems and infectious diseases are at high levels in New Zealand (Minister of Health, 2006; MoH 2006; NZ Child and Youth Epidemiology Service, 2007). A comparison of the data between the district where the study was undertaken and the rest of New Zealand for hospital admissions of children aged 0-14 years by ethnicity for lower respiratory tract infections and asthma, and children and young people 0-24 years for serious bacterial skin infections is shown in Appendix 1. These examples clearly indicate the disparities that exist between Māori and other ethnicities.

Understanding children's health care use is important because patterns of use are established early in life. These patterns are controlled by parents and caregivers so influencing the decisions that parents and caregivers make regarding health care use is essential. The ineffective use of child health services by parents and caregivers may negatively affect a child's health throughout their lifespan (Janicke, Finney & Riley, 2001). A range of known factors, for example, accessibility, the availability and number of providers in lower socioeconomic communities, choice of providers, availability of school-based health services, outreach services, relationships between the community and health service providers and having a regular source of primary health care (Ames, 2007; Chung & Schuster, 2004; Mansour, Lanphear & DeWitt, 2000; Rosenbach, Irvin & Coulam, 1999) all influence use of child health services.

Improvements in child health are critical to reducing health inequalities (MoH, 2006). In order to address health inequalities, initiatives to improve the health of children need to consider services for children in the target populations of Māori, Pacific and low income New Zealanders, as it is within these populations where the greatest inequalities exist resulting in consequential higher need (MSD, 2006; NZ Child and Youth Epidemiology Service, 2006).

A number of government strategies and policy documents set the direction and context within which child health is viewed and consequently inform this research: the New Zealand Health Strategy (Minister of Health, 2000), the Primary Health Care Strategy (Minister of Health, 2001), He Korowai Oranga (Māori Health Strategy) (MoH, 2002a), the NZ Child Health Strategy (MoH, 1998) and the Pacific Health and Disability Action Plan (Minister of Health, 2002). The New Zealand Health Strategy (Minister of Health, 2000) provides the overall framework for the health sector to improve the health of New Zealanders, to ensure accessible and appropriate services for people, and to reduce inequalities amongst New Zealanders with a focus on Māori, Pacific peoples and low

income New Zealanders (Minister of Health, 2000). There is a correlation between almost all the key areas mentioned in the New Zealand Health Strategy with child health, ranging from reducing smoking and improving oral health to improving Pacific people's health and improving the responsiveness of mental health services (Minister of Health, 2000). Ensuring access to appropriate child health care services, including well child and family health care and immunisation is a specific population health priority highlighted in the strategy (Minister of Health, 2000).

The Minister of Health's current priority areas includes child and youth services. All of the New Zealand Health Targets (MoH, 2007b) affect children with indicators for immunisation and ambulatory sensitive hospitalisations included in the measurements (MoH, 2007b). In 2007 a review of the Pacific Health and Disability Action Plan (Minister of Health, 2002) identified child health as a key clinical priority area (MoH, 2007c).

Significance

Services for children within any community are very complex with the need for an infrastructure that crosses health boundaries and relates to the education and welfare sectors (HFA & PSNZ, 1998). Services should be established based upon evidence of population needs rather than being determined by local provider circumstances. There must be rational assessment of the needs and expectations of communities prior to the development of new health services and when reviewing existing services (Eaton, 2000). New Zealand District Health Boards undertake health needs assessments on their populations on a regular basis, however, these reports do not capture the expectations of communities in meeting those needs, or determine how those needs might be best met.

Posavac and Carey (2007) argue that social and health indicators cannot be used as the only source of information about the needs of a community, whilst Clendon and White (2001) note that relying solely on this type of data increases the likelihood that important health issues will be missed. Social and health indicators confirm the existence of problems and where they are most pressing, however, they do not give the fundamental causes of problems. Although social and health indicator data may indicate need, it does not account for the attitudes, beliefs and perceived pressures against, and barriers to, an improvement in child health outcomes (Kidd & Parshall, 2000). In order to best meet the needs of a population and/or a community it is necessary to determine first what is required to address social and health indicators. The determinants and social indicators of the community in this research indicate high need, however, it is not clear whether the health services provided and how they are delivered, is meeting that need. There is no

qualitative data available to inform the discussion on what may need changing in this community in order to improve the health of their children.

Context

Interest in this research stemmed firstly from my personal experience as a paediatric nurse, public health nurse and community ear nurse specialist working with high numbers of Māori and Pacific children and their families/whānau and other socially disadvantaged populations. It became obvious to me during the time that I held primary health care nursing positions that working with communities, using the community development model (World Health Organisation (WHO), 1986) to improve children's health, was of value. I was fortunate to assist the communities in which I worked with projects aimed to make a difference to children's health outcomes.

Child health statistics are improving in New Zealand, however, there are still significant disparities and 26% of our children live in severe or significant circumstances (MSD, 2006). This is not a figure to be proud of and signals a significant challenge for health and social agencies. The district where I currently live has pockets of high deprivation and although a number of new primary health care services have been introduced in the past few years, there remains a need to enhance services provided to children in order to make a real difference to children's outcomes.

My interest in this research also stemmed from my role as a professional leader of nurses who work in many settings across the health sector. I have the opportunity to participate in strategic conversations and to influence the direction and delivery of health care. My experience in nursing has given me the evidence that nursing roles can, and do, make a difference to the health of individuals and populations. I am also very aware that any service delivered to children must be done in partnership with parents and caregivers and their families/whānau.

In my senior nursing role I am aware of the inconsistency and at times, ad hoc manner in which community participation occurs, although more effort is being made. There is still considerable rhetoric surrounding the interaction of health providers with community members, especially with parents and caregivers. Many issues important to parents and caregivers are ignored. It was timely to give the opportunity to parents and caregivers in this high deprivation community to provide some feedback on the services available for their children, and for them to express their views and offer some suggestions for improvement.

Health professionals' views are often taken into account in the development and review of services, but it is the actions of parents and caregivers and communities that will have the most impact on whether or not children access health services and an improvement in their health occurs. Family and whānau are the most important influence on children's health and well being (MoH, 1998) therefore the views of parents and caregivers need to be considered in relation to the delivery of services to their children (Hall & Elliman, 2003).

Community participation

One of the many concepts basic to primary health care is community participation, which is strongly advocated in the development of service initiatives (Hutchinson, Anderson & Gottschalk, 2008; Mason et al., 1999; Minister of Health, 2001). Participation from communities and their involvement in the identification of health issues, and the planning and implementation of health care solutions is crucial if a difference in health outcomes for children is to be achieved. Consumer input is critical in understanding local issues in health care and partnering with communities will ensure services are more likely to reflect the needs and priorities that are set by communities, not just by providers (Higgs, Bayne & Murphy, 2001; Spenceley, 2005). Communities become expert in knowing what policies and practices can contribute to the well being of families and what might hinder that well being (Munford & Walsh–Tapiata, 1999). Consulting with Māori and Pacific peoples regarding the development, implementation and evaluation of services for children will assist in meeting differing cultural expectations as well as health service needs. Community engagement and consultation therefore are fundamental to good decision making and the development of effective plans that lead to better or more appropriate services for children and improved health outcomes.

The community

The district in which this research was undertaken is considered to be largely rural. The community in this study has the greatest socioeconomic deprivation in the district and is an urban community within a medium sized New Zealand township. On the New Zealand Deprivation (NZDep) index the community sits at eight. The NZDep index is a relative scale comparing those who live in the most and least deprived areas, with one being the least deprived and ten being the most deprived (NZ Child and Youth Epidemiology Service, 2007). There are greater numbers of Māori and Pacific residents than any other community within the district. The community has the highest number of solo parent families, the highest number of households without a landline telephone, the highest number of households without transportation and the least educational

attainment of any other district within the region. Unemployment is higher in this district than anywhere else (Statistics NZ, 2006).

Community can be defined in a number of different ways but as Murphey (1999) describes it, “definitions of community should be grounded in locally meaningful realities” (p. 76). For the purposes of this study one primary school (year one–eight) was selected as the school is seen as a focal point for the people living in the part of the township where the school is located. The school’s surrounding physical boundaries and social environment therefore constituted the community for this study. The school is the largest primary school in the district, has a decile 2 ranking⁴ with 6.5% of its enrolled population being of Pacific descent, 52% Māori, 40.5% Pakeha and 1% of other descent, illustrating a similar ethnic breakdown to the wider community.

The community is serviced by a variety of child and family health providers. Lead maternity carer services are provided during pregnancy and following birth up to six weeks of age. Well child/tamariki ora services are provided to children under the age of five years and their families/whānau. These are provided by the Royal New Zealand Plunket Society (Plunket) and through a local Māori Health Provider. Well child services aim to support families/whānau to maximise their children's health status and developmental potential and to establish a strong foundation for ongoing healthy development (MoH, 2007a). „B4 School“ health checks for four year olds have recently commenced as an inclusion to the well child schedule. These checks are designed to identify any developmental or psychological issues in children that require early intervention.

Other services currently provided assist in the treatment of illness and disease, for example, General Practitioners (GPs) and hospital services. Disability support services for children are coordinated through the local needs support agency, a service provided in this district by the local District Health Board. Oral health services are provided through the school dental service and through referral to dental surgeries in the town. Some health providers take a more preventative approach, for example, the Public Health Nursing service provided to the school. Vision hearing testing services are provided at early childhood centres, primary and secondary schools and an outreach nursing and doctor service is provided at the local Pacific Community Centre. An outreach immunisation service is available if required and a clinical nurse specialist

⁴ A decile ranking is assigned to all schools in New Zealand based on socioeconomic status of its student population where one is the lowest and 10 is the highest.

for diabetes and childhood asthma provides a service within the community as needed. A part time Pacific Community Health Worker assists the Pacific community specifically in relation to assistance with service information and access to the Pacific Community Clinic. The school has a part time social worker based on site.

Children from 0–14 years comprise 19% of the community's population. Children and young people in the district are more likely to live in areas of high deprivation, have high rates of hospitalisation, and rates of dysfunctional families and child abuse notifications are high and increasing (NZ Child and Youth Epidemiology Service, 2005). The 2007 New Zealand Child and Youth Epidemiology Service Report for the district showed marked ethnic differences in oral health status and hospital admissions for injury were higher for Māori and Pacific children and young people living in the more deprived areas. During 2002–2006 the most frequent reasons for acute hospital admission overall were injury/poisoning, gastroenteritis and asthma with Pacific and Māori children under five years of age and those living in more deprived areas, representing 69% of lower respiratory admissions, attributable to either bronchiolitis or asthma. Admission rates for Māori were higher (NZ Child and Youth Epidemiology Service, 2007; MoH, 2008a).

Outline of thesis

This first chapter has outlined the context for this research including the researcher's background and interest in the topic, the significance of the study and stated the aim of the research. It provides information about the community within which the study was undertaken as well as the context for exploring the views of parents and caregivers. Chapter two reviews the literature in relation to social disadvantage, access to health services, an understanding of services and continuity of care.

Chapter three discusses the research methodology and the method used, the ethical approval process and the selection of participants. A qualitative exploratory methodology was chosen for this study as it brings the views of parents and caregivers to the forefront. Focus group interviews were chosen as the method for data collection, giving the participants the opportunity to express and discuss their views individually and collectively. Mechanisms used to ensure rigour throughout the study are presented and an overview given of the general inductive data analysis and thematic analysis processes. Chapters four and five present the findings of the focus group discussions in relation to four identified themes that emerged from the data. Chapter six is a discussion of the findings generated by the study in relation to the literature. The limitations of the

study are acknowledged and suggestions made for future research. Chapter seven contains concluding remarks and recommendations for the future.

Conclusion

One of the best ways to prepare for New Zealand's future is to invest in the young (MSD, 2006). The focus of this thesis concerns what parents and caregivers of children from a low socioeconomic community believe will make a difference to their children's health outcomes. The demographics of the community in the study and the associated determinants of health present a clear picture of need, however, the effectiveness of health services delivered to that community is not clear.

This research creates the opportunity for parents and caregivers in the community in which the study was undertaken to identify what is needed to improve the health of their children. Exploring the views of parents and caregivers in regards to health care coverage and access, the quality of care provided, how that care is provided and how provision could be improved in order to better meet the needs of the community's children will contribute to the enhancement of services. This will assist in ensuring children receive timely, high quality, effective and culturally appropriate health and disability services to improve their health and reduce inequalities. Findings from the study will assist in the development of District Health Board (DHB) Child Health Strategies, having actively encouraged Māori, Pacific and lower income family/whānau participation in the discussion around the delivery of health services to children in a community with high needs.

Chapter 2 - Literature review

Introduction

This chapter explores the literature related to children's access to health care. In order to reduce disparities in New Zealand children a better understanding is required of why health service access and utilisation for some children is less than optimal. The review begins with an overview of the effects of social disadvantage on children and their families. Experiences in childhood impact on health behaviours in adulthood, therefore, the importance of investing in children's health and the difference this would make for the next adult generation is discussed. Parents' and caregivers' understanding of their children's need for health services coupled with their use of services is explored. Factors that influence whether children receive appropriate and timely health care are also addressed.

A search of the literature currently available in New Zealand and internationally, revealed a gap in knowledge regarding parental and caregiver views on what could assist them to improve their children's health. To date there has been limited research undertaken on the effects of children's health services in New Zealand, particularly in the primary health care and community setting. The Well Child/Tamariki Ora Framework Review undertaken in 2007 by New Zealand's Ministry of Health identified the lack of quality data available to enable assessment of well child service effectiveness, and whether services provided are improving child health outcomes. The literature and studies referred to in this chapter originate predominantly from North America, New Zealand and the United Kingdom.

Literature criteria

The aim of this literature review was to critically review the published works on the topics identified. The search criteria took into account specific New Zealand populations where disparities exist and where health outcomes for children are less than optimal, that is, Māori, Pacific and those on lower incomes. Due to the lack of New Zealand research dealing specifically with these groups, the search was expanded to include populations internationally where there is disparity in child health outcomes. Further search criteria included children's access to and use of health care, specifically in the primary health care setting and the Emergency Department (ED).

Articles were obtained using searches of CINAHL, Web of Science, Medline, Pub Med and Ebsco databases and a Google NZ and Google Scholar search of the Internet.

Books and opinion articles were used to support the literature where required. Reference lists and bibliographies were searched for additional relevant work. Minichiello et al. (2004) noted that a literature review can use various types of literature, not just research studies, using the terms "...theoretical literature, scholarly non-research literature and scholarly literature" (p.12). The literature for the present study included research, articles and publications dated from 1994 to 2008.

Social disadvantage

It was not the purpose of this study to explore how the effects of socioeconomic disadvantage can be changed; however, it is useful to examine some of the literature as it relates to childhood in the context of environments similar to that in which this study was undertaken. The effects of socioeconomic differences on health in adulthood are well known, but the impact of adverse circumstances earlier in life on adult health is less well documented. A number of authors have undertaken research or commented on the effects of social disadvantage on children's health (Davey Smith & Lynch, 2004; Fergusson et al., 2005; Galobardes, Lynch & Davey Smith, 2004; Hall & Elliman, 2003; Lynch et al., 2001; Mielck, Graham & Bremberg, 2002; Najman & Davey Smith, 2000; NZ Child and Youth Epidemiology Service, 2006, 2007; Starfield, 2006; St John & Wynd, 2008; Turner, Hoare & Dowell, 2008). A brief overview of studies and related discussion is provided in order to alert the reader to some of the literature regarding the effects of social disadvantage on children.

The 2007 report prepared by the NZ Child and Youth Epidemiology Service for District Health Boards in New Zealand highlighted a broad range of areas with poor child health outcomes and a continuation of significant socioeconomic and ethnic disparity in outcomes across almost every health indicator for children. Twenty six percent of New Zealand children are living in families with severe/significant hardship (MSD, 2006) and are therefore placed at considerable disadvantage as a result of their families' limited socioeconomic resources (NZ Child and Youth Epidemiology Service, 2007). Adverse socioeconomic factors such as unemployment, poor housing, low income and family violence are key contributors to poor child health outcomes (Hall & Elliman, 2003; Mielck, Graham & Bremberg, 2002; MoH, 2007a). In New Zealand Māori and Pacific children are most likely to be affected by these variables (St John & Wynd, 2008). Their health status is lower than that of other New Zealand children (MSD, 2006; NZ Child and Youth Epidemiology Service, 2005; St John & Wynd, 2008) according to a number of measures such as infant mortality and infant/child hospitalisation rates (NZ Child and Youth Epidemiology Service, 2006; MoH, 2008b).

Internationally infant mortality is the most commonly used indicator for child health (Starfield, 2004). In New Zealand infant mortality has decreased markedly in recent decades and the immunisation rate is improving although there are still marked disparities overall (NZ Child and Youth Epidemiology Service, 2005). Reducing infant mortality and increasing immunisation rates are priority areas for reducing disparities (MoH, 2007a) but the potential for these variables to affect other fundamental child health disparities in relation to the provision of services, such as access to primary health care, is limited (Beal, 2004).

A review of the health equity literature was undertaken by Starfield (2006). The review revealed that the basis for many types of inequity in health lies in early life, largely due to social disadvantage (Galobardes, Lynch & Davey Smith, 2004) and that inequity is greater at younger than older ages (Starfield, 2006). Davey Smith and Lynch (2004) support these findings reporting that poorer maternal health prior to pregnancy and infant/child infections are the main factors that cause inequity in children's health and are more common amongst socially disadvantaged populations. Similarly Turner, Hoare and Dowell (2008) in an article on the health and human rights of children in New Zealand, note that experiences in utero and early childhood may have a profound effect on long term health and social outcomes with foetal growth being influenced by poorer maternal health. It has also been identified by Fergusson et al. (2005) that issues such as child abuse are more frequent among children and young people who have been exposed to adverse childhood environments characterised by multiple social, educational, economic and related disadvantages.

The findings and discussion by Galobardes, Lynch and Davey Smith (2004) and Turner, Hoare and Dowell (2008) are supported by the Australian Commonwealth Department of Health and Aged Care's national policy statement (Hupalo & Herden, 1999) on socioeconomic inequalities in health (Najman & Davey Smith, 2000). A review undertaken by the Australian Commonwealth highlighted a number of factors regarding socioeconomic inequality, identifying that when inequalities act during the foetal and childhood period they continue on to contribute to adult inequalities (Najman & Davey Smith, 2000).

Lynch et al. (2001) present an international cross sectional study examining associations between income inequality and low birth weight, life expectancy, self rated health and age specific and cause specific mortality. Data for the study was provided from countries

that had previously participated in the Luxembourg Income Study (Atkinson, Rainwater & Smeeding, 1995). Findings from Lynch et al.'s study included a strong association between higher income inequality with greater mortality among infants, and a moderate association between higher income inequality with greater mortality among those from both sexes aged from 1 to 14 years. New Zealand did not provide data for the Luxembourg study; however, evidence from New Zealand shows a similar association between income inequality and infant mortality (NZ Child and Youth Epidemiology Service, 2007).

Social disadvantage affects child health outcomes, however, understanding how poor child health outcomes impact on adult life is necessary in order to provide the rationale for further investment in children's health. A brief review of the impact of less than optimal child health on adult health was undertaken.

Investing in children's health

Child development is a powerful determinant of health in adult life therefore achieving good health during childhood will have a profound effect on their health as adults (Hall & Elliman, 2003). The risk factors for many adult diseases and the opportunities for preventing these diseases arise in childhood (Dowell & Turner, 2007; Forrest & Riley, 2004; Minister of Health, 2006; MoH, 1998; MoH, 2007a; NZ Child and Youth Epidemiology Service, 2005; Poulton et al., 2002). Poor child health and development may also have an adverse impact on broader social outcomes, including sexual and reproductive health, mental health, violence, crime and unemployment (MoH, 2007a).

Poulton et al. (2002) studied the association between socioeconomic disadvantage in childhood with a range of health risk factors and outcomes in adult life. Assessment was undertaken on an unselected cohort of 1000 New Zealand children, born in 1972–73. They were assessed on a number of health outcomes at birth and at 3, 5, 7, 9, 11, 13, 15 and 26 years with the variables tested for an association between childhood and adult socioeconomic status. The combination of a less advantaged childhood and adult circumstances was related to poorer cardiovascular health, dental health and substance abuse resulting in clinical dependence. This suggests that the duration of socioeconomic adversity matters. The authors concluded that protecting children against the effects of socioeconomic adversity could reduce the burden of disease experienced in adulthood.

The findings from Poulton et al.'s (2002) research are supported by Halfon and Hochstein's (2002) American study. Halfon and Hochstein provided evidence that many

important adult diseases such as obesity, diabetes, hypertension and cardiovascular disease and certain mental health conditions such as depression are affected by events during gestation and early childhood. Behaviours developed in childhood can be linked to the incidence and impact of diabetes, cardiovascular disease and poor oral health in youth and adulthood (Forrest & Riley, 2004; MoH, 2007a, Nelson, 2005). Halfon and Hochstein (2002) suggest using the life course model of how health is produced to assist in understanding how children's health is connected to the development of illness and disability among adults. In support of this approach, Forrest and Riley (2004) have identified that the life course model provides the scientific basis required to describe the continuity between child and adult health. As a result of an association between events during gestation and early childhood with adult health, health policies need to more actively foster positive long term outcomes for children and their families and communities (Forrest & Riley, 2004).

In this section a brief discussion has been presented regarding the effects of social disadvantage on children's health and the value of investing in children's health in order to lessen the impact of illness and disease in adulthood. The literature shows that early childhood manifestations of poor health have correlates in health at older ages. The issues raised through these studies and discussion relate to a number of factors in terms of the provision and delivery of health services. Factors influencing the provision and delivery of health services to children, such as access and use, are explored through the literature in the next section.

Access to health services

The notion of access in the context of this research is adopted from that suggested by Goddard and Smith (2001) and refers to "...the ability to secure a specified range of services [for children], at a specified level of quality, subject to a specified maximum level of personal inconvenience and cost, whilst in possession of a specified level of information" (p.1151). In the majority of circumstances it will be the parents and caregivers of children to whom this definition applies as access to health services for children occurs predominantly through them. However, for some parents and caregivers the assistance of many agencies, for example health and social agencies, is required to ensure children have adequate and appropriate access to health services.

All children should have access to services according to their health or disability support need. The Child Health Strategy (MoH, 1998) outlines a number of factors which are required to achieve good health in childhood. As discussed earlier equity is one of those

factors and is important for access to health services, health outcomes and resourcing of services. As found in the New Zealand Well Child/Tamariki Ora Framework review (MoH, 2007a), inequity in access occurs when services do not adequately identify those children with high needs or meet those needs in an appropriate way. Mackenbach (2003) undertook an analysis of the role of health care in The Netherlands in reducing socioeconomic inequalities in health, and identified that health care systems can contribute to reducing inequalities in health by ensuring the absence of differences in access to health care and in the quality of health provided. Similarly, in evaluating the effectiveness of American and British health policies in tackling disparities and inequalities, Exworthy et al. (2006) noted that the lack of access to health care is a major cause of disparity in any system and is largely caused by socioeconomic factors.

The focus of this research centres mainly on access to and use of primary health care services for children, including hospital EDs, and the appropriate provision and quality of those services. Hall and Elliman (2003) and Chung and Schuster (2004) describe the complex factors that threaten access to primary health care services for children as ethnicity, language, education and income. Issues such as the availability and number of providers in lower socioeconomic communities, choice of providers, availability of school-based health services, outreach services, relationships between the community and health service providers, availability of interpreters and cultural sensitivity of providers may also affect access (Chung & Schuster, 2004; Minister of Health, 2001).

There is limited qualitative research available in New Zealand in relation to access to health care for children in general, let alone for those from Māori, Pacific and low income families. In the American literature access is often referred to in light of whether the child's family has insurance which is not applicable to the New Zealand context. However, other issues and barriers identified for ethnic minorities and low income families in accessing healthcare for children in America, to a certain degree, are no different to those that have been identified in this country (Bolitho & Huntington, 2006; Grant et al., 2001; MoH, 2007a; NZ Child and Youth Epidemiology Service, 2007). It was still appropriate therefore, to review literature from the United States as the majority of studies regarding American children's access to health care refer to ethnic minorities and low income populations.

The literature regarding access covers a wide range of categories including barriers to access (Ames, 2007; Mansour, Lanphear & DeWitt, 2000; Rosenbach, Irvin & Coulam, 1999), consumer perceptions of access (Higgs, Bayne & Murphy, 2001), practitioners'

perception of access (Ames, 2007), home based services for children (Barnes-Boyd, Fordham & Nacion, 2001; Fergusson et al. 2005; Freed et al., 1999; Kendrick et al., 2000; MoH, 2007a; Olds et al., 2002; Shute & Judge, 2005), use of the American „medical home“⁵ model (Farmer et al., 2005), and barriers related to access for adults (Spenceley, 2005).

In studies exploring the barriers to children’s access to health care a number of variables were highlighted, for example having a regular source of primary health care, poverty and the probability of an ED visit (Ames, 2007; Mansour, Lanphear & DeWitt, 2000; Rosenbach, Irvin & Coulam, 1999). Ames (2007) sought practitioners’ views on perceived barriers to access of medically underserved American children. Rosenbach, Irvin and Coulam (1999) undertook a comparison between children participating in the American Medicaid Extension Demonstration, a programme experimenting with innovative approaches to providing health care coverage for low income children, with children eligible but not participating in the programme. Mansour, Lanphear and De Witt (2000) specifically explored the barriers to treatment of urban, minority American children with asthma. Spenceley’s (2005) systematic review of the literature regarding access to formal health services for Canadians living with chronic illness pertained to adults only, however, the review is relevant as the findings in the literature are similar to suggested barriers to access for children.

A study undertaken by Ames (2007) identified that poverty, transportation, insurance, parental time constraints whereby parents are unable to take time off work to attend to children’s health care needs, lack of language and education skills, complexity of the health care system, and not having a regular source of primary health care were barriers perceived by parents in accessing health care for their children. These findings are similar to those identified in Mansour, Lanphear and De Witt’s (2000) study, that the most frequent types of barriers to access were parental and child health beliefs, knowledge of asthma management skills, cultural issues, competition of the child's asthma with other basic life needs, followed by environmental factors such as geographic location and transportation. Health care provider characteristics such as lack of continuity, availability of providers and limited hours of operation, as well as health care system factors related to whether parents have access to providers or health care based on their circumstances, were also identified as barriers to care for children with asthma

⁵ The American Academy of Pediatrics (2004) definition of a medical home for children is “the provision of accessible, continuous, comprehensive, family centered, coordinated, compassionate and culturally effective care” (p.1543).

(Mansour, Lanphear & DeWitt, 2000). Spenceley's (2005) review of the literature showed that feelings of vulnerability, provider disbelief of client and family perceptions, devaluing of family and client knowledge, clients' prior negative experiences with a provider, lack of provider sensitivity, issues with language and communication, stigma, humiliation, and differences in identity and beliefs between provider and client/family were all identified as impediments to access to health care.

Structural components of services such as inconvenient service hours, lack of interpreter services, service costs, and services located at a distance were additional factors affecting access (Spenceley, 2005). Other factors identified were inflexible working hours of clients, limited financial resources, and lack of reliable transport, which restricted people's ability to work around the limitations of formal services and prevented access to or awareness of services. Some of these barriers to access were also identified in Ames' (2007) and Mansour, Lanphear and DeWitt's (2000) studies undertaken on children.

Rosenbach, Irvin and Coulam (1999) used the probability of a usual source of routine care, the probability of a physician visit, the probability of a preventative check-up, the probability of an ED visit and the probability of unmet need to evaluate impact on children's access to care. Results showed that children who were uninsured were less likely to have a „medical home“ that is a regular source of care, to visit a physician, were more likely to visit ED and had higher levels of unmet need. Similarly other studies identified that not having a regular source of care impacted on access for children (Ames, 2007; Mansour, Lanphear & DeWitt, 2000). Starfield (2007) notes that a usual source of care is considered a necessary component of continuous primary health care, therefore is useful as a key indicator of access. However, having a regular source of primary health care may facilitate entry to health services but does not necessarily ensure the use of health services.

The „medical home“ model for children was found to be beneficial in an evaluation undertaken by Farmer et al. (2005) into the feasibility and impact of a „medical home“ demonstration project for rural American children with special health care needs. Questionnaires were completed by parents pre and post treatment assessments for their children. Results following intervention for children included a significant increase in parental satisfaction with care coordination and access to mental health services. A decrease in family needs, caregiver strain, parents' missed work days, children's school absences and use of ambulatory services was also reported by parents. The authors concluded that results from the study demonstrated that a team approach to the delivery

of primary health care does improve comprehensive and coordinated care to children with chronic health conditions and their families, even if they live in rural areas. The study identified some limitations as the improvements may have been attributable to chance or external factors and not having a control group meant it was difficult to know exactly why improvements occurred. In addition no independent sources of information were gained to corroborate parental feedback, for example questioning schools regarding child absences.

Possible solutions for improving access to medically underserved children were suggested by the health practitioners that participated in Ames' (2007) study. These ranged from offering public transport to local communities, providing families with services, information and education through locating mobile clinics in churches and other community buildings, having outreach services available outside normal working hours to improve access for working parents, and using paraprofessionals to improve continuity of care and assist those parents with limited English language skills to become more knowledgeable about the health system and services. Providing children with a „medical home“ would also assist with continuity of care. Practitioner participants in the study noted that a mechanism for exchanging information with parents regarding agencies and services would be beneficial in assisting them to provide care for children. Health practitioners expressed a desire to work collaboratively with other providers in order to provide current information about services to families, caregivers, and community services such as schools. Spenceley's (2005) review highlighted factors in the health care relationship that facilitated access including having a trusting provider relationship, sensitivity of provider to client culture, personal follow up by provider, clients knowing a system insider to advocate for their needs, provision of medical knowledge in an understandable form and a personal/social connection between provider and client. Factors promoting access included satisfactory transportation and financial resource, familiar, convenient, local locations for service provision, flexibility in service hours, choice of providers, culturally appropriate information sources and understandable explanations given by providers as to what to expect from services.

A study undertaken with consumers by Higgs, Bayne and Murphy (2001) to determine their perspective on issues related to health care access, found that income, education and ethnicity were the primary factors affecting consumers' perceptions of the degree to which their medical, dental and mental health needs were being met. The quality of care provided, consumer relationships with providers, immediacy of access and cost of services were important concerns for consumers. Major barriers to access identified

were cost, inability to obtain services when needed, discomfort with providers and having to miss work to attend appointments. Although these findings related to adult access to health care they have been identified by other authors as being similar for children (Ames, 2007; Chung & Schuster, 2004; Hall & Elliman, 2003; Rosenbach, Irvin & Coulam, 1999).

Very little literature was found regarding children's access to primary health care in the New Zealand context. The research sourced related predominantly to accessing hospital based services (Bolitho & Huntington, 2006; Grant et al., 2001), rather than primary health care. Bolitho and Huntington's (2006) pilot study explored the experiences of Māori families accessing hospital services for children with respiratory conditions. Participants in the pilot identified the availability of resources to families including financial resources, access to transport and locality of health care services, the choice of health care provider available, flexibility of health care service hours related to parents' ability to take time off work and parents' feelings of vulnerability as issues regarding access for their children. Parents' feelings of vulnerability resulted from health professionals not communicating with them or treating them as if they did not know what they were doing, parents' uncertainty in whether or not they needed to access health services, and parents not wanting to be seen by health professionals as either a hassle or over-reacting about how unwell their child appeared. The findings from this study recognised the part that socioeconomic status plays in relation to access, but additionally identified a number of other barriers influencing whether or not Māori parents access health care in a timely way for their children.

Determining whether there were any ethnic differences in children hospitalised with pneumonia in New Zealand was the objective of a study conducted by Grant et al. (2001). Comparisons of vital signs and intensity of therapy were made between Māori, Pacific and European children. The results showed that Māori and Pacific children hospitalised with pneumonia had more severe symptoms than European children. Differences in disease severity were obvious from initial presentation to ED and during admission. The authors discussed a number of factors that may contribute to the results found, including children's exposure to a wide range of infectious organisms exacerbated by a larger number of Pacific and Māori children living in crowded households, difference in nutritional status and difference in pre-hospital management, however, the study was unable to demonstrate these as specific causes for the disparity between ethnicities in children hospitalised with pneumonia.

The provision of home based services can be interpreted as an enabler to access. The next section reviews the literature related to national and international home based programmes and the potential and realised effect they have on child health outcomes. This section is included in the review as home based services have been identified as a method of improving access to health services for some populations.

Home based services

Home based programmes or the delivery of services through home visiting are umbrella terms that imply a strategy for delivering a service to children and their families, rather than a type of intervention per se. Both international and New Zealand evidence suggests that home based preventive interventions delivered by trained health professionals can improve a range of outcomes for preschool children considered to be at risk of poorer health outcomes as well as enabling access to services for many families who are unable to leave their home or community (Fergusson et al.; 2005, Kendrick et al.; 2000; MoH 2007a; Shute & Judge, 2005). Well child visits provide an opportunity for health practitioners to recognise and address potential problems and concerns that may be seen either in the home or at a clinic (Freed et al., 1999).

The programmes reviewed through the literature included a systematic review and meta-analysis of British home visiting programmes (Kendrick et al., 2000), Starting Well, the Scottish home visiting programme (Shute & Judge, 2005), and the New Zealand Early Start programme (Fergusson et al., 2005). The Scottish and New Zealand home based programmes were established to assist families who are disadvantaged or facing difficulty and stress in their lives. Dubay and Howell (2006) undertook an evaluation of the Los Angeles Healthy Kids Program and Freed et al. (1999) present a study on the demographic and health care system factors associated with the receipt of well child visits in the first two years of children's lives. Olds et al. (2002) and Barnes-Boyd, Fordham and Nacion (2001) examine the effectiveness of home visiting by both paraprofessionals and nurses.

Kendrick et al.'s (2000) systematic review suggested British home visiting programmes were effective in increasing the quality of the home environment. Results from studies reviewed indicated a significant improvement in a variety of measures of parenting using the Home Observation for Measurement of the Environment (HOME) scores. Interventions provided by the home visitors, most commonly nurses, but also teachers and social workers, included education, advice, emotional support, assistance with finding help for within the home, finding housing, and accessing services. In Fergusson

et al.'s (2005) evaluation of the New Zealand Early Start home visitation programme, significant benefits were indicated in the areas of improved use of child health services, reduced rate of hospital attendance for injury/poisoning, increased preschool education, increased positive and non punitive parenting, reduced rates of severe parent/child assaults and reduced rates of early problem behaviours. In Scotland's programme, Starting Well, higher child dental registration rates and lower rates of maternal depressive symptoms provided positive evidence of early programme impact (Shute & Judge, 2005). Fergusson et al. (2005) concluded that small to moderate benefits were associated with the Early Start Programme for children and their families and an improvement was found in child health, pre-school education, service utilisation, parenting, child abuse and neglect and behavioural adjustment. In Kendrick et al.'s (2000) systematic review it was not possible to ascertain which aspects of the programme were specifically effective in improving parenting, however, the authors identified from the literature that the package of interventions provided by the home visitors was associated overall with improvements in parenting and the quality of the home environment. As mentioned earlier the majority of programmes used professional home visitors but some used lay workers with similar results found as those using professional visitors.

A study undertaken by Freed et al. (1999) found that a lesser number of well child visits was associated with maternal delay in the initiation of antenatal care with higher numbers associated with receipt of all outpatient care in private physician offices. If children received an adequate number of well child visits then this was associated with the child being up to date with their immunisations. Results from this study indicate that inadequate receipt of well child visits may delay the early identification of problems in children and the ability to intervene sooner.

Olds et al. (2002) and Barnes-Boyd, Fordham and Nacion (2001) examined the effectiveness of home visiting services provided by teams of nurses and paraprofessionals. In Olds et al.'s (2002) study results indicated that nurses produced significant effects on a wide range of child and maternal outcomes and paraprofessionals produced small effects that rarely achieved statistical or clinical significance. In contrast to those findings results from Barnes-Boyd, Fordham and Nacion's (2001) study indicated that utilizing community health workers as part of the home visiting team was as effective as a nurse only team in meeting the needs of families who were at high risk of poor infant outcomes. In this study comparisons were made with outcomes from a previous programme that used nurses only in the team. The use of community health workers with limited educational backgrounds is a common

service delivery strategy in many home visiting programmes. Olds et al. (2002) argue that if paraprofessionals are utilised they require comprehensive training and the right resources and support provided to them. The community health workers in the nurse managed team in Barnes-Boyd, Fordham and Nacion's (2001) study had received significant training before undertaking their roles and the nurses were prepared to work with them. Ongoing team building occurred and clear protocols and guidelines were developed.

It is noted in Olds et al.'s (2002) study that the paraprofessionals undertaking home visits shared many of the social characteristics of the families that they served. It is not uncommon for some ethnic groups to prefer to have a health professional who shares similar or the same characteristics. Shared social characteristics increase health professionals' ability to empathise with their clients who in turn are more likely to trust those who are similar to them. The benefits found with the use of community health workers in Barnes-Boyd, Fordham and Nacion's (2001) study included the community health worker having an in depth knowledge of the social realities of the community, which increased the likelihood that interventions were more culturally acceptable, responsive, and accessible. Interventions were more likely to be reality based due to the community health worker's local knowledge.

The home visiting programmes reviewed (Fergusson et al., 2005; Kendrick et al., 2000; Shute & Judge, 2005) provide universal coverage at no cost, which is worth considering in the context of overall delivery of services to children. Most New Zealand children can access a GP under the age of six years for free but parents and caregivers pay varying fees for over six year olds, albeit they are still subsidised. The Los Angeles Healthy Kids Program is not specifically a well child programme, however, the results from an evaluation of the programme undertaken by Dubay and Howell in 2006, showed the benefits of the provision of universal coverage, regardless of the setting, to children from low income families, in terms of all health care provided. Factors considered in the evaluation were access to care, use of services and unmet needs, and the quality and content of care. Findings showed that parents had considerable assurance that they could meet their children's health care needs by having their children enrolled in Healthy Kids, however, 30% of parents with children established on the programme reported that they still experienced financial difficulties. The authors suggested that this could have been attributable to factors such as lost wages when parents take their child to the doctor, or when co-payments are required for care.

The barriers to access to primary health care services identified in the literature reviewed are the same or similar in the New Zealand context as to those in North America. Barriers identified include where those services are delivered, how much they cost, whether the service is right for the patient and whether parents and caregivers know about the service.

Need for services

Identifying the health care needs of children can be complex and poses special challenges, one of which is the age of the child. Health status, child psychosocial factors, patterns of parental health care use, access factors, child age, family size and family conflict all influence rates of child health care use (Forrest et al., 1998; Hall & Elliman, 2003; Janicke, Finney & Riley, 2001). Further exploration of the literature looks at why parents make the decisions that they do in deciding whether to access health care services for their children and why those decisions often differ from those of health care providers.

One of the driving forces behind a parent's decision to seek health care services for their child is the status of that child's health (Janicke, Finney & Riley, 2001). Parents want timely, low cost and high quality care for their children, however, they are often required to make decisions about whom to access for their child's health care under circumstances that are stressful and threatening (Waibel, 2001). When this occurs the most appropriate provider for the need at the time may not be chosen. The way in which one illness is managed may influence how parents perceive and respond to subsequent illness (MacFaul et al., 1998).

Literature gathered in this review on parental knowledge of children's need for health care has been sourced from American and British studies. Studies centre mostly on the utilisation of EDs, primary health care and in one study sourced, oral health care service use (Brousseau et al., 2007; Christakis et al., 2001; Cooper, Simpson & Hanson, 2003; MacFaul et al., 1998; Mansour, Lanphear & DeWitt, 2000; Talekar et al., 2005; Waibel, 2001; Woolfenden et al., 2000). A number of the same studies specifically discuss the differences in perception of need for services between parents and caregivers and health practitioners (Brousseau et al., 2007; Cooper, Simpson & Hanson, 2003; MacFaul et al., 1998; Talekar et al., 2005; Woolfenden et al., 2000).

Examining the reasons why children access health care is useful as it forms the basis for the argument that there is variability in the reasons whether parents and caregivers appropriately access services to meet their children's needs. In a study undertaken by

Janicke, Finney and Riley (2001) findings demonstrated that past use of paediatric health care services is the best predictor of future health care use. However, when past health care use is removed from the analysis the strongest predictor of use is a mother's worry about her child's health. A mother's perception of need, more than actual symptoms like pain, is the key factor in whether a mother decides to seek intervention for her child. Results from the study also showed that use of paediatric primary health services was reduced when there was a good number of supports in place for families, as supports acted as a buffer against a mother's worries. There was also a connection found between greater maternal utilisation of services with greater use of paediatric services. Care must be taken in interpreting the results of this study as the sample consisted of middle class socioeconomic status families. Whilst the results may appear obvious, the study shows the importance of maternal perceptions of need in the decisions made to seek timely and appropriate intervention for children.

Talekar et al. (2005) undertook a study to determine parental perceptions of children's oral health status. Having a better understanding of parents' perceptions of children's oral health status may help overcome barriers that parents encounter in accessing care for their children. This understanding is especially important with regards to the preschool aged child as their inability to verbalise their emotions and distress increases their dependence on adults. The study concluded that actual disease and perceived need are associated significantly with parents' perceptions of their children's oral health. Parents belonging to minority and economically disadvantaged groups and with less than a high school education were overrepresented in the poor perception category and were also the ones least likely to access care for their children. This confirms comments made elsewhere that children from minority and low income backgrounds are less likely to receive timely intervention for their health care (Bolitho & Huntington, 2006; Grant et al., 2001).

Use of Emergency Departments (ED)

There are many reasons why parents and caregivers present to ED with their children. Their perception of the need to access an ED specifically, instead of a primary health care provider, is discussed in the following studies. The perception of need in relation to the use of ED may differ between parents and caregivers and health practitioners. In a British prospective study undertaken by MacFaul et al. (1998) GPs, consultant paediatricians and parents differed in their views about whether children always needed to be admitted to hospital for acute illnesses. Parents scored the need for admission significantly higher than severity of their child's illness. Ninety percent of parents thought admission was

necessary for their child compared to 71% of medical practitioners. Despite the difference it is acknowledged that it is difficult to assess illnesses retrospectively when an admission from ED is made on the spot, based on clinical judgment at the time of presentation and parents have been told their child needs admission, therefore, they would believe that to be true. At the same time parents would most likely be experiencing high levels of anxiety and be expecting their child to be admitted (Goodyear, Mulik & Madlom, 1999). Results from MacFaul et al.'s (1998) study showed, however, that alternative services could have avoided admission for 19% of children in the study. The evidence shows that parents will present to an ED with their children when it is not always necessary to do so.

Cooper, Simpson and Hanson (2003) identified the reasons for presentation at an Australian district ED (as opposed to a Paediatric ED), through a cross sectional survey conducted on parents of children and adolescents aged 14 and under. The study explored parents' expectations of the consultation received in the ED. The results showed that the majority of presentations were parent (self) referred and the ED was chosen by parents due to proximity. Most children did not require admission, however, parents expected that their children would be observed and staff would undertake further investigation on their children prior to discharge from the ED. This study further supports the fact that parents and health practitioners often differ in their assessment of illness severity of the child. Additionally it highlights that locality of health services is important. Difficulty with accessing primary health care after hours was raised by parents. Parents also believed that their children needed more assistance than what was provided in a primary health care setting. The ED was considered able to provide a wide range of services including the management of primary health care problems. Starfield (1998) reports that EDs will be used as a source of primary health care if after hours access is a problem, combined with, at times, the issue of financial difficulty for families (MoH, 2006).

Respiratory related illnesses and fever are major sources of worry for parents and are considered to be urgent and appropriate for an ED presentation (Mansour, Lanphear & De Witt, 2000; Woolfenden et al., 2000). In studies undertaken by Brousseau et al. (2007) and Woolfenden et al. (2000) parents felt that health care providers underestimated their fears about having a child with asthma. This often motivated parents to seek care through the ED because they perceived breathing disorders to be synonymous with an emergency. Other symptoms considered to be serious enough for an ED presentation were pain and vomiting, a change in symptoms or a lack of resolution of treatment (Woolfenden et al., 2000). The results from these studies further

demonstrate that parents' perception of the need for intervention for their children differs at times from those of health care providers.

A qualitative study undertaken by Woolfenden et al. (2000) explored parental attitudes, perceptions and beliefs related to the use of an Australian paediatric ED for children with a non-urgent illness. The findings support results from other studies in relation to difference in perception of the severity of the illness (Cooper, Simpson & Hanson, 2003; MacFaul et al., 1998). Other factors such as socioeconomic status, parental anxiety and lack of access to local primary health care services have all been suggested as other reasons for the use of EDs (Mansour, Lanphear & De Witt, 2000; MoH, 2006; Starfield, 1998). Results from Woolfenden et al.'s (2000) study confirm the argument regarding presentation to ED when there is limited access to primary health care services. The expertise of, in this case, a tertiary paediatric ED, parental expectations of good communication from health practitioners, being treated as individuals and being given consistent advice were additional findings from the study.

The association between quality of primary care and ED utilisation has been evaluated in other studies but focuses on the timely receipt of immunisations or the prescribing of asthma medications (Adams et al., 2001; Jha, 2006; Rodewald et al., 1999). The following studies further discuss the use of EDs and primary health care services (Brousseau et al., 2007; Christakis et al., 2001; Waibel, 2001). Brousseau et al. (2007) analysed whether parent reported high quality primary care was associated with decreased non-urgent paediatric ED utilisation. The measures used to determine association were practitioner family centeredness, which relates to whether the primary care provider respects what parents have to say, listens carefully and spends enough time with the child, and timeliness and realised access, a measure of the child's ability to receive necessary care and referrals from primary care. High quality family centeredness and a high level of realised access to primary care were study findings associated with decreased ED visits, but there was no significant association found between timely access to primary care and decreased non-urgent ED use.

A study undertaken by Christakis et al. (2001) found that having a continuous relationship with a primary care provider was associated with a lower risk of ED use and subsequent hospitalisation. Results showed that the risk of an ED visit due to decreased continuity of care for (uninsured) children with asthma was higher than all other children combined in the study. Higher continuity of care has been shown to assist compliance with medications (Kerse et al., 2004) and improve practitioner awareness of children's

psychosocial problems. For children with asthma, compliance with medication could be protective against preventable causes of ED use or hospitalisation, and knowledge of children's psychosocial environment may assist primary care providers to identify which children could be safely managed at home. Positive relationships with physicians might increase parents' interest in seeing a particular doctor when children are non-urgently ill, therefore decreasing the chances of an ED presentation. However, in contrast, Brousseau et al. (2007) found the bond between parents, children and their provider was superseded when parents felt that the provider was not able to meet their child's needs.

Waibel (2001) gathered information from parents in order to identify factors associated with over use of emergency services or underutilisation of primary care services for children. Black, single, unsupported mothers from low income families, with low education and, as the study was undertaken in the United States, lacking insurance, were found to underutilise primary care services and over utilise emergency care providers. The major barriers and factors influencing whether parents accessed primary care services were location of services, lack of transportation and cost. Other barriers such as time of day for working parents or appointment constraints, and primary care providers not easily accessible, influenced why parents took their child to the ED. These barriers have been identified in earlier studies reviewed (Mansour, Lanphear & DeWitt, 2000; Cooper, Simpson & Hanson, 2003).

Continuity of care

A review of the literature on continuity of care was undertaken as results from studies in relation to access and use of services highlighted the importance of relationships between parents, children and their primary health care provider. The New Zealand Primary Health Care Strategy (Minister of Health, 2001) describes continuity in primary health care as having a usual source of care from which people can gain advice and help over time. It assumes that those with a usual source of care will form important relationships with their provider. An association between lower continuity of primary care and higher use of ED and hospitalisation for children has been highlighted in other studies featured in this review (Brousseau et al., 2007; Christakis et al., 2001). Continuity of care has been associated with timely immunisation (Christakis et al., 2000; Rodewald et al., 1999) and an increased number of well child visits (Clark et al., 2008). Findings from Mansour, Lanphear and DeWitt's (2000) study suggest that poorer outcomes for children from minority backgrounds may be attributed to a lack of continuity of care.

The American Academy of Pediatrics (2004) describes the relationship that should exist between children and their families with their primary health care provider as one whereby, “the [health practitioner] should be known to the child and family and should be able to develop a partnership of mutual responsibility and trust with them” (p. 1545). Ames (2007) and Turner, Hoare and Dowell (2008) argue that a regular source of primary health care is a critical factor in children’s access to health care. A regular relationship with a primary health care provider does improve child health outcomes, for example children are more likely to receive all the required immunisations (Rodewald et al., 1999; Starfield, 2005).

The literature related to continuity of care is dominated by the relationship between the doctor and patient and it appears very little relates specifically to children. Two studies accessed relate to child health outcomes (Christakis et al., 2000; Clark et al., 2008). Most nursing literature related to the discharge of a patient from hospital into the community and passing information from one shift to another, that is, information transfer and communication between nurses as opposed to the development of a long standing relationship with their patients/clients in primary health care (Haggerty et al., 2003; Holland & Harris, 2007; Saultz, 2003; Sparbel & Anderson, 2000). Therefore, the nursing literature was not found to be relevant to this study. Mental health care literature describes the relationship the client establishes with the team (Haggerty et al., 2003) so was also not relevant.

The majority of publications on the topic of continuity focus on the preferences of doctors and researchers rather than on patients’ priorities (Schers, 2008), and yet according to Reid, Haggerty and McKendry (2002) any measurement of continuity must focus on the individual patient in order to assess how the experience of continuity translates to improved patient outcomes over time, meaning care delivered over time. As explained by Schers (2008) and Haggerty et al. (2003) patients define continuity quite differently. Patients experience continuity; it exists for them when care progresses smoothly and is coordinated. The definition that Reid, Haggerty and McKendry (2002) developed following the Canadian Health Services Research Foundation’s study on the concept of continuity of care describes the three types of continuity as informational, relational and management continuity (see Appendix 2 for definitions).

Saultz (2003) reviewed the literature on continuity of care in order to define interpersonal continuity, and to determine how interpersonal continuity had been measured. As a result of the review Saultz described continuity of care as a hierarchy of three

dimensions: interpersonal continuity, longitudinal continuity and informational continuity (see Appendix 2 for definitions). The definitions are similar to those developed by Reid, Haggerty and McKendry (2002). By defining the levels into a hierarchy Saultz implied that one does not exist in isolation to the others. The measurement of continuity reported in the studies reviewed by Saultz (2003) related to visit patterns and concentration of visits with a provider. The author concluded following this review that interpersonal continuity is of specific interest for primary health care provision and that a better understanding of interpersonal continuity was warranted.

In 2003 Haggerty et al. undertook a multidisciplinary review into continuity of care. The authors described the definitions of continuity in the context of various disciplines, primary health care, mental health, nursing and disease management. Care of an individual patient and care delivered over time were two themes that emerged across all disciplines, distinguishing continuity from other attributes. Three types of continuity were identified in every discipline: informational, management and relational (see Appendix 2 for definitions), as previously defined by Reid, Haggerty and McKendry in 2002. Each type of continuity can be viewed from a patient focus or disease focus and differs depending on the context of care.

A New Zealand study conducted by Kerse et al. (2004) found an association between patient-physician agreement on care and patient adherence with prescribed medication. Continuity of care and trust in the physician were ascertained prior to the GP consultation, the Patient Enablement Index was completed following the consultation, and telephone follow up occurred four days later to ascertain medication compliance. Results showed that trust and physician-patient concordance were significantly related to one third greater medication compliance, enabling the authors to conclude that consultations in primary care where concordance between the patient and physician is higher, is associated with medication compliance. Greater continuity of care was found to be associated with timely administration of the measles, mumps and rubella (MMR) vaccination to infants in a study undertaken by Christakis et al. (2000). The authors focused on the administration of the MMR vaccination as it is not due until the second year of age, therefore allowing time for a relationship to develop between the parent and the child's primary care provider.

Clark et al. (2008) presented a study on the association of family continuity with infant health service use. As noted by the authors, health care for children occurs in the context of the family, conceptualizing continuity as the "extent to which different family

members see the same health care provider over time” (p. 385). Family continuity was determined in this study as well-baby care delivered to infants by a team of practitioners at the same clinic where their mothers received antenatal care. The clinic where the baby received the majority of well-child visits was defined as the child’s provider and family continuity was achieved if the mother visited the same clinic as the baby during the antenatal period. A positive association was found between family continuity and well-child visits suggesting that family continuity may increase the number of well-child visits. If antenatal and well child visits are provided at the same location by the same team of practitioners a child receives a regular source of care both before and after birth.

Three research studies were sourced relating to patient views on continuity of care. (Christakis et al., 2001; Kearley, Freeman & Heath, 2001; Schers et al., 2002). Kearley, Freeman and Heath (2001) conducted a study on patient reported use of a personal doctor, and where the relationship was most valued, comparing the value of the patient-doctor relationship with one of convenience. Seventy five percent of patients surveyed reported having a personal GP. The relationship was highly valued when the patients had a serious or psychological problem and patients were prepared to wait for an appointment. Independent association with this finding was having a personal GP for a reasonable length of time. A positive relationship with a doctor was found by Christakis et al. (2001) to possibly increase parents' interest in seeing that particular doctor when their children are non-urgently ill.

Schers et al. (2002) explored patient views on continuity of care in general practice and to what extent patient views were based on patient characteristics at the time. The results found that patients preferred their own GP as the GP understood their personal and family background and patients assumed that the GP had a better medical knowledge of them. The majority of patients stated that they wanted to be seen by their own GP if they had a serious problem although this was less important for minor ailments. The authors concluded from these results that most patients regardless of age, sex, place of residence and present circumstances, continued to value a personal relationship with their GP if the matter they were being seen for was considered by the patient to be serious. This finding is similar to the results in Kearley, Freeman and Heath’s (2001) study.

Conclusion

The research aimed to explore with parents and caregivers what health services they perceived would best address the health care needs of their children and how those services should be delivered. The literature reviewed sets the context for the study,

initially highlighting the effects of social disadvantage on children and their families. Evidence provided confirms that improving child health will have a significant impact on the health of the adult population in the next decades as many adult diseases have their genesis in childhood. Factors such as socioeconomic status, educational, social and cultural influences, and relationships with providers has a significant effect on whether children receive the health care they require to meet their needs. The literature suggests that these issues are particularly important for minority families and yet overall there was a lack of studies focusing on the importance of addressing health service needs for minority groups.

In the New Zealand context, it is Māori and Pacific families to whom these issues are most applicable.

Enablers and barriers experienced by families need to be considered when developing and implementing health service provision for children. Studies are presented which enable a better understanding of the reasons why parents and caregivers decide to access primary health care and ED services. Data on the attitudes, beliefs, perceived pressures and barriers which influence appropriate access and use of health services for children is highlighted. The importance of having an established relationship with a primary health care provider has been identified.

A combination of both quantitative and qualitative literature has been reviewed in this chapter. This research project builds on the findings from the literature. The research aims emerged from gaps identified in the literature, specifically within the New Zealand context.

Only two studies were reviewed which related to Māori children, one being a qualitative study relating to children requiring hospitalisation. No research studies were sourced regarding access to health care for New Zealand Pacific children. A significant gap in knowledge exists regarding parental and caregiver views on the delivery of health services to their children and how this could be improved in order to better meet their children's health care needs. Whilst the importance of an ongoing relationship with a preferred primary health care provider is highlighted the preferences of health care providers and researchers rather than patient priorities dominate the majority of publications on continuity of care (Schers, 2008).

This study is relevant considering the dearth of qualitative New Zealand primary health care studies relating to Māori and Pacific children. There has been limited research undertaken on the effects of child health services in New Zealand. The views and

experiences of parents and caregivers in New Zealand have not been widely sought, therefore, the methodology chosen for this study allows for their voices to be brought to the forefront in the context of this research. Services will not appropriately respond to children's needs and quality of care will not be fully realised unless an understanding of the attitudes, beliefs and perceived pressures and barriers of parents and caregivers and their families/whānau is known. This information can be used to inform future delivery of services to children.

The next chapter provides an overview of the methodology used for the research.

Chapter 3 - Research design

Introduction

In this chapter the methodology and methods that were used for the research are discussed. A qualitative research design using focus groups and thematic analysis will be described, including the steps taken to establish rigour, and maintenance of an ethical approach. Semi-structured group interviews were conducted to collect the data from participants and a general inductive approach was used for data analysis. The theoretical framework underpinning the research is presented.

The aim of the research was to explore with parents and caregivers what health services they perceived would best address the health care needs of their children and how those services should be delivered. Recommendations based on the research will address how health services may assist in improving the outcomes of children who reside in a community with high deprivation. The research will not be generalisable to other communities, however, it will add to the body of knowledge regarding the delivery of child health services to socially disadvantaged families and their children.

Conceptual framework

Community participation is one of the basic concepts of primary health care (Hutchinson, Anderson & Gottschalk, 2008) and is of particular importance to this study. The use of a modified „community as partner“ model of needs assessment provided a conceptual framework for the study and was used to inform and guide the collection of data and its analysis (Anderson, 2008; Nardi, 2003). Communities are considered to be the experts in determining their needs (Munford & Walsh Tapiata, 1999; Nardi, 2003). Therefore, for this study parents and caregivers are considered the experts in determining the needs of their children and a partnership was developed with them for the purposes of assessing their children’s health care needs. According to Anderson (2008) residents in a community have the right to identify their own needs and negotiate interventions and service development and delivery. Kozol, as cited in Kamberelis and Dimitriadis (2005), support this view, describing how some of the best ideas for new programmes come out of discussions held with communities, “people are far more likely to participate in something which they or their neighbors have been invited to assist in planning...in which ideas they have offered have been more than heard but given application” (p. 891). Through the „community as partner“ model feedback was sought from parents and caregivers in the community, providing the basis for evaluation of children’s access to health care.

The „community as partner“ model consists of a community and eight subsystems. The community consists of a core of people who create that community. The eight subsystems in the community affect the people and in turn are influenced by the people. The subsystems consist of the “physical environment, education, safety and transportation, politics and government, health and social services, communication, economics and recreation” (Anderson, 2008, p.208). Exploring the provision and delivery of health services for children in this community through participation of parents and caregivers highlighted the transactional relationship that occurs between the community and health providers as they interact with one another. It also offered parents’ and caregivers’ views, perceptions and experiences of those services provided to the community in relation to their children’s health needs (Anderson, 2008).

Whilst it was intended that the health and social services subsystem was the focus of this study it is important to note that this subsystem is not discrete and separate but influences, and in turn is influenced by, the other seven subsystems. The demographics of the community in this study indicate inter-connectness between all the subsystems which in turn influences the overall health status of the community. The results gained reflect that inter-connectedness and the influence of all the subsystems on child health outcomes.

Methodology

Gaining an in-depth understanding of a selected phenomenon is the primary aim of qualitative research (Grbich, 1999; Llewellyn, Sullivan & Minichiello, 2004). Broadly speaking qualitative research focuses on understanding the subjective experiences and world views of participants (Andrews, Sullivan & Minichiello, 2004; Pope & Mays, 2000). Qualitative researchers come from the perspective that the physical and social worlds are very different, as humans are able to “use language to describe their thoughts and experiences, think and reflect on behaviours, and control their reactions to situations, in line with the meaning they ascribe to situations” (Andrews, Sullivan & Minichiello, 2004, p.61). Accordingly qualitative researchers seek to uncover thoughts, perceptions and feelings experienced by informants (Pope & Mays, 2000).

A qualitative design was chosen for this research in order to bring the views of participants to the forefront. Gaining an understanding of what parents and caregivers experience in relation to health services for children in their community is necessary in order to answer the research question. Using a qualitative design allowed specific insights into participants’ worlds and experiences helping to define what the problems

were for the community rather than how many people were affected by them (Andrews, Sullivan & Minichiello, 2004; Murray et al., 1994; Pope & Mays, 2000).

Empirical data has been collected for the community, but the opinions of the community had not been sought in relation to what would make a difference to the child health outcomes evident in the data. An improvement in immunisation rates has occurred and enrolment in the local Primary Health Organisation stands at 96%, however, children from the community are still considered over represented in presentations to the ED and admissions to hospital (MoH, 2008b). Some changes in health service delivery have occurred in the community over the past five years, for example, provision of Tamariki Ora services by a Māori health provider and introduction of a Pacific health worker role, however, the effectiveness of these measures is not clear. The literature review found that overall there was limited child health research using a qualitative approach regarding children's access to and use of health services from New Zealand.

Qualitative designs by nature do not produce results which are generalisable, however, they can provide descriptions of people's experiences, assisting with interpretation of empirical data. Whilst quantitative designs produce the data that an issue exists, it is qualitative designs that assist in identifying the strength of feeling within a community's issues and are more likely to produce the answer to why an issue or problem exists (Murray et al., 1994). Gaining access to „phenomena“, „informants“ and „worlds“ can be achieved by using a methods based approach or a paradigmatic approach (Grbich, 1999). As this study was exploring human social behaviour, a methods based approach for investigation, that is interviewing people through focus groups, was used (Andrews, Sullivan & Minichiello, 2004; Miles & Huberman, 1994; Patton, 2002).

Ethical issues

Ethics approval was granted by the New Zealand Health and Disability Ethics Committee. Respect of the participants in this study was of utmost importance. As an employee of the local District Health Board the researcher was already part of a partnership existing between the District Health Board and local tangata whenua. The researcher consulted with the District Health Board's Māori Health Director and Māori Health team, the local Iwi committee and the local marae committee during the development phase of the study. They supported the aims and outline of the project. This consultation ensured the study processes were appropriate and obligations under the Treaty of Waitangi were undertaken with regard to Māori involvement in the study.

Cultural sensitivity related to other ethnic groups also needed consideration. As participants from Pacific Island cultures would be involved in the study the researcher sought advice from the District Health Board's Pacific Health Worker. Links with the Pacific community leaders were made and the researcher consulted them on the appropriate cultural protocols to be followed for their community members. The chair of the Pacific Community Centre met with the researcher and endorsed the research as being meaningful for the Pacific community.

The principal from the local school was approached as the research began, to explain the purpose of the research and to seek the school's support. A subsequent meeting was held with the school's Board of Trustees who willingly supported the study. Letters of support were gained for ethical approval from the school Board of Trustees, the local Iwi committee, the local marae committee, the Pacific Community Centre Committee, the Pacific Health Worker and the District Health Board Director of Māori Health.

Other ethical considerations for this study concentrated on the right to privacy and protection from harm for participants (Fontana & Frey, 2005; O'Brien, 2001; Parsons, 1999). Informed consent was an important safeguard and covered both these aspects. Participants were approached through a number of avenues, however, the researcher and her assistant were the only two people who knew who the final sample was from the list of potential participants. This lessened the risk of the study affecting any existing relationships between health providers and participants.

Potential participants were given information about the study and told how to contact the researcher if they wished to participate. All pertinent information concerning participation, the focus group interview, analysis, management of the data and dissemination of the study's findings was contained in an information sheet (Appendix 3). Assurance was given to potential participants of the right to withdraw from the study at any time. Opportunities were given for potential participants to ask questions and seek clarification on any matter prior to agreeing to take part. Time was provided for participants to consider the information before they consented to being part of the research project. Consent was gained from all participants (Appendix 4). As outlined in The Code of Ethical Conduct for Research, Teaching and Evaluations Involving Human Participants (Massey University, 2006) and by Walsh-Tapiata (as cited in Munford & Sanders, 2001), it was considered culturally appropriate to offer the option of giving oral consent to the Māori focus group participants, however, all participants were comfortable giving written

consent. Written consent was also obtained from the Pacific group, with a translator assisting to ensure Samoan participants' understanding.

An ethical issue specific to focus groups that required consideration was participants' disclosures being shared with all group members as well as the researcher. Participants received information outlining the processes that would be followed to assist with confidentiality (Appendix 3) although this could not be guaranteed in a group setting. The information sheet clearly stated that participants could withdraw at any time during the study and informed consent was required for participation in the research. These processes ensured that participants were clear that discussions within the group were confidential to the group. At the beginning of each focus group the researcher reiterated the process of keeping the discussions within the group and participants' right to withdraw at any time or withhold information (Bassett, 2004; Llewellyn, Sullivan & Minichiello, 2004).

The researcher made it very clear to participants that no information gathered would be identifiable to any individual in each group or revealed to any health provider in any identifiable form. This was particularly important as the researcher was employed by the local District Health Board and some of the professionals providing health services to the community were known to the researcher. It was critical to ensure participants knew that the researcher was undertaking the research to meet university requirements with no direct connection with service agencies (Fontana & Frey, 2005; Waldegrave, 2003). It was also important that participants knew that the researcher could not intercede on their behalf with any health provider. The researcher gave an explanation of the likely benefits of the outcomes of the study to participants, that results from the research would be relayed to the local District Health Board and considered in the development of the local child health strategy, potentially influencing decisions regarding future health services for their community. Participants were informed that the study findings would be published in an academic journal.

Informed consent was required for permission of the conversations to be taped. The audio tape recordings were only heard by the researcher and the transcriber who signed a confidentiality agreement (Appendix 5), giving the assurance that the conversations held within the focus groups were not to be discussed outside of that setting. Once the transcribing was completed the audiotapes were kept in a locked cabinet along with the consent forms.

Rigour

Rigour is, as described by Grbich (1999), “the researcher’s attempt to use as tight a research design as possible” (p. 61). Mechanisms used to verify data from research contribute to ensuring reliability and validity of studies (Morse et al., 2002). In determining validity, stated as, “the researcher accessing and accurately representing the social world under study” (Grbich, 1999, p. 59), procedures used by the researcher are examined to ensure that the results from the study are trustworthy (Krueger & Casey, 2000).

During the focus groups researcher bias was reduced by the use of discussion generating questions. Open discussion was encouraged without the researcher making any suggestions regarding answers and not manipulating the direction of the conversation (Ruff, Alexander & McKie, 2005). At times it was necessary to guide participants back to the focus of the research topic but this was only necessary on rare occasions throughout the group interviews. Interaction between participants was encouraged as interaction is the key to the focus group method and gives the method a high level of face validity (Krueger & Casey, 2000). Face validity involves the checking of the researcher’s interpretations of the data with participants in the focus groups (Grbich, 1999). In this study the researcher verified that the results accurately reflected participants’ views and experiences in relation to children’s access to health care by asking participants to clarify any areas of ambiguity during the focus groups, and then asking for verification of the overall information gained as the group interviews concluded. Pope and Mays (2000) describe this as respondent validation, which Lincoln and Guba (1985) regard as the strongest available check on the credibility of a research project.

To ensure reliability of the findings the researcher systematically undertook analysis of the data using known methods of coding and categorisation (refer to data analysis section). There were substantively similar viewpoints on the issues discussed across the three focus groups supporting content validity of the findings (Kidd & Parshall, 2000). The themes emerging from the data were compared with themes in the literature (Morgan, 1997). The findings were presented back to a number of the original focus group participants for clarification and verification of the themes resulting from the interviews, as recommended by other authors (Grbich, 1999; Heary & Hennessy, 2002; Kidd & Parshall, 2000; Pope & Mays, 2000; Thomas, 2003).

The researcher, recognising the potential for distance between her and the participants acknowledged the differences of her own ethnic and socioeconomic background and that she held a senior nursing post within the local District Health Board. Grbich (1999) and Pope and Mays (2000) refer to this as (self) reflexivity, which is remaining sensitive to any researcher bias and assumptions that could potentially influence the shaping of the data collection, critically reflecting on this in an ongoing way. Any assumptions the researcher may have had were partially allayed by seeking advice from expert informants in the community: the school, the Pacific Health Worker, the Pacific Community Centre Committee, local Iwi and the Māori Health team, and discussing how the data should be collected and who should assist with that process.

It was very important to collect the data in such a way that was culturally safe for participants, including using an environment in which they felt comfortable. It was made clear to participants that the researcher did not deliver a health service to that community and even though some of the health professionals were known to the researcher, no information that was identifiable would be shared with anyone. The keeping of a personal diary of events leading up to the collection of data and regular discussions and meetings with the researcher's supervisor for the thesis assisted the researcher to remain open minded and not allow prior assumptions and experience to overly influence the research process. This also ensured that the researcher was continually made aware of ethical boundaries as a researcher, discussing the difference in roles between being a health professional and a researcher, not influencing responses from participants and having preconceived ideas of the results. An audit trail was created by the researcher. As recommended by Grbich (1999) the conceptual development of the study was traced from the raw data collection through data reduction, analysis and reconstruction.

As stated by Davidson and Tolich (2003) the strength of qualitative research lies in its validity. The consistency of processes used in this study gives a reasonable assurance that results may be reproducible and credible (Kidd & Parshall, 2000). Regular communication occurred with the researcher's supervisor as the analysis proceeded. This oversight assesses whether the researcher has written persuasively, and has presented a cogent argument in interpretation of the data (Angen, 2000). Although the results of the study may not be generalisable to other communities, the results presented can be interpreted as accurately reflecting the opinions and views of the participants.

Method

Focus groups

Focus groups were used as the major approach to generating data for this research. The issue in question is complex, that is, how to best meet the needs of children in a community with high deprivation. The study seeks to understand perceptions, views and experiences of Māori, Pacific and other low income parents and caregivers when accessing health services for their children with the ultimate outcome of improving the future delivery of child health services. The ability of focus groups as a means of exploring and gaining information about this complex and multifaceted topic was the reason for choosing such an approach (St John, 2004). As previously stated the interaction of health services and the community occurs through a transactional relationship (Anderson, 2008) therefore understanding how this interaction occurs was important in answering the research question.

Use of focus groups in this study provided an opportunity to gain access and insight into the ideas, attitudes, opinions, behaviours, beliefs and values of a particular community (Bassett, 2004; Davidson & Tolich, 2003; Kamberelis & Dimitriadis, 2005; Krueger & Casey, 2000; Llewellyn, Sullivan & Minichiello, 2004; Pope & Mays, 2000). The intent of the group interview is to focus on a particular topic or area of study to which their power is attributed (Patton, 2002). Homogeneity enhances that focus as groups that are alike often have similar experiences enabling a greater depth of response. The strength of the focus group interview lies in the provision of a non threatening environment and the relative freedom that the group situation gives participants to discuss issues of concern (Krueger & Casey, 2000). This is especially relevant for people in vulnerable situations, which the researcher considered some of the participants in this study to be (Patton, 2002). Using the focus group method enabled people to listen to the experiences and opinions of others whilst reflecting on their own perspectives about services and children's health care (Krueger & Casey, 2000; St John, 2004). A wealth of descriptive information about the nature and nuances of the social problems in the community and the service needs of those who experienced the problem was provided through use of this method (Rossi, Lipsey & Freeman, 2004).

Focus groups are suitable for groups with strong oral traditions and low levels of formal education (Grbich, 1999). It was necessary to consider the fact that participants in this study might not have been able to read or write. The demographics of the community in the study showed high numbers of Māori residing in the area and the level of qualification

for all ethnicities was lower than neighbouring communities (Statistics NZ, 2006). As this study involved cross cultural research with ethnic minorities focus groups were a good method to use, as it was expected participants would be more likely to engage in group discussion if others similar to themselves were also participating (Pope & Mays, 2000; Ruff, Alexander & McKie, 2005). The researcher felt that focus groups were an especially appropriate approach for exploring the viewpoint of the participants whose assumptions may have differed from those of the mainstream culture and therefore had a particular need to speak and be heard (Morgan 1997; Riviere et al., 1996).

The group dynamics and discussion that occurred in the focus groups stimulated responses, interactions and reactions from participants. This added to the facilitator's questions, uncovering new and additional data and fostered a greater focus on participants' views (Minichiello et al. 1999; St John, 2004; Stewart, Shamdasani & Rook, 2007). Group interaction allowed easier accessibility of participants' experiences and perspectives (Morgan, 1997). As stated by Krueger and Casey (2000) interaction is the key to the focus group method. Vertical interaction occurred during the discussions between the researcher and participants, and horizontal interaction occurred among participants (Madriz, 2000). Exploration and clarification of views was more easily achieved through use of the group process which, according to Kamberelis and Dimitriadis (2005) is not as easy to achieve with one to one interviews. This view is supported by Krueger and Casey (2000) who state that the interaction among participants in focus groups enhances data quality.

Focus groups were also used as the time involved in undertaking the data collection and the associated cost was required to be kept to a minimum (Bassett, 2004; Grbich, 1999; Minichiello et al., 1995; Morgan, 1997; Patton, 2002). Each of the focus groups produced a very rich body of data expressed in the respondents' own words and context, allowing the opportunity to learn specifically about participants' experiences and perspectives of child health services in their community. Information rich cases were necessary to gain an in-depth understanding of what the needs are for children and their families/whānau, issues of central importance to the purpose of this research. Gaining insight through exploring experiences and views of those in the community of study were needed in order to answer the research question. The data produced through the focus groups resulted in especially powerful insights. A limitation of focus groups worth noting is that the number of respondents in the study, and responses from members of each individual focus group, are not independent of one another which restrict the

generalisability of the results to a larger population (Stewart, Shamdasani & Rook, 2007). Each group therefore represents a single observation.

Participant selection

As suggested by Patton (2002), the rationale behind the use of purposefully selecting participants derives from the emphasis on in-depth understanding leading to information rich cases for study. Mixed purposeful sampling, combining homogeneous groups with snowballing was the method used to recruit participants for this study. Most qualitative researchers purposefully select the sample for the study based on the area of interest (Bassett, 2004; Llewellyn, Sullivan & Minichiello, 2004). Given that Māori, Pacific and children from lower income families have poorer health outcomes than other groups in New Zealand (NZ Child & Youth Epidemiology Service, 2007) it was appropriate to use purposeful sampling to gain participants for the focus groups.

The criteria for participant inclusion in the study were parents and caregivers of children who attended the local primary school and/or resided in the urban community which surrounded the school. One group for parents and caregivers of Māori children, one for parents and caregivers of Pacific children and one group for parents and caregivers of children from other ethnicities were held. Defining a relatively homogeneous population of parents and caregivers with similar backgrounds, ethnicity and socioeconomic status reduced variability between participants. Homogeneous sampling, which involves the selection of a group who are as alike as possible (Llewellyn, Sullivan & Minichiello, 2004), was used so that each of the three groups' common experiences could be studied in more depth. The researcher was aware that homogeneous groups are believed to produce richer data with a greater depth of response, enabling comparisons between different cultural groups (Minichiello et al., 1999; Morgan, 1997) and capitalise on people's shared experiences (Pope & Mays, 2000). Ruff, Alexander and McKie (2005) explain that focus groups provide the opportunity to focus on cultural issues specific to the group under study. Class and ethnicity have been recognised as important sampling variables (Pope & Mays, 2000). The use of homogeneous groups focused, simplified and facilitated the group interview process undertaken by the researcher.

While purposeful sampling was initially used in order to identify the group under study and to ensure the selection of participants met the study's needs, as the study progressed the use of snowballing, that is, word of mouth, was later incorporated in order to access additional participants. Snowballing or chain sampling is described by Llewellyn, Sullivan and Minichiello (2004) as the involvement of key informants in

recruitment of participants or identifying individuals who appear on face value to be able to provide information rich data on the subject of the research. This form of selection took advantage of the community networks within Māori and Pacific ethnic groups as participants and community members identified others who felt comfortable sharing their perceptions and experiences with the researcher. Snowballing can be particularly effective as group members may be more receptive to participating if a friend or acquaintance invites them (Ruff, Alexander & McKie, 2005).

As a diverse group was required for participation in the study it was necessary to enlist the support of third parties with recruitment of participants. The school was known by the researcher to be a focal point for the community so seemed the logical place to use as a focus for the data collection process. Discussions were held with the school's principal and the Māori Health team, and Pacific Health Worker regarding recruitment of participants. Whilst advertising the study in the school newsletter initially seemed like the best approach, it became evident that this alone would not be enough. The school had experience of this not working for their community. The Māori Health team and the Pacific Health Worker were in agreement therefore along with the school, they identified families, parents and caregivers of children who it was felt may be interested in participating. Concurrently the school advised the school community of the study in their newsletter. Initial contact was made by the school, the Māori Health team and the Pacific Health Worker, informing potential participants of the research being undertaken and passing on the researcher's contact details to those who expressed an interest. The researcher was contacted by phone by some prospective participants who were interested and informed by the Māori Health team, Pacific Health Worker and the school of others who were willing to be involved.

Further explanation of the purpose of the study was given by the researcher, who subsequently provided prospective participants with the information sheet. Parents and caregivers who contacted the researcher were asked whether they were aware of any others who would be willing to take part and asked to pass on the details of the researcher. Prospective Māori participants identified others whom they thought could be interested in participating and passed on the researcher's details to them. Two prospective Māori participants were found to be unable to take part due to the fact that they were both involved with health provision in the community. An Asian family who initially agreed to take part did not participate.

Cook Island and Samoan participants agreed to take part via the Pacific Health Worker. It was agreed that the Pacific Health Worker would visit these families with the researcher when the purpose of the study was explained to them. The Pacific Health Worker identified that for Samoan participants a translator would be required for the focus group interview. Whilst they could understand some English, enough to agree to participate, the researcher felt they could need assistance when the questions were asked of the group. A Samoan participant agreed that he could translate (as required) for the group.

The researcher was aware that recruiting participants using a third party can be problematic (Llewellyn, Sullivan & Minichiello, 2004) as the study may not be explained in the way that the researcher intended. This was mitigated in this study to a certain extent by the use of the information sheet which was given to every potential participant by the researcher, and the researcher reiterated the purpose of the study at the beginning of the focus group interviews. The second issue considered in using a third party for recruitment was the possibility of the relationship that potential participants had with the health service workers, which could influence the participant's views of the study. The researcher mitigated this factor by holding the focus group interviews without any health workers or providers present. The third issue requiring consideration was that the researcher was employed by the local District Health Board. This may have influenced participants' decision to participate and whether participants were willing to openly share information during the focus group interview. This last issue was addressed as best as possible by the researcher being very clear to participants about what would happen to the information gathered from the interviews and that she was there as a post graduate university student and not a District Health Board employee (Llewellyn, Sullivan & Minichiello, 2004).

Data collection

Focus group interviews using open ended questions to lead the discussion were used for the data collection (Minichiello et al., 1995; Nardi, 2003; Patton, 2002; Pope & Mays, 2000; Stewart, Shamdasani & Rook, 2007; Waldegrave, 2003). The three groups chosen for the focus groups were representative of the school at the centre of the research, the community's population and children with the highest [known] health needs (MoH, 2008b; Statistics NZ, 2006). The researcher facilitated each focus group with the assistance of an assistant.

Participants

The literature suggests six to ten participants as an ideal number for focus groups (Morgan, 1997; St John, 2004; Stewart, Shamdasani & Rook, 2007). Size is important as there may be less stimulating discussion and generation of views with too small a number, but on the other hand too large a group may be difficult for the researcher to manage the group (Morgan, 1997; St John, 2004; Stewart, Shamdasani & Rook, 2007). Four participants took part in the Māori group, seven in the Pacific group and four in the Pakeha group. The Māori group had equal numbers of men and women participants and included parents, one being a solo father, a grandparent and a nominated caregiver who was not a birth parent. The Pacific group consisted of two men and five women, of whom five were parents of children attending the school and two were grandparents. Participants originally came from the Cook Islands and Samoa. There were two within the Pacific group who required some translation of the questions and discussion that occurred. The other ethnic group consisted of four Pakeha women who were parents of children attending the school. The three focus groups were held over the period of a week. The Māori and Pakeha groups had small numbers of participants, however, participants in both these groups were highly involved in the discussions and the data gathered was as rich as that resulting from the Pacific group.

Interviews

In preparation for the focus groups, the timing of and venue for each focus group was discussed with the researcher's key informants, that is the school, the Pacific Health Worker and the Māori Health team (Bassett, 2004). Initially the views of the school's principal were sought as the school had considerable experience in the holding of events which required parental and caregiver participation. The researcher had been advised that there should be three separate venues for the focus groups, the community centre for Pacific, the local marae for Māori and the school for other ethnic groups. However, it was important that participants would feel comfortable and safe and that the environment in which the focus group was held was non-threatening (Krueger & Casey, 2000). The school advised that it was unlikely that Māori parents and caregivers would attend the local marae.

Timing for the groups was considered with the aim to make it as easy as possible for parents and caregivers to participate. Holding the groups prior to the end of the school day was suggested as parents and caregivers were coming to the school to collect their children. Due to the suggested change of venue for the Māori group the researcher contacted the Māori Health team to seek their advice on this. It was accepted by the

Māori Health team that few families would want to travel to the marae as it was out of town, and the length of time required for participants to be involved would double due to the necessity to follow marae protocol. This was seen as a possible deterrent to involvement therefore to assist with participation of Māori, holding the group at the school was an acceptable change. Consultation with the Pacific Health Worker resulted in the Pacific group continuing to be held at the community centre as it was still considered to be a more appropriate venue for that group and did not involve any travel for participants.

The Māori and Pakeha groups were set for early afternoon prior to school finishing, allowing for a minimum of one and a half hours. The Pacific group was set for late morning. The school provided an appropriate room for the interviews to be held and the lounge in the community centre was used for the Pacific group. When participants arrived the researcher went through the consent form again and gained their consent. The gaining of verbal consent had been discussed with the Māori participants prior to the day, however, it was not necessary to gain verbal consent as all were comfortable giving written consent. Consideration was given to the set up of each environment. Participants were seated in a circle as recommended by Morgan (1997) and Stewart, Shamdasani and Rook (2007). Refreshments were provided for all groups at the start of the session. The researcher's support person assisted with the refreshments and ensured the tapes and recorder were set up. The assistant had signed a confidentiality agreement (Appendix 6).

Following introductions within the group the researcher gave an overview of the topic. Participants were encouraged to share their views and experiences, the researcher reiterated the need to record the discussion and reinforced what would happen with the data. As suggested by St John (2004), a general open ended question was posed to each group to start the discussion, "Are you able to tell me what health care services you believe are available for children in this community?" The interview guide (Appendix 7) was focused on gaining information regarding participants' knowledge and understanding of health services available to the community, eliciting their perceptions of what and how health services in their community could improve the health outcomes of their children and what if anything could be done differently. Participants were asked to discuss the health of the community's children, access to and cost of health services, what was needed for that community and any other issues.

The structure, phrasing and placement of questions following the opening question were at the researcher's discretion. The researcher structured the phrasing of the questions by

using a „funnelling“ approach of asking general questions first then moving to more specific ones as the conversation progressed (Grbich, 1999; Minichiello et al., 1995). The content focused on the issues central to the research topic but the semi-structured approach using the open-ended interview guide, allowed for greater flexibility, allowing respondents to expose their views, provide as much information as they wished and explore their answers with relative freedom. The semi-structured approach to the group interview allowed for extensive exploration of the topic in a way that was as close as possible to a conversation (Grbich, 1999). It was important to pose the questions in language that the participants would understand and use of the translator in the Pacific focus group assisted the researcher with this task (Grbich, 1999; St John, 2004). The interview guide was used to keep the interactions focused on the topic while allowing individual perspectives and experiences to emerge (Morgan, 1997; Patton, 2002). The questions remained open-ended in order to elicit perceptions and experiences of the parents and caregivers, yet focused enough to ensure the aims of the study would be covered.

During each interview the researcher remained aware of group dynamics and the potential for domination of some participants. This was not an issue in either the Māori or Pakeha groups, however, in the Pacific group the researcher was required to ask the translator to repeat some of the questions in Samoan, ensuring that the two women who appeared to have less understanding and who were not participating as much as the others, were offered the opportunity to speak (Ruff, Alexander & McKie, 2005). This assisted with their participation although it was still less than other participants as the Samoan women were very shy.

On occasion the conversation shifted from the focus of the research and the researcher guided participants back on track by using phrases such as “can we go back to what you were referring to earlier?” In order to enable the researcher a better understanding of some comments questions like “can you clarify what it was you were trying to say then?” or “can you expand upon that comment?” were asked. To obtain overall clarity of what had been discussed throughout the interview the researcher asked the group at the end of the session “what do you think are the most important elements of what you have discussed today?” Following this the researcher summarised what she thought participants had said, verifying the adequacy of the summary by asking participants if the main issues were captured and if they had anything more they would like to add (Krueger & Casey, 2000; Morgan, 1997; Ruff, Alexander & McKie, 2005). The opportunity for

participants to qualify their responses or add to them, gave their responses a certain ecological validity (Stewart, Shamdasani & Rook, 2007).

Limitations of focus group interviews may include the reduction in comparability of responses from each focus group within the study as a result of the style of questioning and type of discussion used with focus group interviews, which refers to the flexibility used in sequencing and wording of questions by the interviewer (Minichiello et al., 1995; Patton, 2002). Although many responses were unique to each focus group as expected, there were many common themes that evolved from the data across the three groups. Due to the nature of the group setting the responses of the participants may not have been independent with „group think“ possibly being an outcome of this. This did not appear to be an issue for any of the focus groups held in this study. At times there were one or two members of the Pacific group who dominated the discussion, initially directing the evolving discussion and views being expressed. Once the researcher became aware of this she ensured all members in the group were given the opportunity to participate. There was also limited time in the focus groups for each individual participant response, so the researcher ensured that all participants had the opportunity to speak.

The homogeneous groups appeared to work well together and were productive, confirming Stewart, Shamdasani and Rook's (2007) view of the use of homogeneous groups. The conversations flowed freely amongst participants within the groups which Morgan (1997) describes can be partially due to homogeneity. The discussion was audio taped and transcribed verbatim as soon as possible after each focus group to enable analysis to be undertaken and a comparison between each focus group to be made. Participants were offered the opportunity to confirm the themes from the interviews at a later date.

Data analysis

The interview transcripts formed the data for this study. A general inductive approach (Thomas, 2003) was used to sort and organize the data. Thomas (2003) describes this approach as a systematic procedure with specific objectives guiding the analysis and "...a convenient and efficient way of analysing qualitative data" (p.1). This approach is used when the researcher seeks to identify themes through analysis of the data, serving the purpose of reducing the large amount of data, organizing the data and establishing the links between the research aims and the findings. The data was interpreted through a process of thematic analysis. Thematic analysis is a widely used analytic method for

qualitative studies which identifies, analyses and reports patterns (themes) within the data collected (Boyatzis, 1998; Braun & Clarke, 2006).

The process of analysis began immediately after each focus group as the researcher reflected on the discussions that were held, making notes about what had happened during each group and her thoughts about what participants had discussed. The tapes were transcribed within two weeks of the focus groups being held, allowing the researcher the opportunity to begin the analysis of the conversations with the information still fresh in her mind. As recommended in the literature (Braun & Clarke, 2006; Burnard, 1991) the researcher immersed herself in the data by listening to the tapes and reading and re-reading the transcripts. This thorough familiarisation was necessary as it assisted the researcher to gain a greater understanding of the data, as she began to look for meanings and patterns (Braun & Clarke, 2006).

After becoming thoroughly familiar with the data a process of coding and categorisation occurred to aid the researcher in organising the data. Coding is an analytic process of condensing raw data into relevant categories. An iterative approach was used as the researcher reflected upon the data with categories emerging as interaction occurred with the data (Grbich, 1999; Patton, 2002). Emerging categories from the data were initially organised using descriptive codes with regard to the questions in the interview guide (Miles & Huberman, 1994; Minichiello et al., 1995; Pope & Mays, 2000). A number of other categories were added in order to describe all aspects of the content from the transcripts, excluding those issues that were totally unrelated to the topic, that is, „dross“ (p.462, Burnard, 1991). Internal consistency of coding was enhanced as the researcher was the only person who coded and analysed the data.

In order to further organise the data the coded extracts from the data were placed in matrices (Miles & Huberman, 1994; Pope & Mays, 2000) under a heading for each category with an accompanying descriptive narrative for each individual focus group response. The data for each category was compared and contrasted across all three focus groups and a narrative description included. This process was laborious, however, it did enable the researcher to gain a more in-depth knowledge of the data (Pope & Mays, 2000). Overlapping occurred initially where some data fitted into more than one category (Thomas, 2003). The numbers of categories was reduced by a process of collapsing some of the categories that were similar, into broader categories (Ames, 2007; Burnard, 1991).

An analysis of emphasis and intensity of issues and views raised by participants aided the identification and prioritisation of themes and sub themes from the categories and what was more important or less important in the data (Krueger & Casey, 2000; Morgan, 1997). Emphasis and intensity of comments as described by Krueger and Casey (2000) and Morgan (1997) is determined by the frequency of comments, that is how many times something is said by participants, specificity which relates to comments made by participants that provide more detail, comments made by participants where they show “emotion, enthusiasm, passion or intensity in their answers” (Krueger & Casey, 2000, p.136), and extensiveness, that is how many different people referred to the topic. “Group to group validation” described by Morgan (1997, p.63), as a combination of all the factors used to determine emphasis, provided the best evidence in considering which topics received the most emphasis in the final report.

A great deal of interpretative work is required in the identification of themes (Attride-Stirling, 2001) so, following analysis of the emphasis and intensity of the participants’ issues and views, the researcher developed thematic maps (Braun & Clarke, 2006) to assist in conceptualising themes from the data. The mind map organised and grouped the categories together into themes. Themes were then reviewed and refined, considered in relation to each other to ensure there was limited overlap between them, and a definition developed for each theme. Sub themes were identified at this time, described as themes within a theme for the larger and more complex themes (Braun & Clarke, 2006). The researcher was aware that one of the limitations of thematic analysis is the “projection” of one’s own values and views when interpreting the data (Braun & Clarke, 2006, p. 13). This was partially mitigated by the researcher discussing the emerging themes with her supervisor. The themes that were chosen were validated by linking each theme with the literature.

The data analysis process resulted in four main themes; within the four main themes were nine sub themes:

Reality of life

- Balancing priorities
- Choice of services
- Impact on children

Visibility

- Knowledge and availability of information

Knowing you, knowing me

- Trusted relationships

- The power of attitude
- Need for health care

Kids come first

- Limitations of services
- Future services

The researcher offered participants the opportunity to confirm the themes resulting from the interviews. This is referred to earlier in the chapter as respondent validation or member checking (Guba & Lincoln, 1985; Pope & Mays, 2000), whereby the participants can confirm or debate the researcher's interpretation of the data. This occurred with assistance from the school and Pacific Health Worker who organized venues for the researcher to meet participants again. Ten of the original group of 16 participants responded to the researcher's invitation. The findings were presented in general terms to ensure ease of understanding of the themes that the researcher had developed. There was general agreement with what the researcher had interpreted from the three focus groups, therefore, it was not necessary for the researcher to spend any further time revisiting the themes.

The themes in this study are divided into two chapters, their reporting underpinned by principles from the New Zealand Child Health Strategy (MoH, 1998) (see Appendix 8) and the „community as partner“ model (Anderson, 2008). Extracts which capture the essence of the discussions held within the focus groups and the views and issues raised by participants are presented in the following two chapters. An analytic narrative accompanies the extracts illustrating the relevance of the data to the research question (Braun & Clarke, 2006).

Conclusion

The research methodology and the method used to answer the research question have been described in this chapter. A qualitative research design was used for this study in order to explore the perceptions of parents and caregivers in regards to their children's health and was ascertained as best suited to address the aims of the study. Three semi-structured focus group interviews were conducted with Māori, Pacific and Pakeha parents and caregivers residing in a community with high deprivation. Each focus group interview was analysed using a thematic analysis approach, coding data into categories which were then defined and developed, further refined and developed into themes. The ethical issues relevant to the study have been described and the processes used to ensure rigour.

Using the focus group methodology assisted the researcher in gaining a clearer view of the participants' reality and to examine the relationship between the community and health providers in the social context of the community. Exploring variations, diversity and consensus on the topic was achieved through the comparison of data between the three groups (St John, 2004). Data analysis was an ongoing process of reading the transcripts, coding the data, considering the information and revisiting the data until the categories and themes were finalised. Once this was achieved the data was presented within the themes and the meanings within the data interpreted by the researcher.

The following chapter will present the findings of the study.

Chapter 4 - Children's needs are paramount

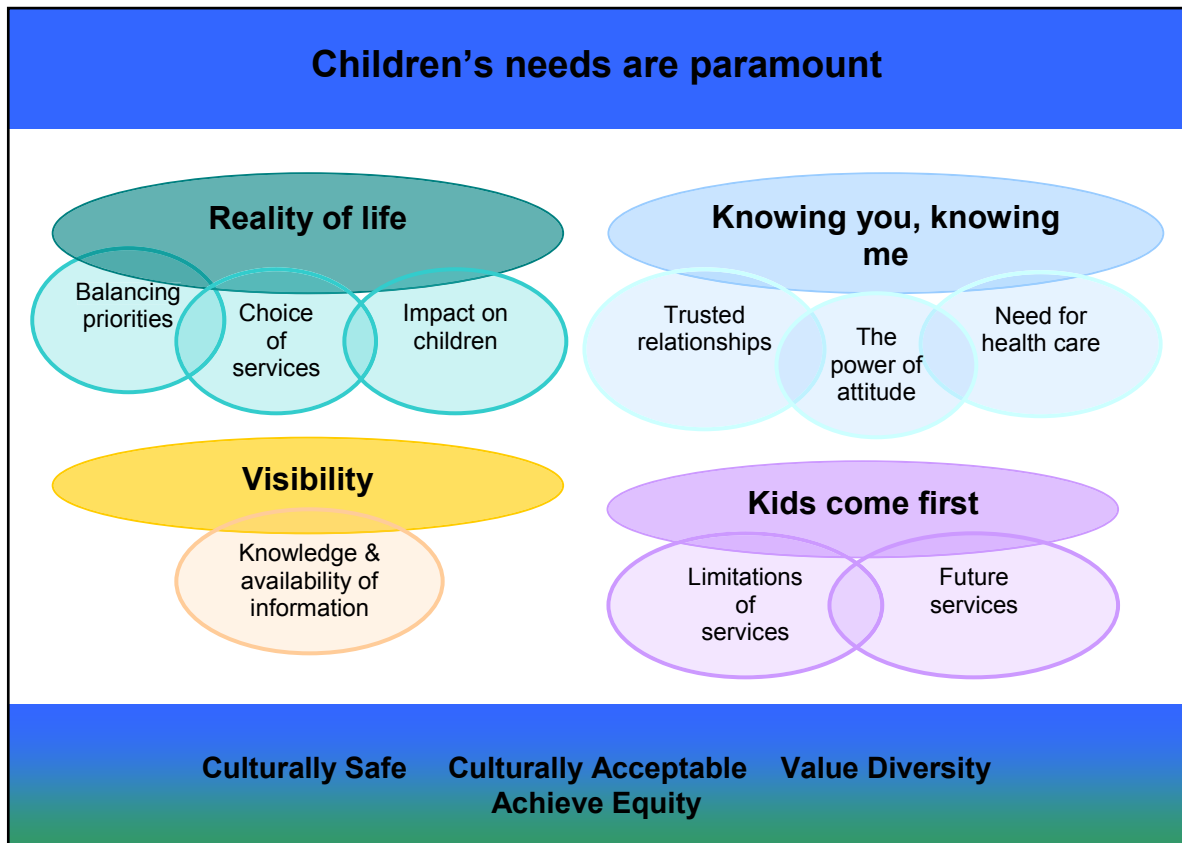
Introduction

In chapter three the research process was presented, detailing the research methodology, and the data collection and analysis process. Data gathered from the focus group interviews was analysed using a general inductive approach (Thomas, 2003) resulting in the development of four themes and nine sub themes. These are presented in the next two chapters, titled: Children's needs are paramount and Focus on children.

According to Thomas (2003) themes can be presented using a model or framework (Figure 1). Each main theme was named to represent the feelings and perceptions within it, such as „knowing you, knowing me“, the importance of parents and caregivers having a good relationship with their health provider. The naming of each sub theme reflected the particular data content, for example, „balancing priorities“ contained parents' and caregivers' reflections on how they were prioritising their family's everyday needs with individual children's health needs. Many of the themes and sub themes fitted into the conceptual model used to inform the discussions from the focus groups and present the data, principles from the New Zealand Child Health Strategy (MoH, 1998), some of which feature in Figure 1, with all the principles outlined in Appendix 8.

The principles from the Child Health Strategy (MoH, 1998) describe what should be in place for New Zealand children in order for them to achieve optimal health, no matter what their environmental, socioeconomic or family/whānau circumstances are. Specifically referred to in this analysis is the paramountcy of children's needs, services focusing on children and their family/whānau, services provided as close to home as possible, to achieve equity, are culturally safe, culturally acceptable and value diversity and that child health providers should work together with each other and other sectors to benefit children.

The data collected from each of the three focus groups will be presented in order to differentiate between the different ethnicities whilst still comparing and contrasting comments and perceptions across the groups. Each of the four themes will be presented in detail with the connections between the themes incorporated into the narrative description and discussion of the data.



Source: Adapted from the NZ Child Health Strategy Ministry of Health 1998

Figure 1 Conceptual model

Throughout the findings chapters each sub theme is introduced with a quote from a participant. Each quote has been selected to present a snapshot of the data contained in each sub theme.

The purpose of the study was to explore with parents and caregivers what health services they perceived would best address the health care needs of their children and how those services should be delivered. Most services and some individuals providing primary health care services to the community are mentioned in participants' discussions, but it came through clearly in the discussions that participants were referring predominantly to medical practitioners as the key provider of their children's health care.

In this chapter the data is presented in two themes. The first theme is titled „Reality of life“ and has three sub themes: „balancing priorities“, „choice of services“ and „impact on children“. The second theme is titled „Visibility“ and has one sub theme: „knowledge and availability of information“ (Figure 2). The second theme, „Visibility“ captures some further reasons why parents and caregivers do not always respond appropriately to the needs of

their children and links both with the discussion in the first theme regarding the balancing required in people's lives in relation to their children's health care, as well as people being aware of health services.

Reality of life

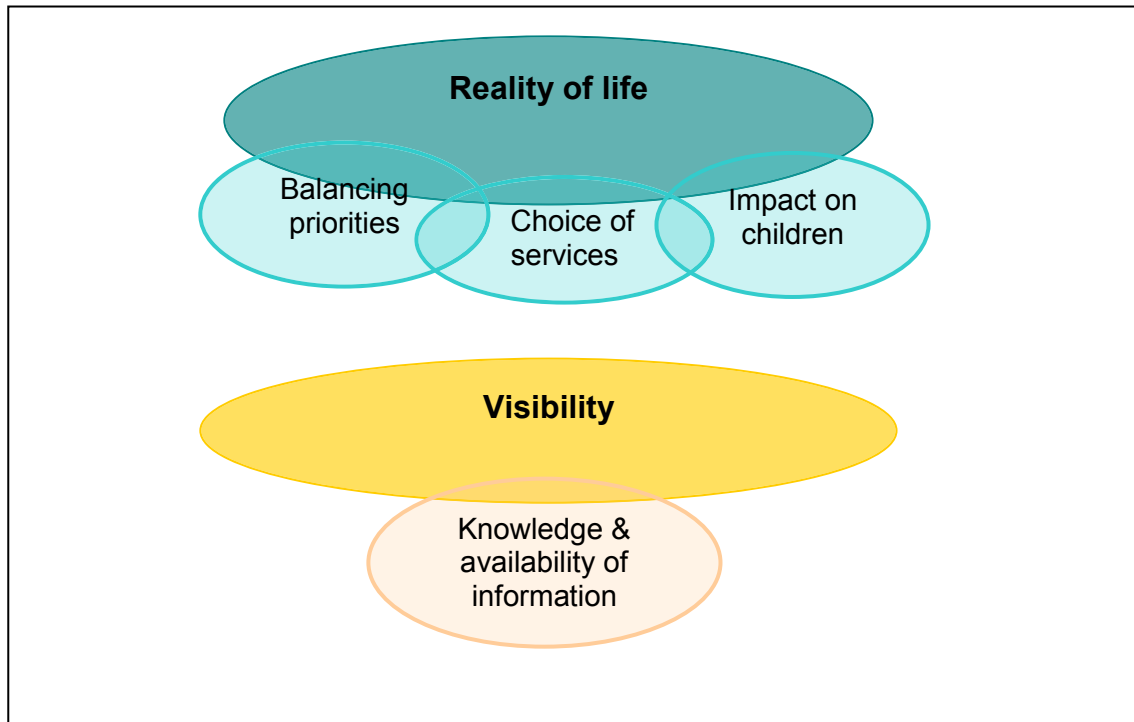


Figure 2 Children's needs are paramount

"People are struggling": Reality of life

Health service is too costly at the moment and if you're not subsidised, good grief, good luck on your health altogether. (Pac/9)⁶

Some of the literature reviewed for this study focused on the significant effects of the socioeconomic determinants of health and their influence on health care for children (Farmer et al., 2005; Hall & Elliman, 2003; Hall, 2004; Mielck, Graham & Bremberg, 2002; MSD, 2006; NZ Child and Youth Epidemiology Service, 2006, 2007; Turner, Hoare & Dowell, 2008). This literature confirmed the impacts that occur as a result of social disadvantage. Therefore, the analysis in this chapter begins with presentation of data related to the influence of social disadvantage and health system structures and processes that affect whether children receive the health care they require to meet their needs. The effect of social disadvantage on children's health was considered to be of

⁶ In both analysis chapters participants will be referred to by focus group ethnicity (i.e. Pac = Pacific; M = Māori; P = Pakeha) as well as the page number where the data originates from.

equal importance by all focus group participants, therefore comments from each of the groups are interwoven throughout this chapter.

Three sub themes emerged from the data that influence parent and caregiver access to health services for their children's care. The first sub theme, „balancing priorities“, reflects the impact of the socioeconomic determinants of health on child health. The second sub theme, „choice of services“, presents the discussion in relation to parents and caregivers seeking free services for children, and the third sub theme, „impact on children“ incorporates the effects on children of the decisions parents and caregivers make in their every day lives.

In this discussion which is focused on the realities of people's lives, participants shared their perceptions of the balancing required by parents and caregivers in providing for their families while meeting (or not), their children's health care needs. Participants were clearly emotional when they spoke about the cost of health care for children and in many cases the inability of parents and caregivers to reconcile that cost with other priorities. It is difficult for some parents and caregivers to meet the health needs of individual children in the context of the whole family, casting doubt on whether children's needs are, in reality able to be treated as paramount. It is interesting to note that at the time the focus group discussions were held for this study food prices had risen by 10% in the previous six months and petrol prices by approximately 50%.

***“Every pay day they have to make a choice”*: Balancing priorities**

...being able to pay for it. You'd look and think you know I gotta take my kid [to the doctor]... I don't know if you gotta card - \$15... or should I get milk, bread and butter for the night ... and you're gonna feed them [the family]. (M/19)

Affording health care is a challenge for those on low incomes and balancing family expenditure entails some prioritising of needs. Participants from all three focus groups referred to the conflict for parents and caregivers between being able to afford assistance from general practice when a child is unwell, feeding their family, or paying for some other item such as the power bill. One Pacific participant explained that the cost of living was an issue for parents and caregivers, “Like I say, funds is an issue” (Pac/1). As discussed in the literature, struggling to provide for more pressing needs such as food on the table may mean that health needs generally will be given a lower priority (Mansour, Lanphear & De Witt, 2000, Voyle & Simmons, 1999). Parents' and caregivers' decisions about paying for health care are reflected in the economic subsystem within the

„community as partner“ model (Anderson, 2008) and illustrates the explicit relationship between that subsystem and the health and social subsystem.

One Māori participant expressed their thoughts on the effects of the current cost of living for some families.

... people are struggling, they're lucky to make ends meet. Every pay day they have to make a choice whether to not pay the power bill or not pay something and these kids are going to get even worse „cause their parents are way over their head. (M/25)

Some families have to make difficult decisions when it comes to balancing their income between the bills they have to pay and providing for the basics of life. This is the reality for many people but this participant has assumed that children's [health] status will worsen with the struggle for families in meeting their daily living expenses. The consequence of balancing expenses was further explored with each focus group in the context of access to health care. Two Māori participants felt not having enough money was a major consideration for parents and caregivers.

I think that money is a big deal. I suppose the biggest eh? (M/16)

Huge, Huge. It's probably the majority of the problem. Can't even afford to buy food, you know go and get yourself a hundred bucks worth of groceries, you know these solo mothers, even solo dads they're not on enough, not enough and what's the Doctor, \$15? (M/16)

Affording to buy food is a big enough issue in itself for some families, let alone affording health care. These participants believed that the cost of health care was a „huge“ issue and have assumed that some parents and caregivers cannot even afford to buy food. The impression given is that solo parents would not be earning enough to cover daily living costs before even considering the cost of accessing a doctor for their children. Other participants also described cost as a barrier to accessing health care for them, “It is a big barrier for us” (Pac/9) and “Yeah cost is a barrier” (M/16). Cost has been identified as a major barrier to access to primary health care services in the literature (Higgs, Bayne & Murphy, 2001, MoH, 2008b; Schoen et al., 2000; Spenceley, 2005; Waibel, 2001).

One Pakeha participant voiced their concern stating that the cost would prevent some people from ringing for an appointment, let alone seeing the doctor. Even if the visit was free for some children there may still be associated medication costs.

People just won't do it, they just won't ring. A lot of people can't afford to go to the doctors anyway knowing that the kids until a certain age are free and then you've got your medicines on top of it, even though it's subsidised. (P/10)

The participant implied that, due to financial difficulty a decision would be consciously made not to contact the doctor regardless of the fact that visits and prescriptions are subsidised. The requirement for a co-payment when visiting general practice may also contribute to parents and caregivers not accessing health care for their children (Dubay & Howell, 2006).

It is common knowledge that one pays a fee in New Zealand to be seen in the general practice setting. Whilst it is acknowledged that the cost of taking a child less than six years old to the doctor and associated prescription costs have been minimised (Dowell & Turner, 2007), an issue with the cost for children over six and for after hours access to general practice was identified. One Pacific participant outlined the average cost for over five year olds to be seen in the town's general practices, "Any child from five or over you get charged 15 bucks" (Pac/8). Fifteen dollars was still considered to be too high, "I mean 15 bucks is still 15 bucks" (M/17). Māori participants put the cost into perspective with other daily living costs such as petrol and milk (the cost of petrol had risen to \$2.19c a litre at the time of the focus group discussions), "These days five bucks is five bucks, two litres of petrol" (M/17), and "You get a two litre bottle of milk which is five bucks now" (M/ 26).

One Pacific participant experienced higher costs seemingly because she had not been seen at the practice before, "That one I think cost me \$22 because I was new to the place and couldn't get into my own GP" (Pac/8). It is interesting to note the cost implications of having to go elsewhere for care. One Pakeha participant described the cost to them, "You've got \$21 for after six year olds and then you've got, I don't know \$5 to \$10 [for medications] if you haven't got a community [services card]" (P/10). Another Pakeha participant did not have to pay for one child with a disability, but paid the going rate for another child, "My son's got a community services grant because he's a disability child, so he's pretty cheap. My daughter nah, she pays what we pay" (P/11).

The cost of telephone consultations with the GP on call and for a house call after hours was discussed by Pakeha participants, “I rung them up [doctor] and got charged \$15 on the phone just to say what was wrong with my son and he said, Oh! You’d better go to the hospital then” (P/7). The participant expressed annoyance as she had followed what she thought was the „right“ protocol, that is to contact the GP on call after hours when a child is unwell, and thought she would be seen by that person first before being directed elsewhere. She was not happy that she had been charged for a brief telephone conversation with the GP on call when they were not seen in person and referred elsewhere, “The way I got charged 15 bucks in the middle of the night – it’s like, oh my god I got charged 15 bucks for that” (P/10). It appears that parents and caregivers who follow the „right“ protocol are penalised with, at times significant expense involved in accessing after hours GP services. Exploration of the actual cost of after hours consultations found that participants were charged for both telephone consults as well as a call-out, “Yeah they do charge [for telephone consultations] and if you have to call them out they put their normal charge of \$60 on top of it” (P/7).

The issue of after hours cost was not raised by Māori or Pacific participants as they generally attended the ED at the local hospital after hours. Māori participants reported that they consider ED first when they require health care, “The Māori community they would go to the hospital and that would be the first port of call” (M/8), and “Where do Māori people go? They go to the hospital” (M/8). For Pacific participants they also considered ED to be an appropriate place to take their children, “When our kids get sick or we need help we go to the emergency [at the hospital]” (Pac/5) and, “If I need help at night time, we go to the emergency.” (Pac/10)

It is clear that the balancing of life’s priorities with the cost of accessing health care for children over six years has been identified as an important issue by participants. Participants identified other options available to them when considering the issue of expense.

***“If you can’t afford it you go there”*: Choice of services**

Alternatives to seeing the GP were discussed by participants as the cost factor associated with visiting general practice was perceived to be a barrier to access for children and their families. The strength of the relationship parents and caregivers have with their primary health care provider may positively affect whether they decide to visit them or not (Reid, Haggerty & McKendry, 2002; Saultz, 2003). However, if there were associated costs with a GP visit then Pacific and Māori participants sought other options.

This approach was also suggested by some Pakeha participants. There are a number of other providers or settings in the community where services are provided and no fee is requested of attendees, for example, the Pacific Community Clinic and local marae clinic, however, awareness of these services was identified as an issue for some people. ED services are free for everyone in New Zealand. As mentioned earlier the ED at the hospital was identified by Māori and Pacific participants as a service to access after hours and also as a service to access when people could not afford to see their GP.

Actually that's a good idea too, going to emergency and that. I've done that a few times if I can't afford to pay straight out cash for the kids, take them up there and 9 times out of 10 they will do it anyway, look and care for the child. (Pac/10)

The literature identifies that where issues such as transport or financial difficulties impact on access to a primary health care provider, parents may use the ED for non-urgent conditions (Brousseau et al., 2007; Grant et al., 2001; Waibel, 2001). ED was identified by one Māori participant as the place to go as everyone knew about the hospital's service and because people's socioeconomic circumstances meant accessing ED was a preferred option, "...the hospital is known about by everyone...and also because of socioeconomic circumstances" (M/8).

One Māori participant explained that health providers do not always inform parents and caregivers of what is available, "...there's other services out there that can help you to keep going to the same GP..." (M/15). Most Pacific participants in the focus group were aware of the free services provided at the local community centre and were proactive in informing others who were unsure about where they could go without incurring any cost. There was a sense that it was important that people were made aware of services that could be accessed at no cost.

We do say, right if they have a certain problem, right there's this [Pacific Community Clinic], this is free, so don't go there. We are aware of certain places like [name of Māori Health Provider] it's a free service, this clinic is a free service, Plunket is a free service but GPs ain't! (Pac/14)

Participants were aware that, generally in New Zealand, the accepted avenue for accessing primary health care for their children when they are unwell is through the general practice setting. It was accepted that mostly they would access the general practice team for assistance for their children during normal working hours, but some Pacific participants in particular preferred to access their local community clinic as

opposed to general practice, because it offered a free service. As explained by one participant, “We come here [Pacific Community Clinic] and not that one [doctor] for the money” (Pac/10).

There was further discussion amongst participants regarding the free services with acknowledgement that use of a free service was a good option for those having trouble finding the money to pay the doctor’s fee. One Māori participant stated that “If I was on the bones of my backside I would take my children there” (M/5). A Pacific participant felt that, “This service here [community clinic] provides well for the ones that can’t afford it” (Pac/2).

Even though the Pacific participants appeared well informed about their local community clinic it was felt by one Pacific participant that Pakeha participants living in the area were not aware of clinic services, “Quite a few didn’t know this was here. Especially the European society that does live around here, they weren’t aware this service was here” (Pac/20). The clinic has been running for several years although services provided previously were predominantly provided for adults only. This may indicate that there has been less need by Pakeha members of the community to access this particular service or it may relate to how the service is promoted, appearing to be only for Pacific and Māori people. As identified earlier, however, Pakeha participants generally access primary health care through the general practice setting. One Pakeha participant was aware of the community clinic as well as the marae service and was supportive of choices for those who could not afford to see the doctor in the general practice setting, “That’s where the [Pacific] community clinic and the marae, that’s where if you can’t afford it, you go there” (P/26). The other Pakeha participants were, however, unaware of the availability of these services, confirming the belief of the Pacific participant.

Not all participants’ decisions regarding access to general practice were influenced by cost. One Māori participant, aware of the cost involved in accessing their GP, did not allow that to influence their decision, “I’ll worry about the costs tomorrow you know, their health comes first” (M/13), although another participant considered that to be unusual, “I think you’re a minority, I really do. I believe you are a minority” (M/13). Two other participants had established a payment system for themselves that meant they did not have to worry about finding the money at the time of the visit, “I’ve got a sub scheme going at the doctors where I pay \$14 or \$21 a fortnight and that covers all of us” (P/11).

I've got an account where funds go straight through. If my children need to be seen then there it is, I don't have to worry about funds. I just take it as it comes; mine's already paid. (Pac/8)

Implementing another plan for payment as these participants have done has reduced the cost barrier of access to primary health care for their children. However, it also raises issues regarding expectations placed on low income families to find money on an ongoing basis, when much of the time that will be difficult.

Outstanding debt owed from previous visits may contribute to parents and caregivers' decisions not to access general practice for their children. One general practice in the town was known by a Pakeha participant to demand payment prior to being seen, „Cause the [named] doctors, now I know, if you owe money, they won't let you see the doctor until you pay up the money that you owe them" (P/11). Although it was not raised as an issue by Māori and Pacific participants in this study, this has been noted as a barrier to access in other literature (Bolitho & Huntington, 2006, Tracey & Cooke, 2005). It can be assumed that parents would seek out other options for their children like the ED at the hospital or the free marae and community clinic services, rather than return to their general practice to be presented with an account.

***“They wait until they're really sick”*: Impact on children**

Lack of access to health care is largely shaped by socioeconomic factors (Exworthy et al., 2006, Paterson & Judge, 2002). The discussion regarding the impact on children of not accessing health care resulted from participants' issues with the cost of health care for their children. Not contacting the doctor was highlighted in the previous discussion in terms of not being able to afford to attend the general practice setting therefore alternatively accessing free services. The effects of decisions being made regarding whether assistance is sought from health services and which services would be accessed, if any, for their children, was described by participants from all three focus groups.

One participant felt the cost was clearly the reason why parents and caregivers were not accessing primary health care, “It really is like I say, it's the money that's got a lot to do with why they stay away and [the kids] suffer” (Pac/10). Participants felt that parents and caregivers were waiting to get their children seen. This at times resulted in presentation to ED due to the seriousness of the child's condition. ED was also used because it was free. One participant expressed her concern about what she was seeing through her line of work, that children are really sick before being seen by a health practitioner,

Well you see a lot of people wait until their kids are really, really sick or don't take them sooner, which I've been seeing, or they end up really, really bad and end up in hospital because they don't have to pay for it and end up having the ambulance. They wait until they're really, really sick.....they can't afford to go to the doctors sooner because they haven't got the money to get the prescriptions, the medicines. (P/10)

The use of ambulance services is mentioned by this participant indicating that by the time a decision is made that a child needs intervention, they may require assisted transfer to the hospital's ED. This participant believed that an inability to pay for the prescribed medication was the reason parents and caregivers delay getting their children seen.

One Pacific participant indicated that some parents and caregivers are waiting until the Pacific Community Clinic is open to have their child seen by a nurse and/or doctor. This could be appropriate but the impression was that children are suffering due to that wait.

Sometimes during the afternoon when we've got the doctor here [at the clinic], sometimes we've only got an hour. In an hour a lot of us can't see the GP.

So they wait and see the doctor when he comes here? (researcher)

Yep.

But that's only once a week for an hour. So what happens in-between times? (researcher)

Well, a lot of them suffer. (Pac/6)

Pacific participants had previously identified that they would use their local clinic because it was free; subsequently identifying the trust participants had in the community clinic nurse and doctor. The literature supports use of the same service if people trust the provider delivering the service (Christakis et al., 2001; Neufeld et al., 2002; Sanghera, as cited in Spenceley, 2005).

Not having the money or a telephone to call for assistance when their child is unwell may result in embarrassment (whakamā⁷) for Māori parents and caregivers as well as the

⁷ Whakamā is a Māori term described as the notion of culturally appropriate shame or shyness (Cram, Smith & Johnstone, 2003)

child not receiving, at times, much needed health care. One Māori participant described how a mother was embarrassed that she didn't have any money and couldn't afford a telephone, "She was embarrassed ... when her baby was unwell and yeah no money, no telephone to ring [for help]" (M/19). The effects of whakamā for Māori is raised in the NZ Primary Health Strategy (Minister of Health, 2001) and the Child Health Strategy (MoH, 1998), as having a significant impact on whether parents and caregivers access health care.

In this sub theme participants discussed some of the impacts on children of the cost of health care and how, at times, this affects whether children are seen in a timely and appropriate manner.

Visibility

In this second theme the availability of information regarding health services and visibility of providers was explored with participants. These factors influence whether parents and caregivers are comfortable accessing services or whether they are aware of all health services that are available for their children.

"People need to know about it": knowledge and availability of information

I think getting access to services is relatively easy but it comes back to my initial point that people need to know about it... (M/13)

In order to respond appropriately when children need health care parents and caregivers require a level of knowledge of what services are available for children and an understanding of which provider to access for what (Ames, 2007; Rosenbach et al., 1999; Waibel, 2001). Not having that knowledge has been identified as one of the barriers to accessing primary health care services in the New Zealand context (Minister of Health, 2001).

It was identified that mostly people find out about services through „word of mouth“. One Māori participant identified that they find out via "Word of mouth or my family" (M/6). This was corroborated by one Pakeha participant, "Basically word by mouth" (P/3). As explained by Pacific participants, "Word of mouth does travel a fair way here" (Pac/2), and "I had friends that were coming here, but they only knew about it because of word of mouth" (Pac/3). The Pacific community are also informed of services by the Pacific

Health Worker, “I’m glad we’ve got [named person] here for all the new comers that do not know” (Pac/14).

Knowledge of general practice and Plunket services was not an issue for any participant. When participants were asked if they knew about other services delivered in their community, it was evident across all focus groups that knowledge of health services, what exists and what providers deliver was variable. Pacific participants commented that, “Some do know and some don’t” (Pac/1), and “The others no, Plunket’s probably the only one” (P/5). This was supported by one Māori participant who felt that people would not know about some services, “I bet people don’t know that there’s like, not just Māori services..., there’s heaps of them...” (M/7). Another Māori participant was sure that a lot of people were unaware of what the local Māori providers delivered,

I’ve been here two years and other than word of mouth or my family members that have lived and stayed in [named town] and one of my brothers works at WINZ, other than that, I don’t think you’d know what these outfits [Māori providers] are. (M/6)

If the community is unaware of how a provider may assist them then people are less likely to access the appropriate provider when required. One Māori participant accepted that it was their responsibility to know what services were available, but pointed out that information regarding what services provided should be readily available, “I take responsibility for that because I don’t go out looking for that information, but by the same token if that information isn’t readily available – so it’s a two pronged thing” (M/1). There is shared responsibility between providers informing people of what services they provide and the community seeking out the information about services through their own means.

Communication was raised in general terms by both Māori and Pacific participants, and was considered to be quite an issue for some Pacific parents and caregivers. For some Pacific parents new to New Zealand, lack of awareness about services was perceived to be partly attributed to little command of the English language. Complex social factors associated with ethnicity and language may compromise consistent access to primary health care (Chung & Schuster 2004; Hall & Elliman, 2003). Parents and caregivers who speak little English are often unaware of the children’s services that exist within a community (Ames, 2007) or cannot understand information regarding services when it is provided to them.

Someone may be able to read the information in English but if you're a Samoan or Rarotongan... looking at something in English you can't understand that. So things need to be addressed in all languages depending on what ethnic group you are in. If you are Samoan it would be nice to have things done in your own language, if you're Rarotongan – done in your own language, just in case you may have only the basics in English. (Pac/11)

This Pacific participant implies that Samoan and Rarotongan parents and caregivers may have limited understanding of the meaning of the information they are receiving if it is only provided in English. Providing information about services in one's own language may assist these parents and caregivers to access the services they require for their children's needs (Hall & Elliman, 2003). Alternatives to written communication needs to be considered as the role of the Pacific Health Worker has been identified as an alternative way for the Pacific community to be informed of services available to them and their children.

Understanding information provided by a health practitioner was described by one Pacific participant in relation to medication administration.

It would be nice to know that when you've been given medication [for your child] you know how to administer it properly and for someone to speak to you in your own language than you hearing gobble-de-gook. (Pac/22)

This implies a desire to have someone communicate with parents in their own language to enhance their understanding. The participant also raises a very important point, knowing that any medication prescribed is being administered appropriately. An information leaflet sent out by the local school had been received the day before the focus group, informing parents and caregivers of symptoms to look out for in their children as a child at the school had been diagnosed with an infectious condition. Whilst participants appreciated the school sending home the information, "I appreciate that because we have to be very careful of what to watch out for" (Pac/16) and "I think the school is brilliant dealing with different [health issues]" (P/16), it was noted by both Pacific and Pakeha participants that not everyone may understand the information as the leaflet was written in English only. One Pacific participant posed the following question to another in the group "If this was done in your language you'd understand it better eh?" (Pac/16), with the response being "Aye" (Pac/16). Another Pacific participant also noted that those whose first language was not English would not understand something written in English.

The availability of information in English only was considered by Pacific participants to contribute to a limited understanding and knowledge of childhood illness and recognition of the symptoms of illness in children. A lack of knowledge of services and understanding of information may correlate at times with a delayed response by parents and caregivers. The relationship between the health and social subsystem and communication subsystem in the „community as partner“ model (Anderson, 2008), specifically as it relates to the school in the dissemination of widely understood health information, is highlighted with the issues raised by the Pacific participants.

Conclusion

Social disadvantage is known to affect access to health services. The struggle that some parents and caregivers have in catering for their family needs has been described by participants and financial concerns discussed. The issue has been explored in this chapter through the data presented, alongside the impact on children of the cost of health care. Structural influences and processes can make it difficult at times to get advice when needed from health practitioners. The cost of both attending general practice and for medications, albeit subsidised for children six and over, is reported to be too high. The cost of after hours access to a GP is also an issue. If parents and caregivers delay getting their children seen by their primary health care provider it may result in children being far sicker by the time they eventually present to the GP or the hospital, than if they had been seen sooner. Knowledge of available health services, coupled with language issues amongst some of the Pacific population has been identified alongside other known barriers. All of the factors and barriers highlighted by participants give cause for concern regarding whether parents and caregivers are able to treat their children's needs as paramount.

Improving children's access to health services needs further consideration given the barriers to access identified through the data in this chapter. In the following chapter further themes from the data will be presented and the connection with the concepts described in this chapter will be highlighted. The discussion regarding prioritisation of children's health care and enabling improved access will be expanded in chapter six.

Chapter 5 - Focus on children

Introduction

In chapter four the data from two themes relating to children's health care was presented. The participants described the reality of people's lives and the impact on children's health care. The analysis continues in this chapter with presentation of data related to the influence of relationships and connections between parents and caregivers and children and health providers, and an understanding of the need for health care and how these factors affect children's access and use of health services. Limitations of services are discussed along with an exploration of future service provision in the context of the community.

In this chapter the data is presented in two themes linked to the following principles in the Child Health Strategy: "children's needs should be treated as paramount; health and disability services delivered to children should be focused on the child and their family/whānau, be culturally safe, culturally acceptable, value diversity, achieve equity and be provided as close to home as possible" (MoH, 1998, p. vii, 1998). The first theme is titled "Knowing you, knowing me" and has three sub themes, which explore factors that influence connectedness: „trusted relationships“, „the power of attitude“, and „need for health care“. The second theme "Kids come first" has two sub themes, „limitations of services" and „future services" (Figure 3). An exploration is undertaken of whether „kids come first" with consideration given to the degree to which current services are meeting children's health care needs and whether services provided to children are culturally safe, culturally acceptable and value diversity.

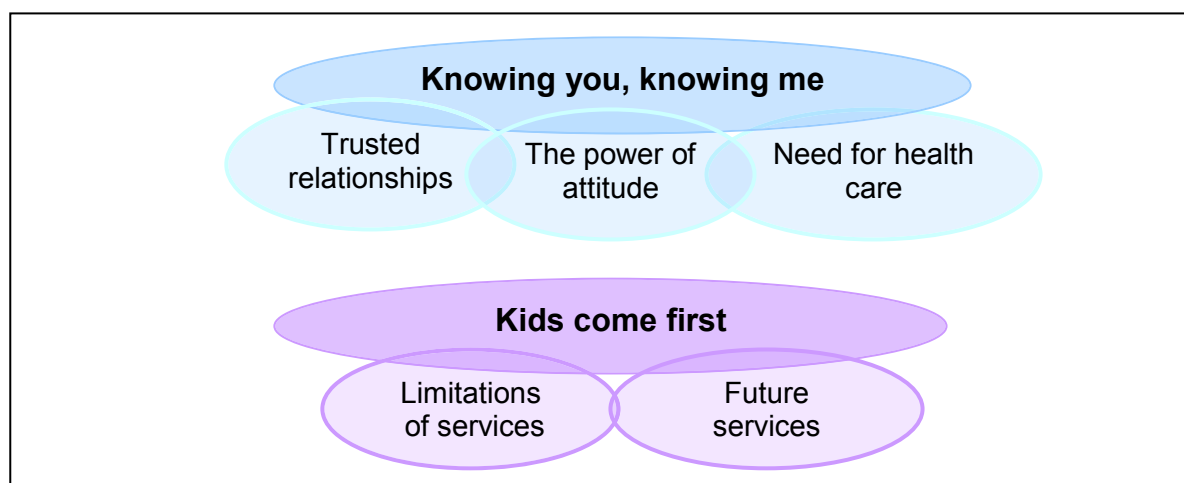


Figure 3 Focus on children

Knowing you, knowing me

***“Knowing you, knowing me”*: Connectedness**

Participants from all three focus groups made reference to their relationships with different health providers and health practitioners that provide services to people in their community. It was evident that at times trusting relationships between providers and parents and caregivers, and children were pivotal in assisting parents and caregivers to make decisions regarding health care for their children. In contrast descriptions of less than favourable relationships were described as a potential hindrance to children receiving the health care they require in a timely and appropriate manner.

The first theme explores the importance for children and their families/whānau, of feeling connected to a health service and health practitioners. An analysis is undertaken on the effects that on going relationships with preferred primary health care providers, that is continuity of care, may have on whether children receive the care that they require to meet their health needs. Measurement of continuity is not easy. Continuity is about the experience of the individual [patient] and it refers to care delivered over time (Reid, Haggerty & McKendry, 2002). In the literature review the three levels of continuity of care were: interpersonal/relational continuity, longitudinal continuity and informational continuity (Appendix 1). Interpersonal/relational continuity refers to an ongoing relationship between a patient and one or more providers, informational continuity uses past information and personal circumstances to make current care appropriate, and longitudinal continuity occurs when a patient has a medical home, allowing care to occur in an accessible and familiar environment (Reid, Haggerty & McKendry, 2002; Saultz, 2003). The data collected in this research focuses on interpersonal/relational continuity and informational continuity. Currently there are only a few areas in New Zealand that use the „medical home“ concept (American Academy of Pediatrics, 2004). The community in this study is not one of them, therefore views on longitudinal continuity were not obtained.

***“He knows them, he’s got our file”*: Trusted relationships**

... for my children’s health ... I prefer my own GP. We’ve had a good bond for years and years and I’m not really interested in anyone else assessing us but my own personal GP. (Pac/7)

The importance of establishing an ongoing relationship with primary health care providers emerged from the discussion regarding access to services for children. The concept of „knowing you, knowing me“ was identified by participants in each of the three

focus groups. Interpersonal⁸ and informational continuity were equally important to Māori, Pacific and Pakeha parents and caregivers therefore their quotes are interwoven throughout this section of the chapter. Trust, or in some cases lack of it, became apparent as participants described their relationships with primary health care providers, that is GPs, “I have faith in my GP, I trust my GP” (Pac/22), Plunket nurses, “Plunket has always been up there for me” (Pac/3), Public Health Nurses, Māori Providers, the Pacific Community Health Worker, “If my kid is sick every time I come and tell [named person]” (Pac/4), Midwives, Child and Adolescent Mental Health Services and the registered nurse and doctor at the local Pacific Community Clinic. It appears that trusting a provider is paramount to children receiving quality care (Mansour, Lanphear & De Witt, 2000).

Participants in all three focus groups trusted those primary health care providers or practitioners that were well known to them and their children. One of the Māori participants stated a preference for staying with the same GP, “I think it’s more with me – it’s better the devil I know. He knows my whole family and [we] stick to the same person” (M/15). The length of time participants had been seeing their primary health care provider was part of the reason a trusting relationship existed between them and the health practitioner. This is identified in the literature as necessary for interpersonal continuity of care (Reid, Haggerty & McKendry, 2002). One participant expressed their desire to stay with the same GP as he had been caring for the family since the children had been born and he had information on all the family, “... like to stick to my GP, my own GP. He was there at the kids’ birth you know, he knows them, he’s got our file.” (M/14)

The reference to having their own GP suggests a sense of affiliation and connection with the GP, which is implicit with interpersonal continuity (Haggerty et al., 2003; Saultz, 2003). Informational continuity is also evident as the GP has the family’s file implying that the GP has all the necessary information to treat them appropriately. Informational and interpersonal continuity is referred to by another participant, highlighting the importance of the practitioner knowing the child and family and their history coupled with having all their details available when treating them.

For me it is very important [that the doctor knows my child] because my son is an asthmatic and is an eczema patient too; he gets severe eczema. Now since he was born I’ve always had him with her and she has grown with my child and me.

⁸ For ease of reading the term interpersonal continuity will be used throughout the chapter which has the same meaning as relational continuity

By looking at our files when she bumped it up onto the computer, she is aware of what our history is and what medications we've taken and what to medicate us with and what not to. (Pac/7)

The parent implies that the doctor has all the information necessary to care for her child due to the longstanding relationship between them and everything the doctor needed to know was on the child's file or in the doctor's memory. The same participant refers to being seen by an unknown practitioner and describes her perception of this,

... a lot of the other GPs, if we go through an on call duty GP they may look at a file but don't go right through and don't realise, hey this had been administered way back in the past and this did not work for us. You know that personal issue of a GP knowing you as time has gone by compared to someone who has known you for a few moments in an office. (Pac/7)

A practitioner who regularly interacts with a patient accumulates knowledge regarding them, not only in the records kept on the patient but in the practitioner's memory, therefore it is difficult for an unknown practitioner to be responsive to the context surrounding the patient (Haggerty et al., 2003). The literature suggests that if a doctor is unfamiliar with a patient's recurring symptoms and medical history then they are less likely to manage the problem promptly (Brampton, 2000; Haggerty et al., 2003). The participant above described the difference for the family of knowing the GP over a period of time. Establishing an ongoing relationship with the doctor was described by another participant as being advantageous for both parties, "If you've got the right relationship with your doctor that becomes a win-win, because you're learning off each other" (P/19). The participant appears to interpret the „right relationship" with their doctor as an experience where the doctor learns from the patient as much as providing a service to the patient.

Continuity of care may be particularly important for parents and caregivers with added challenges, for example, having a child with a disability. One parent felt it was important for her child with a disability to be seen by the same practitioner. She explained that her son did not like change and if he was seen by a different practitioner then he would not do what the practitioner asked him,

With my son I stick with the same doctor „cause he has a problem with change and if he has a person seeing him that's different he won't sit there and do whatever. It has to be Doctor [named]. (P/12)

Interpersonal continuity of care may assist a child with a disability to feel more comfortable with the health practitioner examining them and undertaking any necessary procedures required.

Generally Pacific participants accepted that, at times, it would be necessary to be seen by other GPs, however, one participant expressed their unhappiness about this whilst accepting that at times there was no choice.

I will get somebody else to assess, an on call duty doctor that's at the centre but very rarely. Only if it's a must will I go to an on call duty GP if we can't get my own GP. I won't be happy about it but I will have no choice. (Pac/7)

Providing consistency of practitioners at the local Pacific Community Clinic was considered by Pacific participants to encourage attendance. The nurse and doctor assisted, by the Pacific Community Health Worker that regularly provide the service at the clinic, have formed relationships with the community which encourages attendance. One participant felt that it was not helpful when a new practitioner was introduced into their community, "It doesn't help when a GP is a new comer to the community" (Pac/9). Another participant explained that any change in personnel caused people to reconsider whether they would attend the clinic, "The ones that work in the health system, you've got to have the same ones coming or you won't get people coming and they'll think oh, I'm not going there, there's a new person there." (Pac/19)

Furthermore, as described by another Pacific participant, practitioners who regularly provide services and are known to be based within a particular provider or setting instil a degree of confidence and faith in their ability, "You'd get to know the nurse who is here and the doctor who comes...you've got a lot more faith with the ones that are actually registered at your clinic than the ones who come and go." (Pac/13)

Some Māori participants expressed a lack of trust in some providers, in contrast to previous examples given of trusting relationships between parents and caregivers and providers. Māori participants implied that the Māori providers were not well connected with the community. One participant commented that the providers are there, they are visible, but that they were still not in touch with the community, "They're out there, they're all seen, but are they in touch? No they're not" (M/18). Another participant described the providers as needing to "...be more tangible and not be untouchable" (M/32). An observation from another participant was, "You see all these people around and you see them in cars, they're very visual but that's all you see" (M/15). Another issue raised by

participants was that Māori providers were not asking the community what they required or using pre-existing relationships as community members, “They don’t go that extra step to get involved in the community” (M/15). Participants felt the Māori providers were not making the effort to gain the community’s trust.

They need to get out into the community. They need to knock on doors; they have full knowledge of who needs help and who doesn’t, because I know several of them that live here.... You know they already have the relationship. They can take advantage of that relationship and get out there and get in there with them people. (M/26)

The participant implied that the Māori providers need to spend more time in the community making connections and building trust as the providers already know who needs assistance.

If parents and caregivers do not feel connected with a health provider then it was implied by participants that they are less inclined to trust them and the services they provide. In some cases participants’ perceptions of poor relationships translated into criticism of providers. This is explored further within the following section where the attitude of practitioners is discussed.

***“You haven’t even looked at them”*: The power of attitude**

The attitude of practitioners can at times be destructive, preventing the establishment of a relationship between the practitioner, children and parents and caregivers. Some Māori and Pacific participants identified the attitude and skills of providers as being an issue on occasions. One participant felt that at times providers did not „see” them as individuals and were only interested in the money they received from treating them, “To some I feel you are just a number and you are just funds” (Pac/13). Another described their disbelief when a practitioner did not undertake a physical examination on their child, “Sometimes a doctor will just look at them [child] and go yeah they’ve got this or that wrong with them, but you go, you haven’t even looked at them” (Pac/8). The attitude of health practitioners was identified in the 1998 Child Health Strategy (MoH, 1998) as one of the barriers to access to health care for the children of Māori and Pacific people.

One Māori participant acknowledged Plunket’s (well child health provider) ability regarding care for their grandchild/mokopuna, but at the same time gave the impression that other well child services may be less than credible.

... I'm used to taking my moku to the doctor and Plunket. My boys under Plunket, he goes to Plunket and he gets weighed and that there and I think can they [other child health provider] do it? I know Plunket can. (M/24)

The participant trusted the skills of Plunket [nurses], but questioned the ability of the other available well child service which is provided by one of the Māori health providers. Plunket has a long standing history with New Zealanders having provided well child services since 1907. The Māori Health Provider has been providing well child/tamariki ora services in the community for only four years. The knowledge power of providers in relation to their credibility has been identified elsewhere in the literature (Sanghera, as cited in Spenceley, 2005).

The attitude of a practitioner can engender feelings of disbelief and mistrust in a parent. A Pacific participant reflected on a time when she had to take her child to a doctor they did not know. She explained that the doctor had taken no notice of her child and based his conclusions entirely on what she was telling him in response to his questions.

As it happened one time with [named child] and we were at the Doctor ... and he asked questions, she was saying she had migraines and headaches and stuff and he just asked questions ... He hadn't even looked or done any examination on the child or anything, just asked me questions and I thought well that's stupid – why are you here? (Pac/8)

The participant was left questioning the ability of the practitioner to undertake his role when he did not examine the child. Mistrust of health providers may impact on whether parents and caregivers will access health services again for their children (Cram, Smith & Johnstone, 2003; Grant et al., 2001).

One Māori participant indicated that being made to feel that a service was only provided for those with little money exacerbated their embarrassment. This comment also implies a degree of stigma associated with attendance at this service, "...when word gets out that you have to be on the bones of your backside to go to that place, it then makes the people like ourselves more whakamā about going" (M/27). For Māori the concept of whakamā appears to play a role in whether they feel comfortable accessing a service; whether they take action when required and whether that action is timely. However, as described earlier in the chapter, where a level of trust has been built between providers and the community Māori parents and caregivers were more comfortable accessing some services.

One Māori participant felt that another possible reason why parents and caregivers may not seek assistance for their children when required relates to a perception that health practitioners may judge the child and family. They described how a parent may perceive their child is dirty (padu) when the child contracts a skin disorder and that a health practitioner may judge them for that, "...they might get school sores and they [parents and caregivers] like ooh my kid is padu [dirty]. That has a lot to do with it. Yeah how people [health practitioners] will see them" (M/18). As identified by Peckover (2002) parents and caregivers may be concerned about what might happen if they are not seen in a positive light by a health provider and the possible repercussions of that impression.

Some parents and caregivers may have encountered insensitive or judgmental health practitioners in the past which can engender feelings of embarrassment (whakamā) and shame (Morgan et al., 2002; Sanghera, as cited in Spenceley, 2005; Schilder et al., 2001). These feelings can adversely affect relationships with health care providers especially for those parents and caregivers from lower socioeconomic or minority backgrounds, causing them to avoid services for their child when required (Mansour, Lanphear & DeWitt, 2000). The examples given in this study do not necessarily suggest that local health providers' attitudes were judgmental towards participants, however, given that this issue was raised by Māori and Pacific participants implied that it is another perceived barrier to access for these groups.

Cultural factors such as whakamā were highlighted in the Child Health Strategy (MoH, 1998) as one of the barriers for Māori and Pacific people regarding access to care for their children. In this study the concept of whakamā has been identified by Māori participants in relation to not identifying a child is unwell and intervening sooner. Māori participants' descriptions of parents' and caregivers' embarrassment when they felt they were being judged by a practitioner indicates a potential barrier to early intervention.

In this sub theme participants have described the attitude of some practitioners, their trust in the knowledge of some providers whilst at the same time questioning the skills of other providers. How these factors influence parents' and caregivers' decisions in regards to accessing health care for their children has been discussed. The next sub theme explores further reasons why parents and caregivers may not respond appropriately to the needs of their children. The discussion links with sub themes in the previous chapter, balancing priorities in relation to children's health care, and having an awareness of services.

***“They don’t see the value of it”*: Need for health care**

It has been identified that other family/whānau priorities can take precedence over children’s health needs (Bolitho & Huntington, 2004; Voyle & Simmons, 1999). Some of the conflicting priorities in families’ lives have been explored in chapter four when comparing the cost of daily living with the cost of health care. That aside, upon further reflection some focus group participants, Māori in particular, considered that not enough emphasis was placed on their children’s health needs.

A lack of proactiveness on the part of some parents and caregivers was raised by both Māori and Pacific participants in this study. One Māori participant commented that they felt Māori were not as proactive as their European counterparts in seeking assistance for their children, “Māori people by nature in society are very sedate people. We won’t go out and proactively look for the health providers that our European counterparts would who are more proactive” (M/8). Research undertaken with Māori by Voyle and Simmons (1999) found that Māori referred to a “prevailing apathy” (p.1044) amongst themselves when discussing the value that they put on health programmes. This may contribute to reasons why some children do not always access health care in a timely fashion.

One Māori participant openly stated that some Māori parents and caregivers do not always prioritise their children’s health, “They don’t prioritise that the kids are the first things that come. I know that’s really harsh but it’s true. That goes on in the community; that they don’t prioritise their kid to be the main thing” (M/18). The comment implies that „not putting kids first“ could be an issue for some in their community. Another participant expressed their view that at times some Māori do not take too much notice of what is happening with their children’s health, “...as Māori people we tend to not take too much care of what’s going on with the health of our children” (M/31). Other Māori participants identified that some parents and caregivers cannot identify when their children have something wrong with them or else do not consider it an issue when children are unwell.

A lot of people don’t identify or take it quite casually that their kids have got something [wrong] that’s confusing them [the parents and caregivers]. (M/22)

Their kid gets sick and they haven’t taken notice of it when they first got sick and then it gets too sick so they’re embarrassed because they should have taken it before now. (M/18)

A lack of knowledge of the symptoms of illness may be the reason why parents and caregivers do not recognise what is wrong with their child. The value put on taking a

child to the doctor may also be affected by the beliefs that the family/whānau has about illness and disease (Bolitho & Huntington, 2006).

How parents and caregivers make decisions about dealing with their children's health issues influences whether children receive the care they require. Participants from all three focus groups identified that having the skills to identify when children need assistance appeared to be lacking in many parents and caregivers which in turn influenced their decisions about their children's health care needs. One Māori participant admitted they did not bother much with advice "I really haven't gone into or sought much advice" (M/10), and a Pacific participant referred to lack of knowledge in relation to health issues for children, "Some people don't know [what to do]" (Pac/13).

One Pacific participant identified the issue of parents not recognising that their children are unwell and subsequently still sending them to school.

Maybe a parent cannot identify what's wrong with their children and they go to school with whatever might be going around and pass that on to everybody and come home and by then it's too late. (Pac/1)

Parents and caregivers may sometimes fail to recognise or understand the significance of symptoms of illness in their children, even when they seem obvious to others (Hall & Elliman, 2003).

Participants discussed why parents and caregivers may not take their child to be seen by a health practitioner when their child is unwell. One Māori participant expressed that, "There's a lot of reasons why [that happens]" (M/17), whilst another Māori participant directly related the inability of parents and caregivers to recognise when the child needed assistance as a lack of parenting skills, "I really can't think of anything else [why parents and caregivers don't act] apart from the lack of parenting skills and I think it's a major one" (M/23).

A comment made by one Pacific participant during the discussion identified that some parents needed encouragement to get their children seen by a health provider.

... with some parents they don't want to do much with their life and when it comes to their children's health you need other members of the family to direct them or ensure that they get their child here [local clinic] to be seen. I won't say all but there are some who require a lot of encouragement. (Pac/3)

The lack of motivation described by this participant, coupled with a possible lack of knowledge of illnesses, embarrassment, shame or language issues could all be reasons why some Pacific and Māori parents and caregivers need encouragement to take their child to a health practitioner (Chung & Schuster, 2004; Hall & Elliman, 2003; MoH, 1998).

A lack of understanding of when to intervene may be an additional reason why children's health is not valued as highly by some parents and caregivers. There are other influencing factors such as cost, ability to take time off work to care for a child or take them to the doctor, and accessibility of providers which all contribute to whether parents and caregivers are able to give their children's health the priority it may require. These influences are discussed later in the chapter in the second theme. There is also the possibility that previous negative experiences with health practitioners as discussed earlier in the chapter may also be a factor why children's needs appear to be at times, not highly valued. Notwithstanding these additional factors, the value placed on children's health needs further exploration. If parents and caregivers do not have the knowledge to care appropriately for their children, whatever the reason, then they will not necessarily know when to seek assistance. This, coupled with parents and caregivers not „putting kids first“, may contribute to children's health needs not always being met in a timely and appropriate way.

In this theme, „knowing you, knowing me“, the importance of trusted relationships and continuity of care for children and their parents and caregivers has been explored, as well as the impact of provider and practitioner attitudes on parents' and caregivers' access to health care for their children and parental and caregiver understanding of the need for health care.

Kids come first

***“Kids come first”*: Limitations and opportunities**

This theme presents the perceived gaps in current service delivery in the community and considers how services might need to change in order to better meet the needs of the community's children. Participants discussed what could improve access including where services could be provided and by whom, and suggested what extra considerations need to be made in relation to those services.

The premise that primary health care services should be provided as close as possible to where people live, work and play (Hutchinson, Anderson & Gottschalk, 2008; MoH, 1998; Minister of Health, 2001) was supported by focus group participants. Barriers such as

parents" and caregivers" income levels were identified in chapter four. Other barriers raised by participants from all three focus groups were transportation, hours of operation, location and timing of services, lack of available information regarding services and parents and caregivers not being able to take time off work to attend to their children"s health care needs. This is consistent with other research regarding access to primary health care services (Bolitho & Huntington, 2006; Clendon & White, 1999; Higgs, Bayne & Murphy, 2001; Neufeld et al., 2002; Waibel, 2001).

***“You can’t say my kid’s going to be sick on Tuesday”*: Limitations of services**

Transportation for those living in this community is an issue even though the town is not large. The community in the study has the highest number of households without a car in the district (Statistics NZ, 2006). There are limited public transport services in the town. The relationship between the safety and transportation subsystem and the health and social subsystem in the „community as partner" model (Anderson, 2008) is reflected in the following comments. It would appear that some services appear to be less accessible as a result of lack of transport as described by one Pacific participant, “I think for some it [distance] is [a barrier] „cause its quite a long way up there [marae clinic]. This is more central [Pacific Community Clinic]" (Pac/5). Not having a landline was also raised as a possible barrier to accessing services, “Transport"s a barrier, phone access is a barrier for some of my friends" (M/16). Service provision closer to where children live and go to school in the community needs further consideration.

The timing and flexibility of services limits access to primary health care providers for some children of working parents and caregivers (MoH, 2007a). Having to miss work to attend appointments for their children and the subsequent loss of wages has been identified in the literature as a major barrier (Higgs, Bayne & Murphy, 2001; Dubay & Howell, 2006). Greater flexibility of service hours was perceived by Māori and Pacific focus group participants to be necessary, “...there always has to be flexibility especially with working families" (M/32). Other than the hospital, providers in the community set their hours of operation generally on an 8am–5pm working day. Some Māori and Pacific parents are unable to access their primary health care provider during those hours.

Yes it [the Pacific clinic] is [accessible] but you have to consider the working parents who cannot get their child here after hours. ... some parents work and can't get here on time and it"s closed before they finish work. (Pac/2)

The clinic is open for a limited period of time (12noon–4pm on a Tuesday) which is not necessarily conducive with hours of work for some parents and caregivers. This has been identified as an issue particularly for Pacific families, in other parts of New Zealand (MoH, 2007c). If parents and caregivers have inflexible working hours then it may limit their ability to work around the limitations of formal services ultimately preventing access for their children to needed services (Neufeld et al., 2002). Identifying that parents and caregivers are unable to afford to take a day off to care for their sick child and/or take them to the doctor has a direct correlation with the timing of services, as there is limited access in the town to primary health care services after normal working hours. As one Pacific participant summed it up, children get sick all the time, not just around the time that a limited service is being provided,

Your child may not get sick that day or be fine the next day or unwell the previous day, you cannot, you just can't see in the future and say my kid's going to be sick on Tuesday. It doesn't happen like that. (P/17)

One Pakeha participant who worked as a caregiver at a local day care explained that children are attending day care when they are sick due to the fact that their parents are unable to afford to take a day off work, "...the thing is what I notice at work is they [children] come to day care [sick] „cause the parents can't afford to have a day off" (P/29). The flow on effect of losing some wages may be significant for the family but the likelihood of the child's condition worsening and then needing greater intervention is also possible. One Pakeha participant indicated that it would depend on the time of day as to who they would access for services,

Depends on what time it is... you know it's coming to five or six o'clock and you know there's heaps of people waiting at the doctors, you're not going to get seen, you're just gonna go to the hospital. (P/9)

Being aware of the fact that there may still be „heaps" of people waiting to be seen in the general practice setting meant this parent would take their child directly to the hospital. Parents may make a conscious decision to bypass the GP and go directly to the hospital, not an unlikely decision if children are quite unwell, however, the time of day appears to be a significant consideration in taking that particular action. If difficulty is encountered in accessing primary health care, especially after hours, then parents are more likely to present to an ED (Cooper, Simpson & Hansen, 2003; Grant et al., 2001).

Participants from all three focus groups agreed that there was a need to raise awareness of children's health issues in order to enhance parenting skills. This would enable parents and caregivers to identify earlier when they needed to intervene themselves, or seek assistance from health providers for advice and treatment for their children. Participants wanted to see more promotion occurring, "I'd like to see more awareness stuff going on" (P/17), "get that message across" (M/34), and "this is what needs to be communicated out there" (Pac/14/15).

One Pacific participant perceived that the Pacific Health Worker was doing their best to promote the service provided at the local Pacific Community Clinic, "[She has] made them aware that these health services are here. [Named Pacific Health Worker] has really done her job to get that information out. She's done her part to try and help everyone here" (Pac/6).

Generally the Māori participants felt that Māori should know what services are provided by Māori providers, but thought that some people were unaware because of inappropriate promotion. Participants described their thoughts on how the services are promoted, "it's not presented in the right format" (M/32), "[it is] how they deliver that message" (M/33) and "Māori people should be aware of the Māori health providers but where the system's broken down is, it's not promoted the right way" (M/8). These comments made by Māori participants indicate that Māori providers may need to consider how they promote their services.

In this section the current limitations that exist in ensuring children are receiving health care have been discussed. Transportation, flexibility and timing of services, location of services close to where children live, and the promotion of services have been highlighted. Greater flexibility of primary health care services may assist in ensuring that children receive more timely access to health services.

"We're wondering if the school can have a nurse?": Future services

Earlier in the chapter participants commented on the fact that health providers needed to connect more with them and the community. In order to achieve this it would be necessary for providers to work alongside the community. The theory underpinning this research, „community as partner" (Anderson, 2008), means that health and social system providers must work with communities when planning, developing and implementing services. One participant described what they thought should happen,

It's not about the community going to the social provider. It should be the other way around. But that's the way it is. It should be the other way around, the social service going to the people, that's the core. (M/34)

This suggests that there is a one way relationship currently occurring between services and their patients/clients. It may not be always achievable for providers to go to the people, however, a more flexible approach to the delivery of services may be required.

Participants identified what they believed to be gaps in service delivery for their children. Pacific participants had earlier indicated their connection with the Pacific Health Worker and how important that role is for their people. It was felt by Pacific participants that the person in this role was crucial for ensuring that locals knew what was available for their children. In discussing who parents and caregivers would access if they needed advice regarding their child, comments included, "[Named person] always comes to us" (Pac/5), "She would refer to [named person][if child is sick]" (Pac/5), "[Named person], she really knows" (Pac/6). Trust in the Pacific Health Worker is implicit in these comments from participants. Pacific participants had previously presented evidence that the role was assisting their people to gain an awareness of services for children, informing them of what is available in a culturally appropriate way, for example developing and delivering flyers in the languages of those who reside in the community. It was felt, however, that more support was needed.

We probably need more [named person] (Pacific Health Worker) around because she's only one person and one person can't be relied on to do everything. (Pac/22)

More Pacific Health Workers out there for the sake of our kids, you know to let everyone know that this place is here for that very reason and in order to expand it. (Pac/22)

As explained earlier the times the Pacific clinic is currently provided are very limited, and access is difficult for working parents and caregivers. Pacific participants imply that increasing the Pacific Health Worker resource may ensure that more people could be informed of the clinic's service and the service could be expanded. As one participant explained, "I'd like to see this place open more regularly on a health service basis for everyone in the community around here" (Pac/17). When questioned who should provide an expanded service one participant responded with, "the same health system but a few more days through the winter." (Pac/19)

The issue of communication has been discussed in chapter four, however, Pacific participants would like to see this addressed for their community. As expressed by one participant, “It would be nice to have somebody on board that can speak different languages” (Pac/22).

School based services

Comments were made by one Māori participant that the local school needed more resources in order to raise awareness of children’s health and that health providers should have more of a presence in the school. The impression was given that more could be done to promote children’s health through the school environment.

...there’s not enough when it comes to the health provider generally inside the schools, there’s not enough emphasis or targeting of ethnicity of children. You know different groups have different health issues and yeah that’s not strong enough and there’s not enough resources that go into the schools. (M/30)

The perception was that there is a lack of promotion in schools, not enough is done to meet the needs of different groups through targeting, and there is a need for more health provision in the school. These thoughts were supported by one of the Pakeha participants, specifically in relation to health promotion.

I think the school also has a responsibility to raise awareness like we do the healthy eating here. „Cause the schools can’t do everything, it’s the community, the whole system has a part to play and as parents, it’s our responsibility to make sure the school is doing stuff as well and has it in their policies and is implementing it. So if we all play our part it works. (P/23)

This participant raises an important point that it is not just the school’s responsibility, but the whole community to raise awareness about children’s health.

Whilst Pacific participants were very supportive of their clinic they, along with participants from the Māori and Pakeha groups, felt services could be expanded in the school environment, “Based around [named] community, what I would really like to see is a registered nurse to stay on board for all these children that go there [school] and are ill” (Pac/1). This was supported by another participant, “We’re wondering if [named school] can have one [nurse] so you know a child can go to them if something is wrong without the parents’ consent” (Pac/1).

Currently the local school has a visiting Public Health Nurse who has limited availability. The school environment was perceived to be „safe“ for children to be seen by health practitioners, as described by one participant.

It's a safe place for her to be, and she doesn't have to go anywhere, and it's in the school grounds and she doesn't have to go anywhere different where she doesn't know anybody. „Cause that's half the problem and if you go and take her somewhere else she probably won't talk. (P/34)

The parent implies that the child may not feel comfortable being seen in another environment. Being comfortable is connected with trusting the health provider. Providing services close to where people live, work and play is identified in the Child Health Strategy (MoH, 1998) and is a concept basic to the provision of primary health care (Hutchinson, Anderson & Gottschalk, 2008). Another participant felt that a school based service would be another way that children could be cared for, „Like [named school] could have their own nurse there just to do some tests for the kids.... then their child will get help there being at school and it would be really great“ (Pac/15).

Māori participants felt that the Māori providers should be more available through the school and if they were to have more of a presence then it could assist the providers to connect more with Māori parents and caregivers and the wider community.

If you had a health nurse like the school does and one that was Māori and it's unfortunate most Māori will still identify with other Māori, that's just the way it is, and if the school provided a Māori health provider here by default, you'd all get a better reception from the Māori parents and children. (M/28)

„By Māori for Māori“ services was raised by this participant, stating that this philosophy is a way forward for health service delivery to children as many Māori parents and caregivers and their children identify more with their own people.

In this theme some of the limitations of service delivery and the flow on effect in terms of why parents and caregivers do not always respond appropriately to the needs of their children have been explored with participants. The ideal of providing services closer to where children live and go to school has been raised along with the need for health providers to increase flexibility of service hours to accommodate the working hours of parents and caregivers. Working parents and caregivers have limited ability to get time off work to care for their children when they are sick or take them to a health practitioner.

Conclusion

The influence of ongoing relationships between children and their families/whānau, and preferred primary health care providers was a predominant theme arising from the discussions about access to health care services for children. In the first part of this chapter data has been presented that demonstrates how the relationships health providers and practitioners develop with their communities and clients influences whether children receive the health care they require. Other influences on access are the knowledge of practitioners, the power of attitude and parental and caregiver understanding of the need for health care.

Knowing who the provider is, connecting with them, and developing a relationship with them over time (continuity of care), makes a difference whether parents and caregivers access a service. Having confidence in the provider's ability was also considered important. Trust in a provider was highlighted within and across all focus groups, as well as consistency of provider. Knowledge of a family's history contributed to the strength of the relationship between the primary health care provider and parents and caregivers and children. There is evidence of a connection between trust in a provider/practitioner and whether their advice is sought by parents and caregivers when assistance regarding children's health care is needed.

Accessing a provider is problematic if little is known about who and what the service provides, or if a practitioner is new to the community. The strength of the relationship established over time with a primary health care provider may mean the difference between children receiving services in a timely way and whether children are appropriately treated. The participants that knew their provider well trusted their ability to care for their children. The negative attitudes that exist on the part of some health providers and the concept of whakamā for Māori can affect whether children are seen in a timely fashion. Both are barriers in their own right to children receiving appropriate health care. Lack of awareness, difficulty in understanding English, the need for more promotion of services along with understanding the value of children's health care are also highlighted as contributing to children's needs not being appropriately met. Limitations to current services have been identified and opportunities to improve access for children in the community have been discussed by participants. This discussion will be expanded in the following chapter.

The data presented in the last two chapters contributes towards answering the research question in terms of whether children receive health care in an appropriate and timely

fashion. The implications of continuity of care and children's needs being paramount in the provision and receipt of children's health care will be discussed further in the following chapter.

Chapter 6 - Improving children's access to health care

Introduction

The aim of this research was to explore with parents and caregivers what health services they perceived would best address the health care needs of their children and how those services should be delivered. In discussing the findings it is important to note that the benefits of health services occur only if they are delivered appropriately. Equal access does not necessarily equate to equal outcomes. The mere presence of, and access to, health services does not mean a change in outcomes for people, therefore careful consideration needs to be given to the appropriate delivery of services in the context of the population being served and their environment (Goddard & Smith, 2001; Paterson & Judge, 2002; Starfield, 2007). Participants in this study have described what they believe to be some of the gaps in service delivery, and the barriers and difficulties facing parents and caregivers regarding their children's access to health care. Broadly speaking the discussion has captured the positive aspects of relationships between the community and health providers including trust in preferred primary health care providers, the role of the Pacific Health Worker, and the Pacific Community Clinic service. The less positive aspects have included a lack of knowledge of some services, communication issues for some Pacific people, the promotion of Māori provider services, the cost of general practice services for children six years and older and after hours care, and a limited awareness and understanding of children's health issues coupled with, at times, an inadequate response by parents and caregivers.

Four important factors relevant to improving the chances of access to health care for socially disadvantaged children will be discussed in this chapter. Firstly, the findings from this study suggest that it is important to provide continuity of primary health care for children. The parents and caregivers in the study identified that having a trusting relationship with, and feeling connected to a primary health care provider is important when it comes to accessing health care services for their children. Secondly, acknowledging and supporting parents and caregivers in relation to promoting children's health and closing some of the knowledge and life skill gaps for Māori, Pacific and other low income families is crucial. The difficulty in balancing the basics of life, giving priority to one child as opposed to the whole family, knowing about services that are available and a lack of general knowledge of children's health issues were all identified by study participants. Thirdly, with the support of the community and parents and caregivers, the provision of services requires review in order to minimise barriers to access for children most in need of health care. Finally, the profile of children's health needs to be raised

across the community, particularly in relation to the importance of keeping our children healthy, therefore reducing the impact and burden of disease in adulthood. It is acknowledged that this is not the mandate of health services alone, but health providers play a significant role in advocating for optimal child health and reducing disparities. The relationships between each of the subsystems within the “community as partner” conceptual model, “physical environment, education, safety and transportation, politics and government, health and social services, communication, economics and recreation” (Anderson, 2008, p.208) emerged throughout the findings, variously contributing to the issues faced by parents and caregivers in providing health care for their children. This chapter concludes with a discussion of the limitations of the study and implications for future research.

Within a healthcare system inevitably challenged by adult health needs, particularly in the context of an ageing population, specific and conscious attention has to be given to ensuring that the very different health needs and requirements of children are appropriately prioritised and addressed. The principles of the Child Health Strategy (MoH, 1998) (Appendix 7) describe what needs to be in place for every child in New Zealand and underpin the discussion in this chapter. Children and families/whānau need effective, available and acceptable health care (Ministry of Health, 2002a). Enabling timely and appropriate access is particularly important for the children of populations that face barriers to care due to low income, cultural barriers, lack of adequate transportation, lack of education, or other factors.

Overall the parents and caregivers in this study believed that the influence of socioeconomic determinants of health, along with the structure and systems and cultural appropriateness of health services, did at times prevent parents and caregivers from accessing health services for their children. The findings from the study are consistent with the literature (Hall & Elliman, 2003; Starfield, 2007), suggesting that enhancement of primary health care services delivered to the community could contribute to a reduction in the barriers that parents and caregivers face in meeting their children’s health care needs. Participants who had positive relationships with their primary health care provider indicated that this influenced whether their children received care when required.

Continuity of care

It is important to understand parent and caregiver perspectives on the relationship between their primary health care provider and their family/whānau as it assists in understanding the decisions parents make when deciding where and when to seek care

for their children (Brousseau et al., 2007). A significant finding from this study was the importance of participants knowing their provider and the feeling of being connected to them, having developed a relationship with them over time. It is not friendship they are seeking but a relationship nonetheless, which enables them to feel comfortable and trust the individual practitioner or team caring for their child. Some participants spoke of the positive relationships they had with their GP, how they trusted them and had confidence in their ability. Conversely participants also described relationships with practitioners which were less than desirable. If a practitioner's attitude was off hand with parents and caregivers or they were disinterested in the child then participants were reluctant to see that practitioner again.

The length of time participants knew their GP appeared to contribute to their trust in the practitioner. In a study undertaken by Mansour, Lanphear and De Witt (2000), parents and caregivers believed their children received quality care partially as a result of their trust in their provider. It takes time to establish an empathic trusting relationship and most adults, let alone children, are reluctant to disclose their problems and concerns to a stranger (Hall, 2003). Time has been identified as a necessary factor in achieving interpersonal continuity of care (Reid, Haggerty & McKendry, 2002). Most patients want a health care provider that knows them but it may take several interactions to get to know the provider and to build trust (Kearley, Freeman & Heath, 2001; Schers et al., 2002). Patients prefer their personal doctor as they consider that person has the best medical, personal and family knowledge of them (Schers et al., 2002).

Continuity of care in the context of this research related to both interpersonal and informational continuity (Appendix 2). The views expressed by the focus group participants support other research findings on the importance of both interpersonal and informational continuity, as it relates to relationships with primary health care providers (Haggerty et al., 2003; Kearley, Freeman & Heath, 2001; Reid, Haggerty & McKendry, 2002; Schers, 2003). The concepts of interpersonal and informational continuity were considered to be important aspects of why parents and caregivers preferred to see some practitioners. In some cases, however, the positive effects of having a trusted relationship with a GP were mediated by issues such as affordability, as ED, the Pacific Community Clinic and the marae clinic were identified as places to go when participants could not afford to see their preferred GP.

There are times when interpersonal continuity is unnecessary, for example when a repeat prescription is required (Guthrie & Wyke, 2000). There will be occasions when

some patients may prefer to see another GP or nurse in order to better meet their needs at the time (Minister of Health, 2001). It is noted in this study and supported by the literature (Brampton, 2000), however, that when a practitioner is unfamiliar with a patients' history and their treatment, lack of continuity can lead to inefficiency and ineffectiveness, for example more than one visit may be required. Interpersonal continuity is a challenge for today's health care services as practitioners are working more in teams and there has been a decline in after hours primary health care services. Informational continuity appears to be more achievable, although patient management systems are rarely integrated between providers. Continuity of information is seen by practitioners as a priority and District Health Boards in New Zealand are endeavouring to achieve it. General practices tend to have better information systems, however, the current interface between primary and secondary/tertiary services is considered far from optimal.

Reviewing the systems that encourage families to establish an ongoing relationship with a primary health care provider may improve children's access to care (Rosenbach, Irvin & Coulam, 1999). Mechanisms whereby parents and children can establish and maintain existing relationships with providers need to be created and fostered. The „medical home“ concept (American Academy of Pediatrics, 2004) for children is not well known in New Zealand but if adopted could assist in ensuring children receive more “accessible, continuous, comprehensive, family centered, coordinated, compassionate and culturally effective care” (p.1543). The model introduces the concept of longitudinal continuity of care whereby care occurs in an accessible and familiar environment from an organised team of providers. The team assumes responsibility for coordinating the quality of care, including preventive services (Saultz, 2003) (Appendix 2).

Adopting the medical home model could assist in ensuring improved continuity of care for those children who are least likely to receive it. The model was found by Farmer et al. (2005) to be beneficial for rural American children with special health care needs. Under this model children would have one plan of care, overseen by a team of practitioners. As the majority of care people receive over a period of time is delivered in the primary health care setting, it is appropriate in New Zealand that a primary health care team provides the overall coordination of care for children. General practice will be the most likely base of the primary health care team for the majority of children, but in order for this to be effective further consideration needs to be given to how general practice teams would work more in an outreach capacity, delivering services underpinned by the principles of the Child Health Strategy to Māori, Pacific and other low

income communities as close to home as possible, in the most culturally acceptable manner and in order to achieve equity (MoH, 1998).

At times participants felt that their trusted GP was hard to access as they were unable to get an appointment to see them when parents and caregivers felt it was needed. Structural influences such as inaccessibility could be addressed through a team approach to the provision of care, increasing the mobility of some services and providers and changes to scheduling in general practice. Given the challenge as mentioned earlier with achieving interpersonal continuity with one provider in today's context a more focused team approach to the delivery of child health care is worthy of consideration (Minister of Health, 2001) and would provide longitudinal continuity of care (Appendix 2). Child health teams (as a subset of the aforementioned primary health care team) could be comprised of a GP, registered nurse, community health worker and receptionist based in the general practice setting. Another alternative could be an outreach child health team consisting of a registered nurse(s), school social worker, and community health worker with links back to the GP. Other practitioners, for example Asthma Nurse Specialist, Community Paediatrician and Dietitian, could be visiting team members. A child health team could become the trusted provider of services in the future, ensuring that children receive continuity of care. The team could be overseen by general practice, but in keeping with the Child Health Strategy (MoH, 1998) and the provision of services as close to home as possible, be located closer to the community, for example, at the local school, the Pacific Community Centre or co-located with a Māori provider.

Access to services

Participants in this study accessed a variety of primary health care providers. All accessed general practice services, this being the preferred choice of primary health care provider for Pakeha participants. For many Pacific participants the Pacific Community Clinic was a preferred option due to its location close to home and lack of fees. Participants in all groups sought assistance from the ED at the hospital, however, it was accessed more by Māori and Pacific participants as it was an accepted choice of provider for them and is free.

The issue of equity of access to care still exists for the community in this study, therefore further consideration regarding the distribution of resources in relation to need is required. The barriers to access of services highlighted in this study: cost, transportation, cultural issues, attitudes of practitioners, availability of providers and competition of children's illnesses with other basic life needs are similar to those found in the literature (Ames,

2007; Chung & Schuster, 2004; Mansour, Lanphear & DeWitt, 2000; MoH, 1998; Spenceley, 2005). Delays in seeking access to health services may be minimised if access is not impeded by cost and other non-financial barriers (Hall & Elliman, 2003; Higgs, Bain & Murphy, 2001). Delay in getting children seen by a primary health care provider may result in children ending up at the GP or hospital far sicker than if they had been seen sooner.

Results from the 2006/07 New Zealand Health Survey (MoH, 2008b) show that access to primary health care for children is very high, however, Māori children are more than twice as likely not to access a GP because of cost than any other ethnic group. The data in this research supports the survey results in relation to cost for Māori when accessing a GP, but also found that cost was a barrier to access for Pacific children. Many of the participants in this study identified the co-payments expected by general practice for children six years and older, as a significant barrier to access. The cost of after hours services was also identified as an issue with the majority of participants stating they would access the ED as it was free and a well known service in the community. Reviewing after hours primary health care service availability would be beneficial as it may improve access for children. Requiring visits outside normal hours and getting appointments soon enough or at suitable times were other reasons reported by parents and caregivers in the New Zealand Health Survey (MoH, 2008b) for not accessing a GP. These results are corroborated by the findings in this study.

Findings from a cross national study sponsored by the Commonwealth Fund in 1998 on health care access, identified that where universal coverage occurred and no payment was required, such as in the United Kingdom (UK), this facilitated access to health providers, and access reflected need more than the ability to pay (Shoen et al., 2000). New Zealand was included in this study and due to high patient user fees at the time was one of the countries where the greatest inequalities in access to primary health care occurred. Further results from the Commonwealth Fund study show that where there was universal coverage little difference was reported in access to, or quality of, health care between income groups in the UK (Shoen et al., 2000).

Universal coverage does not exist in New Zealand but the Primary Health Care Strategy (Minister of Health, 2001) has facilitated an increase in access to primary health care services with the introduction of measures such as reduced patient user payments (Dowell & Turner, 2007). Enrolment percentages in Primary Health Organisations indicate that significant numbers of Māori and Pacific are enrolled in general practice

(MoH, 2007c). This does not necessarily mean that inequalities have been reduced, as there are still disparities in access to primary health care for children (NZ Child and Youth Epidemiology Service, 2007). Fee reductions have reduced some of the barriers to access, however, as evidenced from this study, general practice co-payments and associated costs of medication, continue to be a barrier for attendance at general practice. Universal access may not be possible in New Zealand so better targeting may improve access for children over the age of six years for those who cannot afford to pay. As it is now, low income groups do have better access to primary health care but so do higher income groups (Barnett, Coyle & Kearns, 2000).

Cost is only one variable affecting the appropriate access and use of health care services for children. There are other non-financial barriers to service access and utilisation including cultural, social, and behavioural considerations for ethnic groups, health system variables such as geographic distribution, availability of provider and lack of transport, as well as issues such as parents having time off work to look after their children. These have been identified in this research and illustrate the interdependence between all the subsystems in the „community as partner“ conceptual model (Anderson, 2008). Further consideration of the variables across all of the subsystems is required and involves agencies other than health services, but in the short term health providers need to consider cultural barriers, geographic distribution (Rosenbach, Irvin & Coulam, 1999), availability and flexibility of services and raise awareness of services in order to improve access for children.

Hospital based services (ED) continue to play a major role in providing a service for children, which is entirely appropriate for an acute event. However, as indicated by participants in this study there are some parents and caregivers who use the service for their children's primary health care needs. This reflected the overall availability of primary health care providers, the cost associated with visits to the GP for children six years and older and after hours service cost and availability. Equally this finding could be associated with the perceived capability of primary health care providers as implied by some participants in the study, and identified in other studies that EDs have the resources to care more appropriately for their children than primary health care providers (Brousseau et al., 2007; Mansour, Lanphear & DeWitt, 2000; Waibel, 2001). The proportion of children using ED in the district where this research was undertaken is higher than the New Zealand average (MoH, 2008b), and the numbers of Māori and Pacific children compared to all other children presenting at ED is higher (MoH, 2008a). The highest number of children presenting from the district come, not

unexpectedly as it is the community with highest deprivation, from the community in this study (MoH, 2008a). The literature suggests that socioeconomic status is one reason for the use of EDs (MoH, 2006; Starfield, 1998; Waibel, 2001).

Perhaps it should be accepted that people who are struggling financially will use ED on occasion as a primary health care provider. With that in mind consideration could be given to providing an ongoing „first point of contact“ service at the ED for children with non-urgent needs from Māori, Pacific and other low income families. Co-location of primary health care services/accident and medical centres with ED occurs in other parts of New Zealand, for example, Wanganui. Co-location may also alleviate some of the after hours issues identified in the study. Another option is the possibility of introducing a children’s triage nurse either based in ED or general practice, who, working along side a community health worker, could assess children’s needs and determine who is the most appropriate health practitioner to see them. This role could enhance the current Health Line service and could be a virtual role or work in an outreach capacity.

Greater use of community health worker roles needs consideration by the local District Health Board and the Primary Health Organisation. The role of a paraprofessional, such as the Pacific Health Worker, was identified by Pacific participants as being pivotal to the services provided in the community. The person in the role was visible, active, one of their own, and trusted by them, all attributes that have been identified in the literature as necessary for such a role (Barnes-Boyd, Fordham & Nacion, 2001; Olds et al., 2002). Pacific participants felt that the community needed more community health workers. These roles can be the boundary spanners between communities and health practitioners as their knowledge of communities is usually broad and they understand the specific sociocultural factors that need consideration in the delivery of health services. They are valuable members of primary health care teams and can assist in ensuring that services provided are culturally safe and acceptable (MoH, 1998).

Community health worker roles could form part of a school based child health team, working between the school, children and their families/whānau. Given the demographics of the population a Māori Health Worker and a Pacific Health Worker could work alongside a registered nurse in the school based team. These workers, with the appropriate preparation and support from health practitioners are able to educate parents and caregivers, families/whānau about services available and how to access them. They can provide advice on child health issues and on occasion, transport a parent and child to a clinic/surgery appointment. Community health workers, as mentioned earlier, could

also be a part of a child health team based out of the Primary Health Organisation, general practice or a Māori Health provider.

Location of services

There are a number of primary health care services which currently contribute to reducing access barriers for Māori, Pacific and other disadvantaged groups by providing services close to home, such as Plunket nursing, Public Health Nursing services, the Pacific Community Clinic service and Māori provider services. No general practice service is available in the community except for one hour a week at the Pacific Community Clinic. The findings in this study indicate that the current availability and distribution of services does not always meet the needs of children and their families. Participants identified the Pacific Community Clinic as an appropriate location for services but felt that services provided there are not offered often enough and do not meet the needs of working parents. Mobile, outreach services have been identified by other Pacific communities as assisting in keeping them healthy (MoH, 2007c). Consideration needs to be given to an increase in the hours and flexibility of the service provided at the Pacific Community Centre.

Māori and Pakeha participants felt that there needed to be more health resources available in the local school. All participants believed that the school was an appropriate place to provide services as it was a place where their children felt safe. Some openly stated that they wanted to have their „own“ nurse based at the school. In the context of these responses and given that the school has a decile ranking of two, the suggestion of having a nurse delivering a comprehensive school based service to the community is worth exploring. One Māori participant felt that the nurse should be Māori, in keeping with the „by Māori for Māori“ concept. The Child Health Strategy (MoH, 1998) recommended that partnerships between „by Māori for Māori“ providers and mainstream providers would achieve the best possible outcomes for tamariki. Whilst it would be appropriate to have a Māori nurse it may not be achievable, therefore in order to ensure acceptability of non-Māori nurses, the nurse could work as a child health team member (aforementioned) working closely with the Pacific and Māori community through Pacific and Māori health workers. It is important that the team is trained and experienced in child health, has good support from GPs and paediatricians and is culturally competent, the latter being essential for the provision of a culturally safe service. A child health Nurse Practitioner role, supported by Pacific and Māori Health Workers and the school’s social worker, may be one way to meet the needs of children. It was identified in a feasibility study undertaken by Clendon and White (2001) that it was appropriate to establish a

Nurse Practitioner led primary health service in a primary school environment. School based health services are an efficient and effective way of providing health promotion and education to children. The service can also be a point of entry into the health care system. It would be important for the community to be involved in deciding the composition of any team.

Raising awareness

The parents and caregivers in this study highlighted the variability in community awareness of how health providers can assist in meeting the needs of children. If children are to receive adequate healthcare their parents and caregivers need to understand the importance of preventative care, be able to recognise the signs and symptoms of conditions requiring intervention and know where in the community to take their child (Ames, 2007; Rosenbach et al., 1999; Waibel, 2001). Parents and caregivers in this study found out about services predominantly through word of mouth, or through the Pacific Health Worker for the Pacific population. These methods are useful in the dissemination of knowledge about services, but the study found that some participants were still unaware of all the services available. Therefore a more concentrated interagency approach is required by health providers to ensure the community knows what each service provides and how to access them. The Child Health Strategy (MoH, 1998) clearly states that services should work together and with other sectors to benefit children. The Māori Health team, Pacific Community group and parents and caregivers can advise on the best approach to achieve this. Participants in the study suggested that using community functions and celebrations, for example, „Matariki”⁹, Waitangi Day¹⁰ celebrations, the local balloon festival, and the school gala, as ideal opportunities to market services and raise awareness of children’s health amongst community members. Creating an opportunity for the community to participate in an interactive activity was another example suggested by Māori participants, for example, holding a friendly rugby game and barbeque at the local park, and in doing so inform the community of the health and social services that are available.

For Māori especially, portraying services in a particular manner may also affect access to health care for children. Notwithstanding the aforementioned suggestions the importance of how services are promoted and who promotes them was raised by participants. It appears from some comments made by the Māori participants that they would like to see

⁹ The Seven Sisters (stars). First appearance before sunrise of Matariki in the north eastern sky indicates the beginning of the Māori New Year – about the middle of June

¹⁰ New Zealand Day, celebrating the signing of the Treaty of Waitangi between the Māori tribes of New Zealand and Pakeha (European) New Zealanders

the Māori providers make more of an effort to connect with them and the community. Increased targeting by Māori providers of those who need assistance could strengthen some of the relationships Māori providers have with this community. Improving connections with this community may strengthen relationships and assist people to trust the providers and more appropriately access services for their children. Providers need to consider how their services are marketed and work with the community to describe what services they provide and, more importantly, who they are there for. This communication needs to be carried out in a culturally effective way. Community health worker roles, as shown in this study with the Pacific Health Worker role, in conjunction with the community function approach suggested above, have a significant role to play in raising awareness and informing their communities.

Cultural considerations

Complex social factors associated with ethnicity and language may compromise access to primary health care services (Chung & Schuster, 2004; Hall & Elliman, 2003; Minister of Health, 2001). An understanding of the cultural differences in beliefs and practices in the care of children is important for the successful delivery of health messages and services to diverse populations (Abel et al., 2001) and assists in the provision of culturally competent care. He Korowai Oranga (Māori Health Strategy), (MoH, 2002a) states that in order to be effective, services provided to Māori need to be coordinated around the needs and realities of whānau and incorporate Māori cultural values, beliefs and practices. Services that are culturally safe and acceptable are necessary for every child in New Zealand to achieve optimal health (MoH, 1998). In 2007 the Well Child/Tamariki Ora Framework review (MoH, 2007a) identified that there is still room for improvement in the way health services are delivered to tamariki Māori and their whānau. In keeping with that review the findings from this study also indicate that the delivery of services to Māori children could be improved upon, largely through a refocusing of current service provision. As suggested by participants this could include using the local school as a base for both nursing and community health worker services and Māori health providers.

Pacific participants in the study believed that for some of the Pacific community a limited understanding of English language may contribute to a lack of awareness of services and understanding of health information. It was highlighted that not all community members could read. The issue of understanding written communication raises questions about parents' and caregivers' ability to assist their children when required. A lack of ability to comprehend the information and instructions from practitioners may

mean that parents and caregivers may delay seeking treatment until the child's health condition becomes serious or a crisis occurs (Ames, 2007; Weller, Minkovitz & Anderson, 2003).

Providing health information in an understandable form may assist parents and caregivers to recognise and intervene when they need to for their children, and appropriately care for their illnesses (Fitch et al., 1998; Minister of Health, 2001). The Pacific Health Worker distributed information regarding the local Pacific clinic in Pacific Island languages, but this information did not include the availability of other services and the findings suggest there is the need to ensure better understanding amongst Pacific parents and caregivers of all child health services. The Pacific Health Worker's role in raising awareness was recognised by Pacific participants as important, indicating cultural acceptability for the role and the individual by the Pacific community (Olds et al., 2002). The hours of the Pacific Health Worker are limited, therefore greater use of this role should be considered to enable time to work with community members regarding all services that are available, and also to assist health practitioners to deliver messages to those who have limited English or who cannot read. The issues raised in regards to language provide a good example of the relationship between the communication and health and social subsystems within the „community as partner“ model (Anderson, 2008) and the role of the Pacific Health Worker in disseminating information to her community.

In this study participants discussed how some providers' attitudes created a further barrier to accessing health care for their children. The literature has highlighted that previous negative experiences with health practitioners may engender feelings of hostility, mistrust, embarrassment and shame in parents and caregivers (Morgan et al., 2002; Sanghera, as cited in Spenceley 2005; Schilder et al., 2001). The attitudes of practitioners, as participants reported in this study, can have a profound effect on whether parents from lower socioeconomic and minority backgrounds feel comfortable seeing someone with whom they and their child have not yet established a relationship. This finding is supported by other studies (Cram, Smith & Johnstone, 2003; Grant et al., 2001; Mansour, Lanphear & DeWitt, 2000), and may result, as suggested by Brousseau et al. (2007), in parents and caregivers choosing to take their children to be seen by an unknown practitioner at an ED rather than a primary health care provider. All providers need to be culturally competent in order to relate to their patients in the most appropriate way and for children and their parents and caregivers to feel culturally safe (MoH, 1998). Continuity of care may assist in achieving cultural safety and acceptability for children

and their parents and caregivers as the practitioner or team that cares for them knows the patient and their family/whānau.

The findings from this study support the literature regarding the many barriers that prevent parents and caregivers accessing health care for children. Exploring other methods for the dissemination of information regarding services is necessary. The provision of information in other languages to the community may assist in raising awareness of services as well as enabling parents and caregivers to better understand the signs and symptoms of illnesses so they can appropriately care for their children's health needs.

Limitations

Three main limitations should be noted when considering the results from this study. Firstly the nature and size of this qualitative exploratory study means that the results can not be generalised to other communities. As participation in the study was voluntary and involved mixed purposeful sampling the participants may not be considered to be representative of the population within the community. Secondly it is important to recognise the researcher's standpoint which could influence the interpretation of the findings. Whilst attending to issues of validity in the study, the researcher's own child health nursing experience, current position, ethnic and socioeconomic perspective could influence interpretation of the data. Thirdly the study was limited to the participants' view of their experiences with no participation from health professionals who deliver services to the community and may have different views of the issues facing the community.

These three factors have been taken into consideration when analysing and interpreting the data. The consistency of responses from participants suggests that their issues and experiences were not isolated but were a true representation of their views at the time. Similarly the information obtained from participants was consistent with the issues identified in the literature. The processes used in this study give a reasonable assurance that results may be reproducible and credible.

Implications for future research

The findings from this study suggest several areas for future research. The study has provided the opportunity for participants to speak about their experiences, which were mainly consistent across all three focus groups. This consistency suggests that the participants' issues were not isolated and much of what was identified was consistent with the findings in other reported studies and the literature. Ascertaining the views of

those who deliver services to the community would offer a different perspective of how health services could better meet the needs of children. Further exploration of the issues faced by Māori and Pacific populations in meeting their children's needs would enhance understanding of the impact of those issues on children's health. This would contribute to any development of primary health care services for these populations. A feasibility study involving the use of a child health team, including a Nurse Practitioner role, for this community would be beneficial considering the lack of GP services available to the community, and would inform the introduction or improvement of any services for low socioeconomic communities.

Conclusion

The data presented in this research suggests there is not enough investment in our children in terms of meeting their health care needs in a timely and appropriate manner. There is also variability in the application of the principles of the Child Health Strategy (MoH, 1998) in the approach to and delivery of child health services. There are a number of factors and influences which lead to these assumptions, including gaps in knowledge of child health problems, education of parents and caregivers about the health services available, lack of promotion of services available, practitioner attitudes and cultural competence and environmental factors such as cost, proximity of services and transportation. Initially the researcher envisaged exploring the „health and social services“ subsystem in the „community as partner“ conceptual model (Anderson, 2008) but all the factors highlighted in this study that influence children's access to health care illustrate the interdependence of all the subsystems and that no one subsystem can function in isolation to another.

It was the belief of the parents and caregivers in this study that continuity of care, having a trusting relationship with and feeling connected to a primary health care provider, is important when it comes to accessing and utilising health care services for their children. The barriers that exist for Māori, Pacific and Pakeha low income families have been described by participants as contributing to why some parents and caregivers do not always treat their children's needs as paramount. Coupled with perceived gaps in service delivery these factors affect whether or not the community's children are receiving the health care they need.

In this chapter the barriers and influences identified by participants have been discussed in relation to how child health services could be built upon, adapted or changed to better

meet the health care needs of children in a low socioeconomic community with high numbers of Māori and Pacific residents.

Chapter 7 - Future gazing

Introduction

The aim of this study was to explore with parents and caregivers how health services could better address their children's health needs. The New Zealand literature indicates that there continues to be significant disparities in the health outcomes of children from Māori, Pacific and low income families/whānau. The issue is complex and the provision of health services alone will not solve the problem, but the way health services are provided does not necessarily meet the needs of communities either, often centring on the health service provider as opposed to the child and their family/whānau. The literature review supported the need for qualitative research that could provide some insight into why children from Māori, Pacific and other low income families/whānau do not always access health care in a timely and appropriate way. The research aims could not have been achieved through observation, or the analysis of documentation or communication (Bassett, 2004), therefore focus groups were chosen as the method of data collection.

The voices of parents and caregivers have been brought to the forefront through this study, giving them the opportunity to express their views, perceptions and experiences, mainly in relation to accessing health services for their children. They have expressed what they believe needs to change in their community in order to improve the chances of children accessing health care. Participants have identified some of the issues faced by them and their community in meeting the health care needs of their children. They have highlighted perceived gaps and suggested some possible solutions; solutions that are aligned with the economic and sociocultural context of their community. Strengthening relationships between health care providers and this community and involving parents and caregivers in the future design of health services will assist in ensuring children access those services when needed.

Overview

This qualitative study was undertaken in a community with high deprivation and a resident population comprising mainly of Māori and Pacific peoples. One of the basic concepts of primary health care is community participation (Hutchinson, Anderson & Gottschalk, 2008) which incorporates working with communities to identify, plan and implement services. A modified „community as partner“ model was the conceptual framework used to underpin this research. Using this framework enabled the researcher to connect with the community in relation to children's access to health care. The use of

homogeneous groups allowed the researcher to gain a better understanding of the issues, specifically those facing Māori and Pacific parents and caregivers. The willingness of participants to share their views and experiences was a humbling experience for the researcher. Notwithstanding the issues they identified, it was evident that the participants themselves did see the importance of treating children's needs as paramount. Therefore in order to understand what health providers need to do to improve child health outcomes, it was entirely appropriate to ask parents and caregivers as the seekers of health care for their children to provide their views.

The context surrounding the issues raised by participants in the study has been previously described, putting into perspective the enormity of the challenge required to address some of the issues facing the community and health providers. Participants want to see a change in some services, enhancement of others and introduction of new services in an attempt to improve access to health care for the children in their community. The discussion regarding change centred mostly on the local school and the Pacific Community Clinic, two environments that appear to engender trust in participants and their children. The recommendations made focus on improving equity of access for Māori, Pacific and other low income children. This does not mean that equity of outcomes will be achieved as that is an even bigger challenge, however, adopting the recommendations may contribute to the ultimate achievement of that goal.

In planning future services we need to look further than the child. The child must always be considered in the context of the family/whānau, therefore the views and experiences of parents and caregivers as well as parenting and societal influences need consideration when planning services. The basic philosophy is that services are built around the needs of the child, not of the health professionals who provide the care. In keeping with the principles of the Child Health Strategy care must be available as close to home as possible with emphasis placed on community based or outreach services wherever possible and appropriate, and that child health services should work together with each other and with other sectors to benefit children (MoH, 1998). As the „community as partner“ conceptual framework (Anderson, 2008) underpinned the research it is important that the development and implementation of any new or revised services must involve the community and its children.

The recommendations made are based on the discussions from the three focus groups. They are outlined in terms of refocusing and enhancing services currently provided, the introduction of new models, how to ensure that children are able to access health services when required and how to assist parents and caregivers make the decisions

they do regarding their children's health care needs. Given the current economic environment in New Zealand it is necessary to ensure future services will be both clinically and financially sustainable. Therefore the recommendations made as a result of the findings in this study will improve the availability of services to children without an extensive outlay of resources. Refocusing and enhancing current services will still achieve an improvement in outcomes for children. Further consultation with the community will be required in order to ensure the recommendations are appropriate.

Recommendations

Participants want to be connected to providers, especially GPs. They want interpersonal and informational continuity of care for their children, therefore consideration needs to be given to enabling this, either through current models of service delivery in general practice or by introducing other models, the latter being necessary given the difficulty in achieving continuity of care with practice and practitioner lifestyle constraints. It is not clear, however, what the current level of continuity is for the community's children.

1. In order to determine current levels of continuity in general practice the local DHB funds a Quality Improvement programme to evaluate continuity of care for children in one or two practices. This would include whether children are seen on the same day, are seen by the same GP, if not why not, whether they are seen by another team member and whether all appropriate information on the child is available.

The „medical home“ model has shown to be effective in the United States (Ames, 2007, Farmer et al., 2005) and is in use in one part of New Zealand (Tracey & Cooke, 2005). Given the New Zealand context and the involvement of a number of health practitioners in the care of children it is proposed that this concept be referred to as the „health home“ model.

2. Further research into the feasibility of adopting a „health home“ concept is required, in the context of a team based approach to continuity of care. It is recommended that initially this model be introduced for those children most in need of child health services. The model could be introduced in corporation with a school based service pilot or with the formation of a child health team originating from general practice.

It was found that participants were unaware of some services delivered to the community. At the same time Māori participants wanted to become more connected to the Māori Health providers. Discussions need to be held regarding the best way to

market services in order to ensure people feel safe accessing them and so people know who in the community the providers serve. A concentrated inter-agency approach to raising awareness is required.

3. All primary health care providers, in conjunction with key informants in the community, need to discuss the best way to market their services to ensure the community is aware of what is available to them.

Enhancement of services in the local school was suggested by parents and caregivers, with the impression given that the school was a safe environment for their children to access health providers. Given the cost of accessing general practice for children six years and older there is a need to consider other options for access for school aged children.

4. The local District Health Board undertake a feasibility study on the need for a primary and intermediate school based health service for this community in order to better meet the needs of school aged children. The possibility of piloting a service centred on a low decile primary and intermediate school could be explored with the New Zealand Ministry of Health.

The Pacific Community Clinic was seen as an appropriate location for the Pacific community to access primary health care, however, the frequency and hours of service were identified as being very limited. The availability of the GP was minimal so other solutions are needed.

5. Consider increasing the number of days the Pacific Community Clinic service is delivered, extending the hours outside of normal working hours to enable better access for working parents.
6. Utilise the role of the community PHO's Family Nurse Practitioner in the provision of services to this community. This would reduce and potentially eliminate the need to have a GP present.

After hours access to primary health care and the cost of that care was raised as an issue.

7. Refocus delivery of after hours primary health care at the local hospital ED. The cost of this service needs to be minimal.
8. Consider the introduction of a child health triage nursing role. The role could be virtual, supplementing the Health Line service or could work in an outreach capacity with a community health worker, assessing the need for children to be seen either by general practice or the emergency department after hours. This type of role could conceivably be introduced during normal working hours as well, based out of general practice.

In order to raise awareness of child health and services available and to ensure that services are more culturally acceptable there is the need to adopt a wider approach to care using the skills of paraprofessionals within a multidisciplinary team.

9. Review current service skill mix and consider further introduction of community health workers into teams, including the proposed school based health service. These roles can assist in raising awareness of child health issues and services in the community and ensuring cultural aspects of care are met when services are planned and delivered.

Consideration needs to be given to reducing the cost for children six years and over to see a GP and for medications, either through further fee reductions or by offering an increased number of free outreach services.

10. Eliminate co-payments and other forms of cost sharing for GP and pharmacy services for children from targeted populations.
11. Provide further free general practice outreach services. This could be via the child health team led by nurses, including the Family Nurse Practitioner and assisted by community health workers.

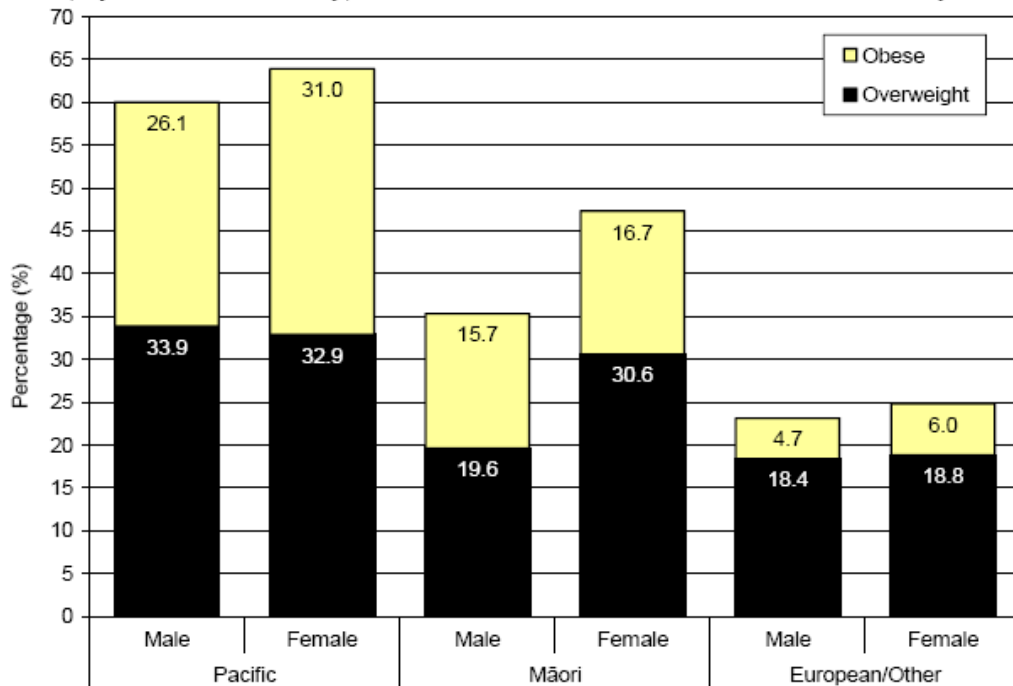
All the issues raised by the participants in this study need to be presented and discussed in the appropriate forum. Therefore the researcher will inform the community, the school, the District Health Board, Ministry of Health and other practitioners of the findings of this study. The researcher will disseminate the findings of this study through publication in an academic journal and with presentations to appropriate groups.

Conclusion

Nurses and other health workers can provide a great deal of care to children in communities provided they have access to the relevant preparation and support of other practitioners and services. Enhancing these roles and adopting the concept of child health teams with appropriate multidisciplinary membership and/or the „health home“ model will refocus the delivery of services to the community’s children and families/whānau.

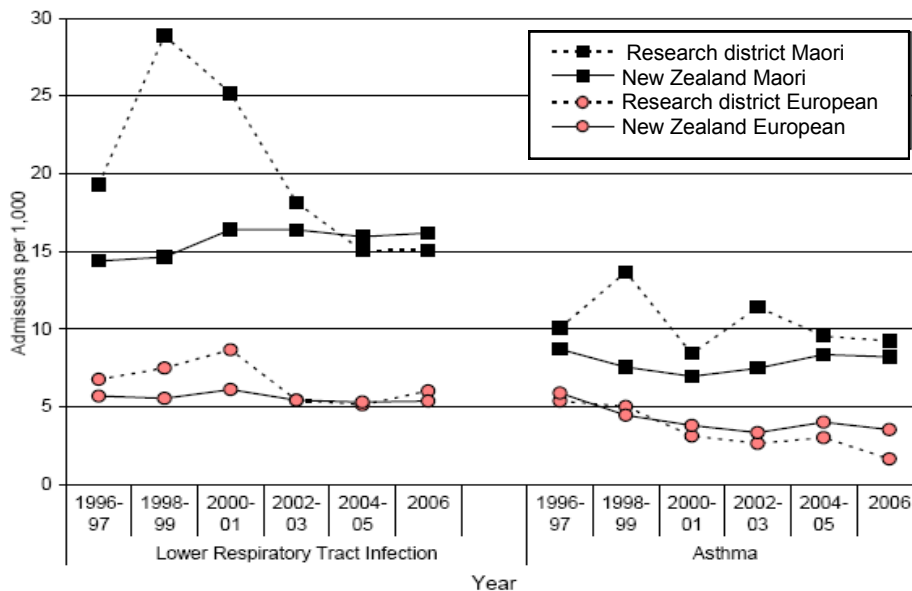
Any proposed changes and introduction of new roles by health providers needs to involve the participation of community members, parents and caregivers and children. The effectiveness of any new intervention or change in service needs to be monitored and evaluated on an ongoing basis with full participation from the community. The recommendations for this study have been based on what parents and caregivers believe will assist in ensuring greater access to health care for the children in their community. The participation of parents and caregivers in this study indicates their willingness to work with health providers to ensure their children receive the services they need, and that services fit more appropriately with the economic and socio-cultural context of their environment. In raising awareness of child health issues and by refocusing and enhancing services provided to this community it is hoped that health services for children will no longer be „hidden“, and that parents and caregivers will actively „seek“ services that ensure their children have timely and appropriate access to care therefore enabling them to better meet their health needs.

Appendix 1 – Epidemiological data



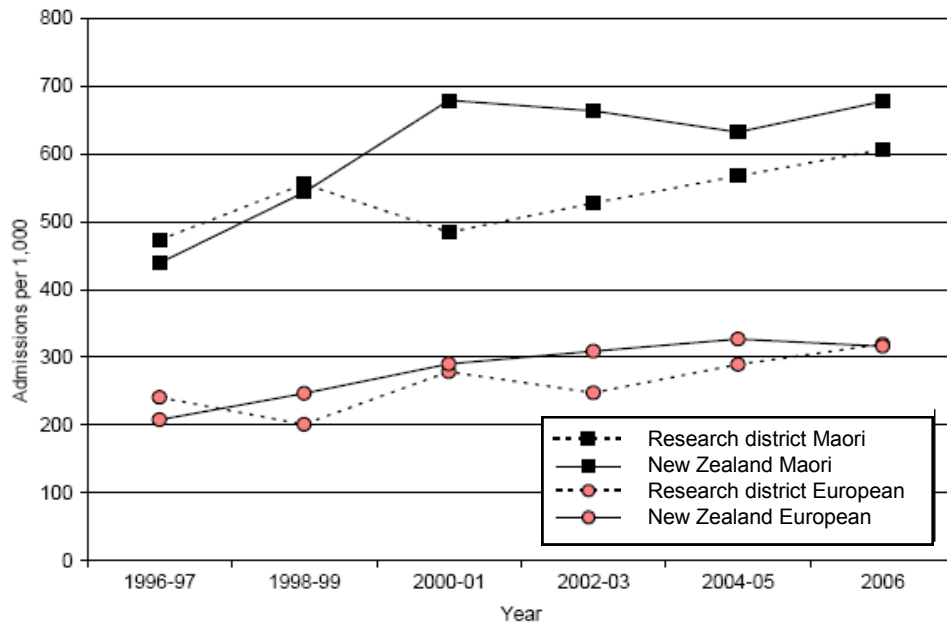
Source: NZ Food, NZ Children: Key Results of the 2002 National Children's Nutrition Survey [88]

Figure 4 Proportion of children aged 5-14 years who were either overweight or obese by gender and ethnicity.



Source: NZ Child and Youth Epidemiology Service. (2007).

Figure 5 Hospital admissions for lower respiratory tract infections and asthma in children aged 0-14 years by ethnicity, 1996-2006



Source: NZ Child and Youth Epidemiology Service. (2007).

Figure 6 Hospital admissions for serious bacterial infections in children and young people aged 0-24 years by ethnicity

Appendix 2 – Definitions of continuity of care

Hierarchical definition of continuity of care		
	Level of continuity	Description
1.	Informational	An organised collection of medical and social information about each patient is readily available to any health care professional caring for the patient. A systemic process also allows accessing and communicating this information among those involved in the care.
2.	Longitudinal	In addition to informational continuity, each patient has a “medical home” where the patient receives most health care, which allows the care to occur in an accessible and familiar environment from an organised team of providers. This team assumes responsibility for coordinating the quality of care, including preventive services.
3.	Interpersonal	In addition to longitudinal continuity, an ongoing relationship exists between each patient and a personal physician. The patient knows the physician by name and trusts the physician on a personal basis. The patient uses this physician for basic health services and depends on the physician to assume personal responsibility for the patient’s overall health care. When the personal physician is not available, a coverage arrangement assures that longitudinal continuity occurs.

Source: Saultz, J. W. (2003). Defining and measuring interpersonal continuity of care. *Annals of Family Medicine*, 1(3), 134 – 143.

Types of continuity		
1.	Informational	The use of information on past events and personal circumstances to make current care appropriate for each individual
2.	Management	A consistent and coherent approach to the management of a health condition that is responsive to a patient’s changing needs
3.	Relational	An ongoing therapeutic relationship between a patient and one or more providers

Source: Haggerty, J. L., Reid, R.J., Freeman, G. K., Starfield, B. H., Adair, C. E., & McKendry, R. (2003). Continuity of care: a multidisciplinary review. *British Medical Journal*, 327, 1219 – 1221.

Appendix 3 – Information sheet

Community Child Health Care Study - an exploratory study

INFORMATION SHEET

Introduction

My name is Helen Pocknall and I am currently completing my Masters degree through Massey University. I am a registered nurse and I work as the Director of Nursing for the local District Health Board.

My special area of interest is child health and the purpose of my research (this study) is to discuss with you, the parents and caregivers of children from the local school community, what health care services you believe will make a difference to your children's health. I also want to discuss with you how you would like child health care services delivered in your community.

How are people chosen to be part of this study?

I would like to invite you as a parent or caregiver of children who live in the community to take part in this study. Three group sessions will be held. These are called focus groups and there will be one each for the parents and caregivers of Māori, Pacific and other children. If you would like further information about the study before deciding whether to take part then please let the staff at the school know. They will ensure that I am informed and I will contact you to discuss the study further with you.

What happens in this study?

Each focus group will have 6 to 10 participants in it. The focus group sessions will be audio-taped. Your consent is required for this - if you are unable to give consent then you will not be able to participate in the study. You are welcome to bring your family and whānau along to support you during the focus group. The only people who will have access to that information are my University supervisor, myself and the person who helps me to transcribe (type up) the tapes.

Each focus group will take no longer than one to two hours. Drinks and light refreshments will be provided at each of the sessions. There are no risks or costs associated with participation in this study, however, it will involve you giving time to come along to the focus group.

I will do a summary of the discussions. A further session of no longer than an hour will be offered to you to discuss and confirm the themes resulting from those discussions.

What are the benefits?

The benefit for you in taking part in this study is the valuable contribution you will make in informing the development of future health care services for the children of this community.

How will my privacy be protected?

Consent will be gained from you if you wish to take part in the study. You will be asked to keep confidential any discussions which you take part in during the focus group session. No information that could personally identify you or your child/children will be used in any reports on this study.

The information from the study will be stored securely in the School of Health Sciences at Massey University for 5 years.

What happens to the results of the study?

The results of the study will be published as a Masters thesis and published in a health journal.

The results will also be presented to the school community, the local District Health Board, the local Community Primary Health Organisation and local Māori Health Providers.

There will not be any changes in the delivery of services at this time for your child/children or the community as a result of participating in this study. However, the information from the study will contribute to the future development of the local District Health Board's child health services as they relate to this community.

Your Rights

You are under no obligation to take part in the study. If you decide to participate, you have the right to:

- decline to answer any particular question;
- withdraw from the study at any time;
- ask any questions about the study at any time during participation;
- provide information on the understanding that your name will not be used unless you give permission to the researcher;
- be given access to a summary of the project findings when it is concluded.
- ask for the audio tape to be turned off at any time during the interview.

Non-participation or withdrawal from the study will not affect the provision of any health care your child/children are already receiving or may need to receive in the future.

What do I do if I have concerns about the study?

My supervisor for this study is Associate Professor Annette Huntington.

If you have any questions about the project please do not hesitate to contact my supervisor or me at any time. Contact details are as follows:

Researcher

Helen Pocknall
c/- local DHB

027 240 5710

Supervisor

Annette Huntington
Dept. of Nursing
Massey University

04 801 2794, extension 6315

This study has received ethical approval from the Central Region Health and Disability Ethics Committee; **Reference no. CEN/07/08/060.**

Appendix 4 – Consent form

Community Child Health Care Study – an exploratory study

PARTICIPANT CONSENT FORM

This consent form will be held for a period of five (5) years

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I have had the opportunity to use whānau support or a friend to help me ask questions and understand the study.

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time and this will in no way affect my child/children's future health care/continuing health care. I understand that if I am unable to consent to the interview being audio taped that I am therefore unable to participate.

I understand that my participation in this study is confidential and that no material which could identify me or my child/children will be used in any reports on this study.

I agree/do not agree to keep confidential any discussions had in this focus group.

I agree/do not agree to the interview being audio taped.

REQUEST FOR INTERPRETER:

English	I wish to have an interpreter.	Yes	No
Māori	E hiahia ana ahau ki tetahi kaiwhakaMāori/kaiwhaka pakeha korero.	Ae	Kao
Cook Island	Ka inangaro au i tetahi tangata uri reo.	Ae	Kare
Samoan	Ou te mana'o ia i ai se fa'amatala upu.	loe	Leai

NB: It has been identified that these are representative of the ethnicities present at the school.

I _____ (Print full name) hereby consent to take part in this study.

_____ (Signature)

Date:

Appendix 5 – Transcriber’s confidentiality agreement

Community Child Health Care Study: an exploratory study

TRANSCRIBER’S CONFIDENTIALITY AGREEMENT

I..... (Full name – printed) agree to transcribe the tapes provided to me.

I agree to keep confidential all the information provided to me.

I will not make any copies of the transcripts or keep any record of them, other than those required for the project.

Signature: _____ Date: _____

Appendix 6 – Assistant’s confidentiality agreement

Community Child Health Care Study: an exploratory study

CONFIDENTIALITY AGREEMENT

I..... (Full Name -printed)

agree to keep confidential all information concerning the project, Community
Child Health Care Study.

I will not retain or copy any information involving the project.

Signature: _____ Date: _____

Appendix 7 – Interview schedule

Community Child Health Care Study: an exploratory study

INTERVIEW SCHEDULE FOR PARENTS AND CAREGIVERS

These questions will be used by the investigator, to guide the focus group session

Are you able to tell me what health care services you believe are available for children in the community? Which of these do you think are well used by the community? How do people know about these services?

Where do people from the community go if they need advice on how to care for their child/children? What about if their child was not well? How easy is it to get that advice? How easy is it to understand and follow the advice that is given to people? Why/why not?

How easy is it to get to see the people providing those services that you have identified? Why/why not?

How much does it cost to access those services? What effect does cost have on whether people will seek advice from a health care provider?

What do you believe are the issues, if any, with those services which are currently provided? Why/why not?

What, if any difference do you think the services provided are making to the health of the community's children? Why/why not?

What sort of services do you think people would want to be available in the community? How could these services be better provided in the community? Where is the best place(s) for them to be provided? Who should provide these services? Why/why not?

What times should they be available? How much should they cost?

Appendix 8 – Principles of the New Zealand Child Health Strategy

(Ministry of Health, 1998)

The principles as outlined describe what needs to occur or should be in place for every child in New Zealand to achieve optimal health, no matter what their environmental, socioeconomic or family circumstances are:

- Children/tamariki should have their needs treated as paramount.*
- Child health and disability support services should focus on the child/tamariki and their family/whānau.*
- Child health and disability support services should be available as close to home as possible, within the bounds of quality and safety.*
- Child health and disability support services should work together with each other and staff from other sectors to benefit the child.*
- Child health and disability support services should be provided to achieve equity.*
- Child health and disability support services should be based on international best practice, research and education.
- Child health and disability support services should be regularly monitored and evaluated.
- Child health and disability support services should be culturally safe, culturally acceptable and value diversity.*
- Child health and disability support services should take into account the available resources.

The principles presented with an asterisk are the ones specifically identified as being relevant to this research.

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