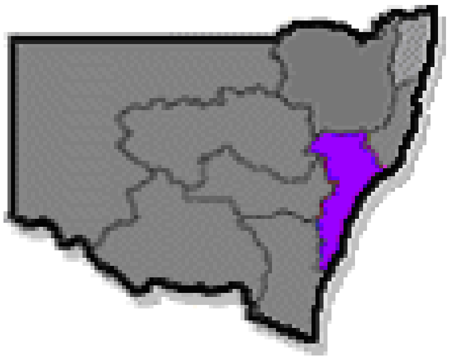
INDICATORS OF SATISFACTION & SUCCESS FOR A PAEDIATRIC OUTREACH NURSING SERVICE IN METROPOLITAN SYDNEY, NSW



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DECLARATION OF AUTHORSHIP

Except where reference is made in the text of the thesis, this thesis contains no material published elsewhere or extracted in whole or in part from a thesis by which I have qualified or been awarded another degree or diploma. No other person's work has been used without due acknowledgement in the main text of the thesis.

This thesis has not been submitted for the award of any degree or diploma in any other tertiary institution.

All research procedures reported in this thesis received the approval of the relevant Ethics/Safety Committees (where required).

Name	Date
	21st September, 2005

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I am grateful to Dr Gordon Waterlow. He taught me what was important about a Paediatric Outreach Service. He challenged me to look beyond what existed to see what was possible as he always argued for what was best for the children accessing the health service. His passion to change and improve service delivery always inspired me to do better. His vision of what was possible and his support of the Paediatric Outreach Service allowed me to continue to develop the service, even when times were difficult.

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ABSTRACT

The purpose of this study was to determine the indicators of customer satisfaction and service success of a newly established paediatric outreach nursing service.

Referring agents and care recipients were both consumers of the paediatric outreach nursing service. Both groups of consumers were surveyed to determine their satisfaction with the service delivery.

Two satisfaction survey tools were developed to measure customer satisfaction. The tools were piloted and refined prior to distributing them. Both tools had a series of closed-ended questions and 3 open-ended questions.

Eight service indicators were developed. These were designed to test the effectiveness of the service provided. The service indicators were piloted over two periods of three months and then modified based on the findings of the pilot period.

The Paediatric Outreach Service (POS) is a positive service model for health care delivery. The survey results indicated that stakeholders were generally satisfied with the service delivery.

When measured against service indicators that were developed for POS, the service performance was above average, with some opportunity to improve practice.

Underpinned by a family-centered framework, POS has the capacity to empower children and their families in the planning and implementation of a management plan for the child's illness. Such empowerment may lead families to practice better healthcare, develop better health-seeking practices and ultimately lead to healthier children.

The results from this study has implications for nursing practice. The data obtained from this study may be useful to service providers considering commencing a paediatric outreach nursing service. Data may also be useful for existing service providers to use in order to review the aspects that consumers value against the service they currently provide.

Keywords ambulatory care; paediatrics; home-nursing; community; evaluation; satisfaction; success; indicators

GLOSSARY OF ABBREVIATIONS

AHS	Area Health Service
CCHC	Cabramatta Community Health Centre
CFHN	Child and Family Health Nurse
CHC	Community Health Centre
CNC	Clinical Nurse Consultant
FF	Fairfield
FHS	Fairfield Health Service
FLGA	Fairfield Local Government Area
GP	General Practitioner
LMO	Local Medical Officer
LP	Liverpool Hospital
NSW	New South Wales
NUM	Nurse Unit Manager
PHN	Primary Health Nurse
POS	Paediatric Outreach Service
PCHC	Prairiewood Community Health Centre
RN	Registered Nurse
SWSAHS	South Western Sydney Area Health Service

CHAPTER

ONE

CHAPTER ONE – INTRODUCTION TO THE STUDY

1.1 INTRODUCTION

> ***"A child should only be admitted to hospital when the care they require cannot be equally well provided at home"***
> (Platt Report, 1959)

This quote from the paper commissioned by the English Government over forty years ago has underpinned the development of alternate models of nursing care to meet the needs of sick children and their families in many countries around the world, including Australia.

Thompson (2000) described home care as an option for medically needy and technology-dependent children and children with acute and chronic health care problems who have been cared for in hospital. Over the past ten years or so, ambulatory nursing care has expanded to become frequently recognised as a unique domain of nursing practice specialty (Schim, Thornburg, & Kravutske, 2001). Despite the increasing focus on the importance of the development of paediatric ambulatory care service models in New South Wales (NSW Health, 2003), paediatric nurses face the increasing skepticism of health service planners and administrators. Paediatric nurses are challenged on the idea that simply because paediatric ambulatory care services better meet the psychosocial needs of children and their families, they should just be implemented (Minutes of the State Paediatric Network Services Group, 2002). An in-depth review of the literature, revealed that there is little **empirical** data to support the merits of such models of outreach nursing care. Much of the available literature describes the *process* of developing services and provided anecdotal reports of their benefits for patients and their families. Further, there is often little consideration given to evaluation, including the development of service indicators in the planning process of service development. Due to the fact that services continue to be developed in the presence of descriptive data and without strong empirical data to support development, a Cochrane Database Protocol entitled “Specialist home-based nursing services for children with acute and chronic illnesses” (Cooper, Wheeler, Woolfenden, Boss, & Piper) was developed in May 2003. It aimed to provide a sound evidence-base to justify the need for paediatric nursing outreach services.

1.2 BACKGROUND TO THE STUDY

The Paediatric Outreach Service (POS) in South West Sydney Area Health Service (SWSAHS), New South Wales (NSW) was conceptualised between 1995 and 1997 by a paediatric steering group for inception at a district hospital in metropolitan Sydney, Australia. It commenced operation in 1998 in response to the NSW Government’s decision to relocate the Royal Alexandra Hospital For Children from Camperdown to Westmead. It was initially considered that this process would eliminate the need to provide paediatric inpatient services at Fairfield. POS was originally planned as an alternative to inpatient services. However, over time, the decision was made to maintain the then current level of paediatric services and that they would be enhanced by the implementation of POS.

Webster & Raphael (2002) asserted that *"evaluation activities form an integral part of the development and implementation of [a] project"* (p 7) but they also pointed out *"evaluation can begin at almost any point in an initiative"* (p6). POS was a very special service in that it was one of the first of it's kind in Sydney, NSW. Nursing outreach service models have existed for many years in the adult care arena but the development of POS saw the first formal extension of paediatric nursing care in Sydney. This was in the form of a specialist paediatric home-based nursing service based at a district hospital to meet children's acute health-care needs.

1.3 JUSTIFICATION FOR THE STUDY

The Paediatric Outreach Service (POS), in the SWSAHS of NSW, was a service developed in response to a number of external pressures, which will be described in detail in Chapter Two. However, a significant oversight in the initial planning process for POS was the articulation of evaluation strategies. Ideally, measurement indicators should have been described prior to POS commencing. This would have provided a set of established and agreed upon criteria against which to evaluate the service after a defined, and again, agreed upon, period of time.

This gap in the planning process, together with a lack of empirical data in the literature, have formed the basis for this study as this author sought to identify and understand measurement criteria that would indicate an efficient, effective and successful service. Such indicators may be useful to future service providers as they seek to establish a paediatric outreach service, or useful to established services looking for criteria against which to measure their success.

Feedback obtained from parents related to aspects of service provision will allow service providers to consider tailoring service delivery to best address the identified needs of families.

1. 4 THE RESEARCH QUESTIONS

The thesis addresses two key research questions. These are:

1. What elements of a Paediatric Outreach Nursing Service satisfy the customers using the service?
2. Which indicators provide effective measurement of successful nursing service provision?

1.5 THESIS OUTLINE

In order to set the context for POS evolution and analysis, this thesis first describes the early development of the POS. Next, this author will synthesize the literature related to paediatric outreach nursing services, customer satisfaction and service evaluation.

Chapter Four will describe the study methodology. It will outline the development of two types of evaluation criteria, namely satisfaction surveys (as the researcher sought to understand consumer opinion about POS, from the first nine months of operation), and the development of service indicators. These two evaluation tools were designed as the author believed they would elicit important data to illuminate elements to describe indicators of service success. It was believed that this would assist in the evaluation of POS and also in the development of future services.

Chapters Five to Seven will provide details of the study findings. The findings will be discussed in depth in Chapter Eight before the thesis is brought to a close in Chapter Nine with a summary of the study, the benefits and limitations of the study, the impact of this study on the current body of nursing research, and recommendations for future research.

1. 6 REFLECTION

This study was designed to assist the researcher to understand the key factors contributing to service success. The relative lack of published evaluative data has offered health services setting up a home-visiting paediatric nursing service little advice regarding what works and what doesn’t.

This study was designed to understand what referring agents and families needed from the nurses providing home-based nursing care in order to value the service. Further, the study was intended to develop some indicators of satisfaction and success for a paediatric outreach service in metropolitan Sydney that may also assist other service providers in service delivery or development.

CHAPTER

TWO

CHAPTER TWO – BACKGROUND TO THE STUDY

2.1 INTRODUCTION

This chapter describes the early development of the paediatric outreach service in metropolitan Sydney, and also provides explanation on some of the philosophical underpinnings guiding the service. Description of the service development will set the scene, and later facilitate analysis of the paediatric outreach service to elucidate the elements of success for such a service.

2. 2 THERE'S NO PLACE LIKE HOME

> ***There's no place like home…***
> ***There's no place like home…***
> (MGM, 1939, cited at
> http://www.filmsite.org/wiza5.html)

Many reading these lines may recognise these words as the mantra recited by Dorothy in the classic story of 'The Wizard of Oz'. Perhaps during her loss of consciousness sustained during the hurricane, Dorothy had a premonition of the pathway that healthcare would follow in the 1990's and into the new millennium. After all the problems encountered trying to find the imaginary "Oz", (perhaps as imaginary as a perfect healthcare system), the wise people of Kansas realised that the best place for Dorothy in her dazed, but stable condition, was at home being cared for by Auntie Em and Uncle Henry, in familiar surroundings with friends such as Toto nearby (1939 MGM Musical).

While this classic story existed long before the drive for community-focused nursing care and really has nothing to do with current health practices, the story can be used to illustrate that *“home is often the best place for sick children”* (Dryden,1986:25), and is, none the less, true.

For the child, there is no place like home (Thompson,1995; Clarke 1994) and the family is the most important aspect of their life. Further, these authors assert that whilst the notion of what defines a family varies in cultures and across generations, the ‘family unit ’ is a pivotal part of all societies. “*Family can be used broadly to refer to the social environment within which parenting is conducted* Franck & Callery (2004: 266).

In *A Picture of Australia’s Children*, published in 2005 by the Australian Institute of Health and Welfare, the concept of family is described. It is said that *“With the changing societal attitudes towards marriage and fertility choices, Australian families have changed dramatically…[resulting in] an increasing diversity of family types within which Australian children are brought up”* (2005:76). Thompson (2000) believes that providing home-based nursing care can be a very challenging experience because families come in many shapes and sizes, but regardless, they are the primary environment in which children are nurtured.

The Australian Institute of Health and Welfare (2005:76) state that *"a number of children …may experience a number of family transitions before they reach adolescence. These types of changes can impact significantly on children."* It is the professional responsibility of the paediatric home-visiting nurse to be able to develop an effective care plan that acknowledges and values the role of the "family"; *"where "family" is used to describe a range of social relations, without assumptions either about conformity to social norms or of value"* (Franck & Callery, 2004:266).

It is very important for the visiting paediatric nurse to take the time to understand the family structure because *"a child's personal experience of family change can sometimes result in poorer health and well-being….[but] the relationship between family structure and child outcomes is not a simple causal one"* (The Australian Institute of Health and Welfare 2005:76)

The term 'family centred care' is used to describe one approach offered by nurses in the provision of nursing care to children (Bond, Phillips and Rollins, 1994). The philosophy of family-centred care acknowledges that in caring for a child, the nurse must work with an entire family because it is often difficult to separate the needs of the child from those of the rest of the family and that *"involvement of the family is essential to the humane healthcare of children"* (Franck & Callery, 2004:266).

This theoretical framework was one used by the POS nurses to ensure that holistic care was delivered to the child, within the context of their family. Family-centered care *“encompasses the concepts of parental participation in children’s healthcare; partnership and collaboration between the healthcare team and parents in decision-making; family-friendly environments that normalize as much as possible family functioning within the healthcare setting; and care of family members as well as of children”* (Franck & Callery, 2004:267).

Over the past decade there has been a gradual re-focusing of paediatric health care provision from in-hospital facilities to community and/or home-based services. This changing focus has not been without it’s critics. However, such a changing focus now underpins New South Wales Government health care planning (for example, NSW Health Care in the Community Re-Investment Strategy – Report on Consultation Workshop No 2, Feb 2001). This report makes recommendations concerning the need to re-channel resources including finances, personnel and equipment, from the hospital setting and in to the community to meet increasing demands created by early discharge and models of care that substitute inpatient care. The Guidelines for Networking Paediatric Services in New South Wales, released by NSW Health in 2003, also espouse the principle of care provision as close to home as possible.

Health-care professionals now describe the elastic walls of the hospital and a seamless healthcare delivery system (Smith, 2000; Pearce, 2001;

Sullivan 1995). Such descriptors have been coined to try and describe the integration of health care services across the care continuum that ideally enable patients to receive the services they require in the most appropriate setting, effortlessly. That is, the terms are used to describe the fact that despite the bureaucratic divisions in service delivery, these boundaries should not be evident to the patient.

There have been many forces evident in the development and implementation of paediatric outreach or community-based nursing programs, some that drove the process and others that reinforced it. These include such things as tightening fiscal constraint in the health system; philosophical approaches to care such as that described in The Platt Report (1959), Parents-in-Partnership, and more recently, Families First (2001). Each of these factors have exerted both positive and negative effects on the process of outreach service development and nursing care delivery.

2. 3 DEMOGRAPHICS OF THE LOCAL STUDY AREA

The Fairfield Hospital is a 175 bed metropolitan general hospital located approximately 32 kilometres south-west of the Sydney central business district (www.ffcity.nsw.gov.au, 2000) in the SWSAHS (see Fig i and Fig ii). It services a Local Government Area (LGA) of a little over one hundred square kilometres with a population of almost one hundred and eighty nine thousand people. In 1998, the hospital had a twenty-four bed children's ward that met a level three role delineation (as described by NSW Health. See Appendix 11). The paediatric service was staffed by four Paediatrician Visiting Medical Officers and worked closely with the paediatric outreach service.

Fig i: Metropolitan Area Health Services

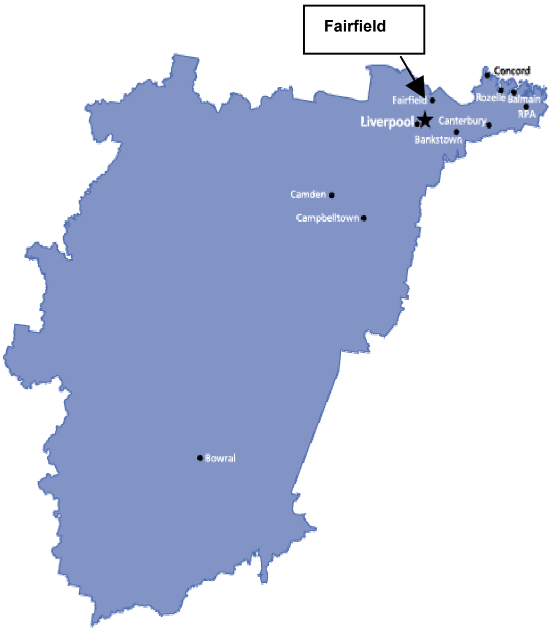

Fig ii: South Western Area Health Service

The population of the South Western Sydney Area Health Service (SWSAHS), which encompasses the study hospital and it's services, is very different to that of any other Area Health Service (AHS) in NSW for several reasons. *"South Western Sydney Area Health Service has the largest number of children of any Area Health Service in NSW. Indeed 1 in 7.5 children in NSW live in South West Sydney. In 2001, 25% {of SWSAHS population] were aged less than 15 years". (*Division of Health Service Planning Report No 04/01 2004:4.2). No other AHS has the multicultural mix of SWSAHS, where there are approximately one hundred and thirty three cultures speaking almost sixty different languages (www. ffcity. nsw. gov. au, 2000).

SWSAHS receives the lowest allocation of health dollars per head of population (Sullivan et al.,1996:24) despite having a low immunisation rate (approximately 62% [the National Goal is 95%]) Sullivan et al.,1996:47); a low breast feeding rate (approximately 27% at three months) (Personal communication with the Chair of the Department of Paediatrics Fairfield, 2000); high rate of teenage and/or single mother pregnancies (NSW Health Mother and Baby Report 2003); a high rate of reported child abuse [1991-95] (Sullivan et al.,1996:62); and the second lowest school retention rate in metropolitan Sydney (Sullivan et al., 1996:71).

In an area of disproportionate health dollar allocation, there was a need to think "outside the square". Allocated money needed to "stretch further" to improve access and/or equity of service provision for residents. It has been well documented that if health dollars are invested in the health of children aged birth to approximately eight years, the Australian Government can make significant future savings in the investment of health dollars into older persons (Alperstein & Nossar, 1998). One such initiative has been the Australian National Government's Families First Initiative.

This philosophical underpinning was introduced by the Government to improve child health by drawing together key Government Departments (namely Health, Justice, Housing, Education) with Non-Government Organisations (NGO's) to address children's health and the social determinants of health to improve outcomes for children. As this initiative is fundamentally a philosophical approach to care that is family-focussed, the flow-on effect has a great impact on the development of a service such as POS. Families First has essentially been an initiative embraced by child and family health nurses, but less so by paediatric service providers. This may be due to the way the fields of care are defined.

The fields of activity for focus under Families First are defined as:

- supporting parents who are expecting or caring for a new baby
- supporting parents who are caring for infants and young children
- assisting families who need extra support
- linking families to communities and communities to families

Whilst there is nothing specific here about child and family health nursing, the terminology here is much more consistent with that of maternity and community based services. Paediatrics (defined as the care of sick children) has historically been very much part of the acute-care domain. As the traditional walls of the hospital are replaced by virtual walls, paediatric care providers need to think differently about the services they provide. Entering the homes of the children needing care (be that physical or psychological) changes the relational dynamic between parents and health care providers. In doing so, health care providers need to look at the context in which they find the child. Context includes the home, the family, the social structures that surround the child. If paediatric care providers can do this, then the fields of activity are just as relevant to them. As a philosophical framework, Families First can provide strong foundations upon which to build a paediatric home-based nursing service. However, to get to this point will require a significant paradigm shift.

2. 4 Royal Alexandra Hospital For Children On The Move

The Royal Alexandra Hospital for Children (RAHC) had been located in the inner city of Sydney for more than a century, servicing not only the local community but acting a referral hospital for the whole state of NSW. Whilst located in the inner city, families would travel great distances to bring their children to *"the"* children's hospital, often passing several hospitals with a children's ward on their way. For example, a parent traveling from Katoomba might have passed by The Blue Mountains

Hospital, Nepean Hospital, Blacktown Hospital, Mount Druitt Hospital and Westmead Hospital to take their child to Camperdown. There may have been several reasons for this. Justifications postulated include the notion that parents may have had little knowledge of the services offered by their local hospital; they had little faith in the ability of the staff at the local hospital; or perhaps a reason was that they believed the best available care was available only at The Children's Hospital (Woolfenden; Ritchie; Hanson; and Nossar, 1999)

Irrespective of the reason, these behaviours created problems for both RAHC and for the family. The fact that many families chose to travel to RAHC, often meant that the waiting time for beds was excessive. In turn, this meant that patients booked for elective surgery often had to be cancelled due to lack of bed availability. Increasing wait-lists mean that children are expected to live with health burdens for longer periods of time and there are knock-on effects from such a situation including increased sick leave (for the child and often a parent); increased family stressors; and children may be in poorer condition when they finally get a date for their elective surgery.

Typically, the long distances traveled also meant that many families had isolated themselves from their normal support and social networks. This then created the potential for parents and children to feel isolated. There were many times in clinical practice where families described, to the author, missing their friends and relatives and the support of their social networks. In such circumstances, families rely heavily on the nursing staff of the ward to provide their socialisation and sometimes the support they needed to help them through the period of hospitalization, particularly when the period of hospitalization is lengthy (Brodie, Nagy, English, and Gillies, 2002).

In addition, the result of families choosing to by-pass their local hospital for routine medical and surgical conditions, due to a lack of confidence in local service providers, was the under-utilisation of the paediatric units in those hospitals. In turn, this may have ultimately resulted in a de-skilled staff in these emergency departments and children's wards, in relation to paediatric-specific skills, thereby increasing the possibility of perpetuating this inappropriate cycle (ie parents bypassing a paediatric ward due to a lack of confidence in the staff at that hospital).

Metropolitan Sydney continued to spread further and further west. This urban sprawl led to an alteration in the concentration of children in Sydney with greater than 50% of them estimated to live west of Parramatta. Up until the mid 1990's there were no paediatric tertiary hospitals in western Sydney, and yet the two tertiary paediatric hospitals of Sydney, were located within about 15km of each other, at Camperdown and Randwick.

In an attempt to improve access to expert paediatric services for children of the west, the NSW Government made a decision in the early 1990's to re-locate RAHC to Westmead. This meant that the hospital would be located almost at the centre of metropolitan Sydney, and much closer to the greater paediatric population of Sydney. This forced health service providers in the west and south west of Sydney to review their services and assess their viability (discussed further in Section 2.5).

The hospital was relocated from Camperdown to Westmead in 1995 with the intent that the relocation would enable the hospital to better meet the needs of New South Wales' children. However, relocation did not change parental practices to bypass other, closer hospitals as they preferred to seek tertiary level health care for their children at RAHC (Wolfenden; Ritchie; Hanson; and Nossar, 1999). Thus, the cycle of bed-block at the Children's Hospital, cancellation of booked elective procedures and reduced critical mass at peripheral hospitals leading to staff de-skilling continued. Staff at Fairfield Health Service (FHS) recognized that they needed to do things differently (ie review and alter the model of care offered) if they were to be able to improve consumer (parental and other service providers) confidence and eventually alter patient flows.

2. 5 REASONS FOR SUGGESTED CHANGE TO THE PAEDIATRIC SERVICES AT FAIRFIELD HOSPITAL

The re-location of RAHC to Westmead led to a number of changes. Firstly, the NSW State Government granted the hospital an increase in bed capacity to meet the anticipated inflated demands generated by the larger local paediatric population. Additional beds were allocated and the outpatient and in-patient services were enhanced.

RAHC also proposed a name change so that the new hospital would be readily recognised and not confused with the old hospital. Consequently, whilst the hospital retained it's full title of The Royal Alexandra Hospital for Children for legal purposes, a marketing and advertising project saw it become known as The New Children's Hospital to most of the people of Sydney, and beyond. They underwent another name change at the start of the twenty first century and became known at The Children's Hospital at Westmead.

With the re-location of The New Children's Hospital, it was the State Government's expectation that the hospital, with it's expanded facilities, would be able to meet the health care needs of the children of western and south western Sydney. To this end, the existing paediatric services in western and south-western Sydney were appraised, with a view to rationalising services, developing new networks, and standardising patient care protocols (Memo from Service Director Community Paediatrics, 1995; Draft Report-Paediatric Ambulatory Care in Sydney's Greater West, 1994; A Department of Paediatrics Response to the Document – Fairfield Health Service- Children's Service, 1995).

The Executive of SWSAHS and the FHS Executive recognised that the planned relocation of The Children's Hospital to Westmead in October

1995 would have a significant impact on the provision of paediatric services within the community of Fairfield and Fairfield Hospital (Memo from General Manager on Paediatric Services at Fairfield Hospital, 1995). Acknowledgment of the links that would be developed between the general practitioners of Fairfield LGA and The New Children's Hospital led to consideration of an altered role for the children's ward at Fairfield Hospital.

Analysis of cost and service provision for paediatric care was undertaken at Fairfield during the mid 1990's and new models of service delivery were proposed for discussion by key stake-holders both within the Fairfield's LGA and other external service providers.

2.6 PROPOSAL OF OPTIONS FOR THE DEVELOPMENT OF A PAEDIATRIC OUTREACH SERVICE MODEL

There were many discussions and consultations over several months, between major stake-holders, about the most effective way to manage Paediatric Services in South Western Sydney, with particular reference to Fairfield, after the re-location of The Children's Hospital (personal dialogue with Fairfield's Chair of Department of Paediatric's, 1999)

These discussions and consultations led to the proposal of four models involving the Children's Ward at Fairfield Hospital for consideration. There were advantages and disadvantages in each of the models proposed. The disadvantages of the proposed models needed to be weighed against the proposed benefits to the community they would serve. The disadvantages would affect more than paediatric services in SWSAHS and, consequently, the list of stakeholders lengthened. All options were somewhat favorable as they presented some degree of cost-saving to SWSAHS.

The Local Community raised major objections to all the plans that would result in closure of the children's ward at Fairfield Hospital. A petition was circulated by individuals in the local community which resulted in more than one thousand signatures from members of the public. There were letters to The Editor in the local press and feature articles, all expressing objections from members of the local community (See Appendix 9 for list of Media articles).

This level of public support was significant. The backing for maintaining the local children's ward most likely was related to the way the local community used the local hospital. Data from Western Sydney and The New Children's Hospital suggested that paediatric emergency services were provided mainly for the 0-4 year age group who required primary health services. This group included a significant proportion of children in the acute phase of common illnesses where up to 24 hours of observation may be required (Draft report – Paediatric Ambulatory Care in Sydney's Greater West, 1994).

Waterlow (1995) described a similar pattern of Emergency Department use at Fairfield Hospital for acute episodes of primary care services (greater than 50% aged less than 5 years and approximately 45% aged 5-16 years). Thus, the pattern of usage described for Fairfield Hospital needed to be taken into consideration when choosing a service model as the Emergency Department was integrally linked to parental choices in seeking health care for their children.

The proposed service models were considered in terms of the money that could be saved, anticipated consumer needs, and how the services within Fairfield would articulate with The New Children's Hospital, and existing paediatric services.

Service planners anticipated that benefits of the new model of care would include encouraging parents with sick children to present to the enhanced Emergency Department at Fairfield Hospital, thus reducing the outflows to other hospitals such as The New Children's Hospital at Westmead, which lay outside the Area Health Service. It was believed that up to 90% of those presenting would not require admission (Cooper 1999). The 90% of patients not requiring admission could be referred to the new home-based specialist nursing service, which was to be established. For the 10% of patients who required admission, transport would be organised to The New Children's Hospital.

Under the proposed model, there would be no change for children who required day surgery. This was already provided by Fairfield Hospital and children would continue to be provided with this service. However, should they require an overnight admission due to unexpected complications resulting from their surgery, then it was proposed that transfer to The Children's Hospital would be organized by the staff of Fairfield Hospital.

The Fairfield Hospital Executive and stake-holders anticipated that the new service model would lead to improved services through the Emergency Department at Fairfield Hospital and lead to the closure of the Children's ward at Fairfield Hospital (Fairfield Health Service-Children's Service Report, 1997). The Fairfield Children's Service (Ambulatory and Primary Care Service, 1997) Report stated that:

> *"Fairfield Hospital is now situated midway between two major teaching hospitals: Liverpool Hospital and Westmead Children's Hospital It does not have the specialised facilities for diagnosis and treatment of children that these two hospitals contain Fairfield Hospital is well placed, however, to provide a specialised Paediatric Ambulatory Care Centre. "*

2.6.1 FAIRFIELD AGREEMENT FOR THE PREFERRED PAEDIATRIC OUTREACH NURSING SERVICE MODEL

On March 7th 1996, recommendations made by the working party responsible for planning Paediatric Services for Fairfield Hospital included the fact that the current bed numbers (of twenty four) at Fairfield Hospital would temporarily remain. Further directives included that avenues to implement the paediatric home-based service would be investigated and that the nurse's staffing levels at Fairfield Hospital children's ward should be maintained as appropriate to manage the current paediatric activity.

A service model for paediatrics was finally endorsed during 1999 for Fairfield Health Service and included the following components:

- A Department of Community Paediatrics to be established to address issues of:
    - Ambulatory paediatrics to improve the Emergency Department interface with the community and with the hospital
    - Paediatric Outreach Service to provide home-based nursing services for children living within Fairfield Local Government Area
    - Population Health through involvement with the Fairfield Immunisation Taskforce and,

  - Developmental Paediatrics to be addressed through the Child Health Medical Officer's role.
- The paediatric ward to maintain it's current bed numbers and staffing profile.

2.7 DEVELOPMENT OF THE PAEDIATRIC OUTREACH SERVICE IN SOUTH WESTERN SYDNEY

SWSAHS is a leader in developing paediatric ambulatory/ nursing outreach services for children in NSW. Fairfield paediatric Outreach Service was established in 1997, with other services established in 2001 at Liverpool, Macarthur, and Bowral. (SWSAHS Division of Health Service Planning Report 01/04 2004:4.3). The next section of the thesis will describe the development and scope of the home-based nursing service, now known as POS (Paediatric Outreach Service).

2. 7. 1 WHAT WAS THE PAEDIATRIC OUTREACH SERVICE?

In February 1998, FHS began the final preparations to make the vision, held by many health professionals and planners within SWSAHS, become a reality. This vision was realised in the development of the service now called the Paediatric Outreach Service (POS, for short). During the final planning, from February to May 1998, the service model underwent many changes, as ideas became practice and procedure. Discussions were centred on how best to meet the needs of the children and their families in the Local Government Area (LGA).

POS was an initiative undertaken by SWSAHS aimed to improve and/or maintain the health of children within the local, defined geographic region. POS commenced in February 1998 and began accepting referrals in May. The challenge for POS was to operate alongside and integrate with the existing community health services. Fairfield already had approximately forty-five generalist Primary Health (community) Nurses (PHN's). These nurses delivered care to all clients from birth to death across the age and health spectrum. POS was expected to provide clinical paediatric expertise and support for the Primary Health Nurses, and sometimes the Allied Health Staff (including Occupational Therapy, Physiotherapy, Social Work), to provide clinical care and support for children and their families. In addition, it was anticipated that POS staff would carry a clinical caseload.

After several months of operation, this consultative service model gave way to a specialist paediatric home-based nursing service when it was determined that the generalist nurses could not meet the families' needs in the same way as the paediatric nurses reflected in several parents' request to have one of the paediatric nurses visit in preference to a generalist nurse; and on several occasions, the generalist nurses handing on care of the child to one of the POS team.

2.7.2 WHERE DOES THE PAEDIATRIC OUTREACH SERVICE FIT INTO FAIRFIELD HEALTH SERVICE?

The aim for POS was described as the ability to provide home-based nursing care and support to parent/carers to allow them to provide care for a sick child in the security of their own home whenever the illness allowed as detailed in the Operational Plan (1998) (see Appendix 12). It was determined that this would be achieved through working with parent's to develop a nursing plan of care based on the medical care plan provided by the child's doctor. It was expected that POS would provide the needed linkage between home, the paediatric inpatient unit and the Emergency Department. Provision of a service to deliver home-based care for children was designed to allow the child to avoid a period of hospitalisation where possible or to shorten the duration of their hospital stay and to reduce the frequency of readmission/ repeat presentations to the Emergency Department. (SWSAHS Division of Health Service Planning Report 01/04 2004).

POS would provide care only for children living in the LGA (as defined in Chapter 2, section 2.3). The service guidelines stated that care would be provided for children aged 0-14 years. Over time, this inclusion parameter, defined by age, was modified to include all children of comprehensive school age (ie up to 18 years) as long as they were still at school. The children needed a medical officer (either a Paediatrician or a general practitioner) to oversee their care who was willing to provide a medical plan of care.

Inclusion criteria for referral to the service were not absolute. Primarily, this was because POS staff did not know what type of cares should or could be provided in the community and the nursing staff did not want to inhibit development of the service by starting out with very strict referral criteria. This was to become a real strength of the service in meeting local consumer needs. POS nurses encouraged referring agents to call and discuss potential referrals on a case-by-case basis. Over time, the types of conditions amenable to home-based nursing care became clearer and the POS nurses found it possible to offer a wide range of nursing care and support to families managing their sick child at home.

2. 8 REFLECTION

This chapter has described the historical and government processes and influences that finally led to the development of the home-based paediatric nursing service called POS, in SWSAHS during 1998-1999. Despite the planning that went into the development of POS, no plans for service evaluation were included in the planning process.

The service was a very new idea as a paediatric service model for NSW Health and therefore new within the Local Government Area. Consequently, no one really knew how the local community would react.

Further, no one knew what the customers' expectations would be. In order to understand these issues, POS service providers needed to be open to feedback from consumers. However, there were no existing mechanisms through which this process could occur.

By 1999, the service was in place and questions were being asked (by NSW Health and other Health services interested in possibly developing a similar service) about outcomes (both process and patient oriented). For the first time there was a recognition of the deficits related to planning for evaluation in the initial planning processes.

This chapter has "set the scene" against which the rest of the thesis unfolds. The actual service delivery executed by POS provided the "domain" for the evaluation process. In subsequent chapters, the process of evaluation will be described and analyzed. The findings of the study will be presented and discussed and recommendations will be made concerning possible nursing research studies to be undertaken in the future.

CHAPTER

THREE

CHAPTER THREE – LITERATURE REVIEW

3.1 INTRODUCTION

This chapter will synthesize the available literature on home-based nursing service models, including their advantages, safety, target populations, driving forces, and measures of success. It will then explore the literature related to customer satisfaction and service evaluation.

3.2 THE LITERATURE REVIEW PROCESS

Published literature was sought using the Clinical Information Access Program (CIAP). The databases for CINAHL and Journals @ Ovid were searched. Trigger terms that were used included “outreach”, “community nursing”, “hospital in the home”, “pediatrics”, “paediatrics”, “evaluation”, “service evaluation”, “nursing”, “children”, “home nursing” (see Apppendix 10). This search yielded many articles for review by the researcher. Attempts to elicit unpublished literature were made by posting a request on the HITH (Hospital in the Home) Line. This process was unsuccessful in obtaining any data. Searching the databases was augmented with hand-searches of current journal issues and old Area Health Service documentation.

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3.3 DESCRIPTION OF HOME-BASED PAEDIATRIC NURSING SERVICES

> ***"If you take a sick child away from its parents,***
> ***you break its heart immediately"***
> (Armstrong, 1767).

This quote, although over two hundred years old, is really no less pertinent in the twenty first century, as it was when it was spoken. Dr Armstrong strongly advocated against hospital admission for children, believing not only did they suffer an extraordinary sense of loss but also that hospital avoidance would lead to less cross infection amongst children. It can be argued that these assertions hold as true for today's children. The Guidelines for the Hospitalisation of Children (1998) developed by NSW Health, reflect this philosophy and state *"children should only be admitted to hospital when absolutely necessary"* (p5).

However, there are times when hospitalisation is not only necessary but also the most appropriate course of action for a child's illness. For example, it would be unreasonable to expect parents to care for a child at home on hourly bronchodilator nebulisers or to undertake neurological observations following a significant head injury.

There is a substantial body of literature that asserts that children should be cared for at home if the illness permits and that hospital care should only be sought if the care required cannot be equally well provided at home (Platt, 1959; NSW Dept of Health, 1998; Curtis Report, 1946;

Knoweldon, J., Westlake, L., Wright, K.G., & Clarke, S.J., 1991; Gow & Campbell, 1996; UK Dept of Health, 1991; Lenihan, 1993 , Dryden, 1986; Fradd, 1994; Ewart and Barnes, 1999).

This section of the literature review will explore issues related to the provision of home-based paediatric nursing care. Information pertaining to paediatrics and home-care were sought.

3.3.1 INTERNATIONAL DEVELOPMENT AND TRENDS IN HOME-BASED NURSING

Even though “the nursing of sick children in the community is being increasingly recognised as a more appropriate option for the child, their family and other carers” (Neill & Muir, 1997:7), the growth of such services to cater to this need has been slow. Describing the growth of services in the United Kingdom, Fradd (1994) also reported that service development designed specifically to meet the needs of children has been slow.

Bradley (1997), pointed out that even though the notion of providing paediatric community nursing services was proposed forty years ago by Platt in 1959, such service provision was rare until recently, necessitating that children spend unnecessary and “potentially traumatic” time in hospital.

In the United States, there are a number of services that have developed to meet the health care needs of children in their own homes. In many cases, these services have been developed as imperatives of the Health Insurance Companies as, in many cases, it is less expensive to deliver the care at home (Information presented at International Homecare Conference, Seoul, 1998).

Also at the International Homecare Conference in Seoul (1998) presenters from countries such as Japan and Thailand described home based services in their countries. In Japan, services are provided as a pay-for-use service and related to their large population and limited inpatient hospital services. In Thailand, their home-based services seemed reminiscent of healthcare in developed countries decades ago. In Thailand, a developing country, home-based nursing services are related to the extremely limited inpatient services, and also to the dispersed population who often live great distances from existing inpatient services. Neither Japan nor Thailand seemed to have dedicated paediatric services, but rather delivered care to children under a generalist model.

3.2.3 NATIONAL DEVELOPMENT AND TRENDS IN HOME-BASED NURSING

A dearth of literature related to the Australian experience was identified during the conduct of the literature review. However, by contacting paediatric specialist nurses at various centres around Australia, the researcher established that a pattern of slow growth in community paediatric services in the Australian system mirrored the pattern described in the United Kingdom and United States above (personal communications).

After it’s establishment, POS became a demonstration service in that many other service providers considering developing an outreach service asked to come and spend time with POS staff to see how the service operated and view supporting paperwork. Such services included the Liverpool and Macarthur services of SWSAHS, as well as staff from John Hunter Hospital, Blacktown/Mt Druitt Hospital in Western Sydney Area Health Service, Blue Mountains District Anzac Memorial Hospital in Wentworth Area Health Service; Barwon Health in Victoria. Most of these services now have a dedicated paediatric outreach service.

The concept of the ill being cared for at home is not a new one: historically, hospital based care was only for the elite. The development of formalised paediatric nursing outreach service models in Australia is a relatively new initiative. There have been many home-based nursing services identified throughout the State of NSW, and more broadly across Australia, which do provide for the needs of paediatric patients. However, only a handful have been identified that cater specifically and ONLY for paediatric patients. Even within this group, there are differences in the foci of care delivered.

The outreach services provided by both of the tertiary paediatric hospitals in metropolitan Sydney cater for the needs of sick children with specific health needs such as cystic fibrosis, cardiac, oncology, or diabetes. Services that meet the needs of children with general medical or surgical needs are really just coming in to prominence as a service delivery model, and POS was influential in their development (Greater Western Child Health Network Minutes, 2002). Two of the paediatric tertiary hospitals in New South Wales have moved to develop an outreach service to address the needs of children with general medical or surgical needs (as well as specialist outreach services) and both have used the experiences of POS in their planning processes.

At a national level, there are a number of services that have been developed to deliver home-based paediatric nursing care. Phone consultation and networking at conferences by the researcher has revealed that these have grown in response to patient needs as well as in response to changing health care systems (Personal Communications).

3.4 WHAT'S IN A NAME?

In Australia, the name given to services providing home-based nursing care to children varies. Diverse names include “hospital-in-the-home”, “outreach”, “inreach”, “homecare”, “hospital-at-home” and “homeward bound”. Often the name of the service indicates the philosophy of the service. For example, a hospital-based service might provide “hospital-in-the-home" care whereby the number of days the patient is seen is included in the hospital length of stay statistics (e.g The Royal Melbourne Children's Hospital)(Personal communication with HITH Service Staff, 2000).

Hospital-in-the-home (HITH) programs have been defined as *"the provision of acute home services for patients who would otherwise require inpatient care for their medical or social condition"* (Montalto, 1998:277). Sheppard & Iliffe (2001:2) add several more criteria when they define HITH as *"a service that provides active treatment, by health care professionals, in the patients home for a condition that otherwise would require acute hospital in-patient care, always for a limited period".*

POS, the service described in this study, is an *outreach service*, that is, it reaches out from a community-health setting into the child's community to provide care at home (or in a nominated dwelling within the region serviced). POS was eclectic in it's approach to care provision and provided support and care for chronically ill children, in addition to acutely unwell children. The aim was to assist parents to keep their children at home when possible. This was a unique feature of the service. A similar service provided at Middlemore in New Zealand divided their service into two with one team to meet the acute care needs of children and another to meet the needs of children with chronic and complex problems (Personal Communication, 2001). When Campbelltown Health Service (also in SWSAHS) looked to develop their ambulatory care services in 2002, they originally planned to offer an acute-care substitution of inpatient hospitalisation. What became apparent early in their planning was the fact that there were many children with chronic and complex conditions for whom there was no appropriate service provider. Campbelltown Staff made a decision to extend the scope of their service and, like POS, offered an acute and non-acute service. This responsiveness was in relation to the community's needs.

Some home-based paediatric services were developed to meet the specific needs of a particular patient group e.g cystic fibrosis, oncology, or neonatal follow-up. Other home-based paediatric services were more generic and met the needs of patients with a broad range of clinical conditions. Services described as generic may be defined by the geographical area they serve (Hughes & Gordon, 1993). The service under study meets the criteria of the latter definition, providing a generic service to a geographical region (as defined in Chapter One). As such, it had never been evaluated prior to this study and so it was unknown whether the service model met the needs of the consumers it served.

3.5 WHO SHOULD RECEIVE HOME-BASED PAEDIATRIC NURSING CARE?

It is considered that there are many conditions for which children are admitted to hospital but who could be managed at home. "Conditions for which hospitalization can be largely prevented with consistent, available ambulatory care and adherence to treatment/self-care protocols” are defined as ambulatory sensitive conditions (Virginia Hospital Healthcare Association, 2004). The Office of Statewide Health Planning and Development (www.oshpd.cahwnet.gov/HQAD/HIRC/patient/discharges/Pivots/ACSC 6/8/2004) go further in their description of ambulatory care sensitive conditions and described them as:

> *“conditions for which timely and effective outpatient care can help to reduce the risks of hospitalization by either preventing the onset of an illness or condition, controlling an acute episodic illness or condition, or managing a chronic disease or illness”.*

Terminally ill children, who are no longer being treated actively, can be managed at home in their palliation if this is desired by the parents (Dryden, 1986). Lenihan (1993) lists the most common reasons for referral for the service in Jersey USA as dressing change, cast care, intravenous antibiotics and diabetic education. Hughes (1999:59) lists the following patient groups as being appropriate to receive care at home. These include children with:

- respiratory, renal or cardiac problems
- multiple handicaps
- cancer
- blood disorders
- intestinal or skin problems
- oxygen therapy, and

- children needing intravenous therapy

Jester & Turner (1998) developed a similar list and added post surgical patients who were eligible for early discharge along with those requiring intravenous medications, and diabetics.

There are a range of conditions that fall into the category of ambulatory sensitive conditions including asthma, hypertension, diabetes, psychoses or extreme prematurity (Virginia Hospital Healthcare Association, 2004). Of these, asthma is the most commonly seen in the paediatric population. Other conditions include *"anaemia, iron deficiency; cellulitis; congestive heart failure; dehydration; ear, nose and throat infections; failure to thrive; gastroenteritis; nutritional deficiencies; pneumonia and urinary tract infection"* (Los Angeles County Department of Health Services, 2000:2).

Management of patients with these conditions and avoidance of hospitalization may be used as an index of service success. The difficulty with actually using these conditions to determine service success is that it is sometimes really difficult to say that hospitalization has absolutely been avoided, particularly in relation to medical conditions. It is a little easier with surgical conditions. For example, it might be difficult to assert that a child with asthma or gastroenteritis managed at home following an Emergency Department presentation has saved inpatient bed days. It is much easier to assert this for a child who presents with cellulitis, is referred to a home-based service and has their ten days of intravenous antibiotics administered at home. The debate amongst service providers within the Greater Western Child Health Network (GWCHN) was which ambulatory care sensitive conditions should be used as service indicators by the GWCHN-sponsored services (2003). The debate still has not been settled.

What the ambulatory-sensitive debate fails to take into consideration is the fact that home is the best place for children in most circumstances, regardless of the cost. In essence, the ambulatory-sensitive platform is an administrator's tool. Beyond cost implications, the provision of home-based nursing care offers children advantages, not necessarily achieved in the hospital setting.

3.6 ADVANTAGES OF HOME-BASED CARE FOR CHILDREN

There are advantages attributed to providing home-based nursing care for children. Health professionals are aware that admission to hospital can have detrimental physical, social and psychosocial effects on patients and is disruptive to a child and to their family. (Jester & Turner 1998, Sikorski, Davies & Senior 1985). Lenihan (1993) described early childhood as a time for rituals and routines, which provide the child with a sense of order and a feeling of security. Children need routines and rituals to organise their lives and in order to develop a sense of trust in their environment and carers (Erikson, 1963). If this security of ritual and routine is threatened, children will often regress to an earlier stage of development where they felt safer. This may mean that they start bed-wetting again, or have nightmares (this might lead to their being allowed to sleep with their parents again) or they may stop talking. All these are manifestations of the child's level of anxiety (Lenihan 1993).

Enabling the child to be cared for in their own home helps to maintain their sense of security (Lenihan, 1999) for *"family is an important resource for the child"* (Thompson, 1995:394). Providing necessary nursing care to the child in their own home environment, within their familiar surrounds and with their usual carers allows paediatric nurses to work around the child's usual rituals and routines as much as possible; thus avoiding the detrimental effects of disruption. For example, when outreach nursing staff attend a toddler needing a wound dressing, the staff may need to negotiate with the parent or carer to do this dressing at a time that will fit around the child's routine, e.g., before their day time nap, or just after their day time nap or before dinner - to enable the family to suffer the least disruption to their lives, despite the intrusion of nursing staff to provide necessary care.

Fradd (1994) identified a significantly improved life expectancy and a reduction in the incidence of hospital acquired infection, for children with a chronic or life-threatening illness, when care is provided at home. Marks (1991) and White (1991) also reported a possible reduction in the incidence of hospital-acquired infections for patients receiving home-care as an advantage of such care. They attributed this to the fact that the patient is exposed to fewer health-care professionals as well as less exposure to other patients. Again, provision of home-based nursing care removed the children from risk factors that they may be exposed to in the hospital setting.

There are also advantages in providing home-based care that are not directly related to the patient. Waterlow (1999) explained that outreach services "*bring services to the family rather than requiring the family to come to the service providers.* " He cited a number of benefits including "*enabling nurses access to families who might otherwise disengage*" and "*the home visit does mitigate transport and perhaps child care costs [for siblings] thus [removing] what are often barriers to service access.* "(p1)

3.7 WHAT DROVE THE DEVELOPMENT OF THE PAEDIATRIC NURSING OUTREACH SERVICES?

There were four key forces that drove the development of the outreach services. These included parent-in partnership programs, the safety of care provided, the standard of care provided, and diagnostic-related illness groupings. These will each be discussed in turn.

3.8 PARENTS-IN-PARTNERSHIP

> *"All the results of good nursing… may be spoiled or utterly negated by one defect, viz. : petty management, or in other words, by not*

> *knowing how to manage so that what you do when you are there is done when you are not"*
>
> (Nightingale 1969)

Parents-in partnership (PIP) is one way that nurses ensure that the care they give whilst there with the sick child continues when they are absent from the home.

"The philosophy of a partnership between a parent and a nurse is widely accepted in paediatric care settings and this practice is increasing in paediatric community services" (Hughes, 1993:36). PIP is one practical application of family-centered care, and recognises all carers as equals in the provision of the care. In PIP, each party has a role to play in returning the child to their optimal level of health and back to their usual life. Underpinned by the principles of PIP, POS nurses gave parents credit for their parenting skills and fostered the nurturing relationships within a family. POS nurses found that in the community setting, perhaps more so than in a hospital, nurses could use the strengths of the family to their best advantage in the provision of care. It was paramount that parents felt valued in their role as partners. If parents did not feel equal in the care-relationship, it may have resulted in them not complying with care regimes or even actively seeking to sabotage care plans (Lenihan 1993) which would have rendered a home-based program of nursing care useless.

In order that children could be cared for at home by their parents and/or significant others, it was imperative that visiting home-nurses developed a rapport with parents at the first visit. The first home visit was where nurses needed to teach parents what care was required and how to perform that care or how to monitor their child's condition.

When providing home-based care, paediatric nurses must also be mindful of the *"potential coercion of parents to take on responsibilities"* (Charles-Edward & Casey 1992:16). In order for home-based care of children to be successful, parents needed to be comfortable in the extended role that was required of them (ie as supporter of their child's health care needs as well as their parental role). Extreme parental anxiety or feelings of threat could either lead to the child being presented at hospital or the parent disengaging from the plan of care so that the child was unmonitored at home. Neither of these were desirable outcomes for the patients who care was being managed by the POS nurses.

As the POS nurses discussed the plan of care with parents, they needed to be open to the cues (verbal or non-verbal) given by parents/carers that indicated their needs (i.e what they felt able to do), and incorporate these into the care plan. This is the process of PIP in practice. For example, the parents of a child requiring dressings following a burn injury may have been happy to give their child's pre-procedure pain relief and able to tolerate no further involvement; or they may have done this and remained present to provide moral support throughout the procedure. Others may have wanted to be involved in the whole procedure including the bath and dressings. Interestingly, parents may move along this continuum of involvement, altering their role in the process, sometimes on a daily basis.

As recommended by Nightingale, and in order for children to be cared for at home, visiting nurses must know how to manage parents (teach, reassure, assess, empower) so that care can continue in their absence. It is considered that nurses must be able to elicit a commitment from parents to continue care/monitoring of the child in their absence. Without this type of assurance, there is *no* alternative but to hospitalize the sick child.

In New South Wales, there are several forces that influenced and drove the development of paediatric outreach services. The belief that it is better for children to be nursed in their own homes is perhaps the strongest moral argument influencing the development of a service to provide care for sick children in their homes. It is not right to expect families to travel, sometimes great distances, *"if the safest, most appropriate paediatric health care [can be provided] as close as possible to the home of a family"* (Nossar, 1999). Indeed, in many instances, it is possible to provide most, if not all, of the required care within the family home. If children are spared the emotional trauma associated with being separated from their family through hospitalisation, then this is the moral justification supporting the development of such a service.

3.9 STANDARD OF CARE AT HOME

When home-based nursing care is offered as an alternative to hospital-based care, then the standard of care offered must be comparable. *"Children being cared for at home have the same rights to good care as those in hospital"* (Hughes, 1999:58). Box (1993) and Jester & Turner (1998) also asserted that care must be provided at a quality equal to that received in hospital. If parents are to choose the environment in which their child recovers from their illness, then they need to know that they are choosing the place that care is provided, not the type or the quality of care provided. Waterlow (1999:2) maintained that *"the standard of care must be patently obvious to parents…[they] need to feel that in accepting the offer of outreach they made the best of all choices for their family".*

There are three major issues that are incorporated in 'standard of care' that need to be considered in the context of home-based nursing care. These issues are the effectiveness of the home-based care, the safety of home-based nursing care services and the type of staff best able to provide quality home-based nursing care services. These will each be examined in turn.

3.10 THE EFFECTIVENESS OF HOME-BASED NURSING CARE SERVICES

Sheppard & Illife (2001:1) in conjunction with the Cochrane Collaboration undertook a systematic review of the literature to *"determine the effectiveness of managing patients in hospital-at-home compared with in-patient hospital care".* This systematic review based on the best possible evidence available did not include any studies pertaining to paediatric home-care services and the researchers recommended that a separate search be undertaken for several specialty groups, of which paediatrics was one such group.

However, the findings of this systematic review in relation to adult-based services, revealed that there were no statistically significant differences detected for patient health outcomes between those receiving home-based care, compared with hospital in patient care (2001). Due to the small number of randomised control trials that were eligible for inclusion in this review (n=5), further research needs to be conducted to establish the effectiveness of home-based nursing care particularly in areas such as paediatrics. Consequently, the need to undertake the current study was identified by the researcher who aimed to close the gap in contemporary paediatric nursing knowledge.

3.11 SAFETY OF HOME-BASED NURSING CARE SERVICES

There is a body of literature dedicated to the issue of safety regarding hospital-in-the- home services. Montalto (1998) contended that this issue remains the subject of debate regarding the provision of home-based nursing care for children. In order that home-based nursing care can be promoted, it must be able to be defined as a ‘safe’ alternative to inpatient care.

One reason home-based care may be considered as a less-safe alternative is “because of the reduction in supervision” (Montalto 1998:277). Supervision in this context relates to the provision of expert observation provided to hospital in-patients which can occur at any time throughout the day (due to the proximity of the patient to nursing staff within the ward). Nurses who provide home-based nursing care attend to the needs of the child and their family for only a “snapshot” of a day. For the rest of the time the parents provide for their children’s health-care needs. This level of supervision is thereby reduced from twenty four hours (by comparison with inpatient care) to minutes or perhaps hours of a day for home-based care provided by a health care professional.

However, many parents are excellent monitors of their child’s condition and very proficient in the provision of care required to facilitate their child’s recovery. Sainsbury, CPQ., Gray, O.P., Cleary, J., Davies, M.M., & Rowlandson P.H., (1986) believed that the idea of paediatric home-care nursing services would become more of a reality, and accepted more readily as health care professionals realised that parents are fully capable of meeting their sick child's needs. In fact, in some cases they will actually be better placed to describe symptoms, provide high level and accurate monitoring and deliver the health care required to meet the needs of their child. Thus, with adequate education and explanation there did not need to be a reduction in the level of supervision, when a child is effectively cared for at home.

Montalto's Australian study (1998) of a hospital-in-the-home unit in Tasmania, investigated the safety of patients admitted to the hospital-in-the-home unit as opposed to being hospitalized. There were several indicators of safety investigated including *"phone-calls to the on-call service, un-scheduled staff call-outs to patient's homes, return to hospital during a hospital-in-the-home admission and return to hospital after discharge"* (1998:278). Montalto's conclusion from the study was that "hospital-in-the-home care is very safe" (p277). In addition, Montalto indicated that *"[this] study may help to define safety standards for hospital-in-the-home care so that future studies can compare them with those of traditional inpatient care"* (1998:277). This study considered dimensions of the patient's physical safety. What is harder to measure but possibly equally as important to consider for the welfare of the child is their psychological safety. This relates back to the moral imperative discussed earlier in this chapter.

Where the family is able to meet the needs of the child and where their physical condition allows it, management of their health needs in their own surroundings and by familiar carers will promote psychological safety as well as physical safety. This study aims to gain understanding of parental perceptions related to the delivery of home-based care to further close the knowledge gap in paediatric nursing.

The safety of home-based nursing-care can also be linked to outcomes through the measurement of the service by pre-determined indicators. This will be discussed in detail in Chapter 4.

3.12 WHO SHOULD PROVIDE PAEDIATRIC HOME-BASED NURSING CARE

The issue of who should provide paediatric home-based nursing care has not been addressed satisfactorily. As far back as 1994 (p34), Fradd reported that, *"to date, no standard team model has yet emerged for others to emulate".* This was another way to raise the question of whether specialist nurses or generalist nurses should staff paediatric outreach services.

In Australia, the most commonly occurring paediatric community nursing care service is provided by specialist nurses, working at tertiary paediatric hospitals, who provide community liaison services to sick children in the community (Personal Communication with Service Providers). In most instances a Clinical Nurse Specialist or a Clinical Nurse Consultant provides the service in a specific, sub-specialty area of paediatric nursing.

In the community, generalist nurses working within established community nursing teams usually accept paediatric referrals as part of their caseload, along with adult, palliative care and early childhood clients. This is consistent with the generalist role of the community health nurse. In this case, the care is sometimes provided to children by nurses without specific paediatric knowledge and experience, but rather from a generalist approach.

In yet other services, nurses may be organised by strands so that they provide care to a specialised group of clients, for example in an early childhood and parenting strand, where “strand” refers to the specialty activities of groups of community nurses within the broader nursing team. Despite stranding, specialized paediatric skills and knowledge may be absent.

In the United Kingdom, Neill & Muir (1997:7) stated that the United Kingdom Central Council of 1994 clearly communicated that *“the care of sick children in the community should be the province of community children’s nurses, and not held to be within the remit of other community nurses. ”* This was also the belief of the researcher when designing this study and another indication to undertake this study.

Children are not small adults and shouldn't be treated as such. Paediatrics is a specialty within nursing. The Australian Confederation of Paediatric and Child Health Nurses (ACPCHN) (the peak nursing body for paediatric and child health nurses in Australia) has identified a number of criteria for a competent paediatric nurse (2002, see appendix 11). This is an important issue because there is clear acknowledgment that nurses caring for children require specific skills to do so.

The professional association that provides support to nurses engaged in the provision of care to children (both well and sick) describe in detail the skills and knowledge required by paediatric and child health nurses for the execution of their role. This philosophy has been endorsed by the New South Wales Health Department who have used the ACPCHN criteria to describe the educational requirements of staff providing paediatric care. The New South Wales Department of Health has determined that, the nursing staff involved in the care of children should have special training to recognise and treat their special health, psychological and developmental needs. (DOH Guidelines for the Hospitalisation of Children, 1998).

Further, they maintained that under a hub and spoke model of care where hospitals have an area role in providing paediatric support to other smaller units, there should be at least one registered nurse per shift with skills consistent with a competent paediatric nurse delivering care or directly supervising the nursing care of children (1998). Again, this is important because of the recognition that the care of children does require specialist nursing skills and expertise.

These are extremely important supporting documents for paediatric nurses to use when arguing for the staffing profile when developing a paediatric outreach service. Where an outreach service model espouses equity with it's hospital counterpart, and promotes safety and child-friendliness, then expert and experienced nursing staff are paramount.

Hughes' (1993) article described meeting the needs of children with cystic fibrosis in the Netherlands, through a community paediatric nursing program. Previously, the primary health-care team provided care for this group of children. This changed over time because, *"as the children's needs have become more acute and a more interventionist approach [was] required, more [children] are now being cared for by Paediatric Community Nurses"* (1993:36). Hughes considered this group of nurses as *"unique in possessing both the knowledge and experience to manage, co-ordinate and deliver care to children in the community setting"* (Hughes 1999:59). One aspect this study aimed to uncover the importance of specialist nurses in the provision of care to the service consumers.

According to Brocklehurst (1996:7*) "many GP's and adult community nurses freely admit that they do not have the skills to care for sick children at home".* Lenihan (1993:6) added, *"a paediatric referral often evokes* *feelings of anxiety, insecurity and inadequacy in some nurses who consider themselves ill- equipped to handle a paediatric patient".*

Beliefs, such as these, open the door to the possibilities of the development of community paediatric care models whereby specialist paediatric nurses provide clinical support and education to adult/generalist nurses and/or GP's in the management of paediatric illness in the community. Hughes (1993) also considered that paediatric nurses should share their skills, knowledge and expertise with their colleagues in the community. It is argued that this should be a "two-way street" of sharing because paediatric nurses can learn from their colleagues about issues particular to community nursing. Mutual sharing of expertise can help to reduce or even remove communication barriers, thus leading to a better health care continuum.

A dichotomy of views exists concerning whether specialist or generalist nurses should be the care providers. Dryden (1986:25) reported the findings of the 1976 Court Report on Child Health which recommended that *"children should be looked after by nurses with special training in identifying and meeting their needs as well as those of their families".* However, Dryden also reports that *"paediatric nurses are concerned that this specialist care is not available in the community"* (1986:25).

It is possible that these concerns promote a model of community care that includes nurses who are paediatric specialists, because *"the specialist* *nurse acts as the front line care giver for profoundly sick children and also as an adviser or resource for other community based nurses "* Fradd (1994:35). As more children with more complex needs are being cared for at home rather than in hospital, the debate regarding the best nurse to provide such care needs to be reopened.

3.13 REQUIREMENTS FOR A SUCCESSFUL PAEDIATRIC OUTREACH NURSING SERVICE

If a service is developed but does not meet the needs of the population it was designed to serve, then a problem with service provision occurs and consequently a problem with service success. There are several issues embedded in service provision which will no doubt influence the service success.

Individuals in the community need to understand what can and cannot be provided by the paediatric services. The establishment of boundaries (Jester & Turner, 1991) that define the shape of the service help to differentiate the paediatric home-based nursing service from other services in the community (such as primary health nurses, child health nurses or GP's). Whilst this opinion is over a decade old, it remains true and consumers do need to know what a service provides. Further, in order to avoid service duplication, which in turn leads to increasing waiting lists and unnecessary expenditure, defining service boundaries is essential.

A key issue related to success is that of service availability. When parents agree to care for their children at home, a nursing service must be available to meet their needs (Bradley, 1997). Stein & Jessop (1984) add that in delivering nursing care, it needs to be organized and designed to address the issues that are of concern to families and children (that is, family-centered rather than nurse-centered).

Families are usually a part of several systems and may have commitments to several of these simultaneously such as extended family, nuclear family, school community, work place, sporting teams and church community. Outreach nurses need to be mindful of this fact and also that parents will often have commitments to more than just a sick child. To this end, nurses home visits need to be scheduled around family commitments whenever possible and practical. This is undertaken in an attempt to re-focus the family from an illness model to that of normality, where the family is able to maintain the child’s rituals and routines as close to normal as possible.

Paediatric outreach services vary in the number of hours they offer outreach support to children with some offering as much as twenty four hour coverage (Jester & Turner, 1998; Smith, 1986) whilst others provide a daytime service with after hours and weekend visits provided on a needs basis (Bradley 1997; Eaton, 2001). The study service provided coverage twelve hours a day on weekdays and between four and eight hours of cover on the weekend and public holidays. The option of providing twenty-four hour cover presented staff security risks for staff that could not be eliminated and so, was not offered. However, until the present study, the appropriateness and acceptability of the operating hours had not been evaluated.

No less important was the issue of communication between service providers. When other health care providers fail to understand what a service purports to offer, then they are less likely to utilize the service. This could lead to the extinction of the service. Marketing and advertising availability of the team and what they do may overcome issues associated with a lack of awareness (Bradley 1997).

Gow & Campbell (1996:366) stated that for a service *"to be effective it is essential that GP's are aware of and understand the service...there does need to be improved communication & liaison between GP's and paediatric community nurses"*. However Hughes (1993:37) found that *"increased communication with GP's has not increased the number of referrals… [possibly] because doctors do not realise what [can be provided] in terms of nursing support".* With regard to the issue of communication, two separate studies undertaken by White (1991) and Jennings (1994) found a lack of knowledge concerning community nursing services and a lack of understanding of the service function. A lack of integration and understanding by all health care providers could lead to disruptions in the continuum of care and may lead to reduced quality patient outcomes. Consequently this study aimed to determine the effectiveness of communication strategies with the GP's and other referring agents, and to determine if the service offered by POS met their needs.

"Communication failures and feedback failures massively erode the confidence of all involved" (Waterlow, 1999). Communication between health care providers needs to be timely in order that decisions related to changes in care are informed by current practice, leading to maintenance of the care continuum. With regard to this issue, Neill & Muir (1997) cite a comment from the Paediatric Community Nurse's Forum (1994) where it was stated that; *"the establishment of appropriate and fast communication channels between hospital and GP/health visitors…should enable better co-ordination of support [to the patients]".*

3.14 MEASURING CUSTOMER SATISFACTION

Customer satisfaction can be described as one index measure of service effectiveness. When a service does not meet the needs of the customers for which it was designed and developed, then it has failed to achieve an intrinsic function of the service. When customers are not satisfied with the service delivered, then it is likely that they will not seek the use of that service again. This will ultimately lead to the demise of the service. POS, having been opened in 1998, but having not measured it's consumer satisfaction, it was considered highly appropriate for the current study to meet this service need.

When a service is established, service operators need to meet the expectations of several, possibly many, stakeholders such as administrators, referrers, patients and families. There are economic expectations, management expectations, and consumer expectations. The difficulty is that it is rarely possible to meet all of the stakeholders needs and expectations simultaneously. The art for service providers is to identify the needs and expectations shared across stakeholder groups. Two sets of the groups of POS stakeholders were the focus of this study, those being the referring agents and the families, the aim being to determine what aspects of service provision were important to be continued, and the aspects seen as less favorable that could be considered for change.

There can be various customers of a single service. In the case of a community nursing service, customers can be those that refer to the community nursing service, agents who rely on the community nursing service to meet the needs of their clients. The second group of consumers are those for whom the community nursing service provides care and support that is, those that rely on the community nurses to have their needs met.

Ervin, Wallcott-McQuigg, Chen & Upshaw (1992) assert that the relationship between the care provider and the client help to determine client outcomes. In fact, they cited a central tenant as being the patients perceptions of those interactions. This means that it is the customer's opinion about the interactions with the health care provider that impacts upon their perception of the care received. In this situation, the patient is the customer. Ervin et. al. (1992) concluded that if the customer and care provider's perceptions about a situation are incongruent, there will be a negative effect on the client's satisfaction.

This in turn may lead to negative effects on client compliance and problem resolution. The opposite must then also be so. If a customer's perceptions are the same as those of the service provider, then the customer satisfaction levels should increase. However, at the time of undertaking the study, there was no evidence to indicate whether POS care provision and customer expectations were congruent.

When the purpose of a service is to effect quality patient care, then customers of the service should be asked about their perceptions. Obtaining customer perceptions is rarely enough. Their perceptions should then be used as a " factor in assessing the quality of the healthcare" (Ervin et al 1992)

As long ago as 1988, Donabedian, an evaluation expert, described client satisfaction as an integral component of the measurement of service satisfaction. Donabedian believed that the customer was the authority on what they expected of the service they accessed and therefore best place to determine if the service "measured up" to meet their needs.

This supports Ervin et al.'s (1992) assertions. They maintained that by seeking customer feedback about services provided, service providers are assisted in their endeavours to ensure that they are continuing to meet their customers needs. Data obtained through such feedback can also inform quality improvement endeavours. During 1998-1999 POS delivered the service planned without any understanding of customer opinion. There were no quality indicators in place to measure aspects of service delivery at the time this study was undertaken. One study objective was to develop indicators to measure service delivery against pre-determined and agreed benchmarks. The literature exploring indicators commences in section 3.5 (p61).

As healthcare providers have become more oriented towards the consumer, there has been an increased focus on obtaining consumer input into service delivery reviews and the measurement of patient satisfaction has been encouraged (Avis, Bond,& Anthony 1995). Hudson (1990) believes that this idea will flourish as care providers acknowledge the need to include patients views when planning and evaluating services.

However, Avis, Bond & Arthur (1995:316) argued that *"there remains several unresolved issues relating to measurement of satisfaction*, *and some serious questions about the validity of the concept".* These authors agreed that achieving customer satisfaction through care delivery was important and necessary but that it should not be the only measure of care effectiveness.

A main method of ascertaining client feedback related to service delivery is the *"self-completion questionnaire which delivers information in a form which can be used for comparison and monitoring [which is] relatively cheap and easy to administer"* (Avis et al.,1995:317). However, these authors go on to say that these same questionnaires often report data which is difficult to interpret because the *"generally high levels of satisfaction recorded in most standard surveys…suggest that patient satisfactions has not…been operationalised as a discriminating measure ".*(p319)

A satisfaction survey asks consumers to respond to items that were predetermined and deemed significant by the service provider. This might not allow customers to raise and respond to issues that are significant to them. Survey results may not be truly reflective of customer perceptions or beliefs.

One way to address this issue is to include open-ended questions that will allow customers to describe issues that were significant to them. There is an old adage which says "you can't please all of the people all of the time". Service providers need to remember this when interpreting the results of satisfaction surveys. Consumers are individuals and as such, they have idiosyncratic expectations (Redfern and Norman, 1990). Redfern and

Norman (1990) saw failure to meet the expectations of an individual not necessarily as constituting sub-standard care, but rather as reflecting poor contracting with clients. Consequently, service providers should look at the trends in responses when evaluating their performance (Refer to Chapters Five and Six for study findings-satisfaction survey responses).

The content of a satisfaction survey should reflect the dimensions of the service that will help to define the quality of the service. Kennedy and Young (1989) described some quality dimensions that they believed applicable to many services. These included concepts related to service availability, responsiveness, convenience and timeliness. In 1990, Parasuraman, Zeithami and Berry refined the quality dimensions they had developed earlier into five categories. These were tangibles, reliability, responsiveness, assurance and empathy.

However, the dimensions being measured must be meaningful to the customer, that is, they must be relevant. There is little point in trying to measure customer satisfaction about the ease of use of equipment when the service they received did not routinely involve the use of equipment. Similarly, the wording in the survey should be highly relevant to the customer. Rather than “responsiveness” it may be more prudent to ask about how long customers had to wait for an appointment, or how easy the staff were to contact. Terminology considered meaningful to the customers experience is likely to elicit more meaningful responses from them. (Refer to Appendix Five and Seven for satisfaction surveys).

3.15 SERVICE INDICATORS

With the trend for earlier discharge from hospital, increased patient acuity, an aging population and the use of more complex technology, healthcare providers are required to provide more services to more clients within ever tightening fiscal constraints (NSW Health Re-investment Strategy, 2001). This is as true of community health as it is of hospital-based care. Weissman (1996) described the process of performance monitoring as the use of a series of tools to assess workplace practices in the pursuit of the best health outcomes.

One way health care administrators, managers and providers have developed to look at service provision is through outcome-based indicators. In essence, the purpose of indicators is to provide a method of "monitoring and comparing the outcomes of health care as a means to improving the quality of health care." (Kendrick, Cline and Finlayson, 1998). Further, these authors described the purpose of indicators as providing a way to high-light possible sub-optimal performance. Lundell and Schonstrom (2002) insisted that when developing indicators for use in community, they should include perspectives about the clinical processes, resource-learning and development and patient perspectives, such as the indicators developed as part of this study (Refer to Chapter Four) where the researcher has endeavored to reflect many of these perspectives.

Outcome measurements are not a new construct within nursing. However, it has only been in the last twenty years or so that outcome measurements have really come under scrutiny. Health managers are required to justify health-care expenditure in terms of value for money and health-care providers are asked to justify their patient-related interventions in several dimensions (Bond and Thomas, 1991; Barriball and MacKenzie, 1993; Idvall et al 1997). In contemporary health care, hospital management may require nurses to justify their care in terms of cost, patient satisfaction and/or productivity.

Measures of outcome have encouraged a change in the focus of health care. Instead of being focused on through-put, that is the number of patients passing through the service, health systems administrators and health care providers are increasingly interested in whether the care provided leads to a change in the patients health status and whether health services provided what they purported to provide.

It is recognized that there are several ways to measure the effectiveness of the provision of patient care. Some measurements seek to determine whether the system works to meet the patient's needs (performance indicators) whilst others seek to identify the degree to which the nursing care provided impacts upon the patients state of well-being (clinical indicators). A really important assertion made by Kendrick, Cline & Finlayson in relation to clinical outcome indicators is that they are *"tools to be used rather than clubs to be wielded…they are about clues and* *suggestions that there may, in certain places, be better ways of doing things".* (1998: www.show.scot.nhs.uk/indicators/publications/less.htm). As already highlighted, one of the objectives in undertaking this study was to determine indicators that would demonstrate quality measures of service delivery and performance.

3.15.1 CLINICAL INDICATORS

The literature provides a number of definitions for clinical indicator measures. The most consistent definition of a clinical indicator was that developed by the Joint Commission on Accreditation of Health Organisation in America. These are defined as:

> *" a quantitative measure that can be used as a guide to monitor and evaluate the quality of important patient care and support service activities. "* (http://www.outcomes-trust.org/bulletin/1196blltn.htm)

To differentiate, a performance indicator is defined as a: *"tool for showing if a service or programme is achieving its goal of improving health"* . Describing the purpose of performance indicators, Weissman (1996) described performance indicators as measures of capacity, resources, processes, or actual health outcomes.

With regard to indicators and outcomes (where an indicator is something used to measure an outcome), the data collected in this study sought to be meaningful to the service (clinicians) being evaluated and to the administrators and or patients. In addition to being meaningful, these indicators were designed to be measurable, interpretable and related to a primary aspect (Balding, Crowley and Cullopy;1990) of paediatric clinical care. It was considered pointless to collect unrelated data because the purpose of measuring the indicators was to measure the standard of the POS service delivery.

The study clinical indicators were *"marker[s] … used to identify (a) if the standard [was] in place; (b) if it [was] operational; and (c) if it produced required health care practice"* (Australian & New Zealand College of Mental Health Nurses Inc 1998:2). In addition, clinical indicators provide a standardised way for a health provider/manager to review the quality of health care delivered and to do this consistently over a period of time (Nadzam, 1991).

Today, services are frequently asked to question what their services achieve, to review their efficiency, and to identify where effectiveness and responsiveness can be improved. In order to answer questions like these, service providers and/or administrators may develop service indicators to collect relevant data. Broadly, there are two classifications of indicators: these can be described as *sentinel events* and *rate based*. For this study, indicators were developed to address aspects of service delivery that met the definition for each type of indicator. Development of the POS indicators will be discussed in detail in Chapter Four.

3.15.2 SENTINEL EVENT INDICATORS

A sentinel event indicator was defined by the Joint Commission of Accreditation of Healthcare Organisations (JCAHO: 2005) as an *"unexpected occurrence involving death or serious physical or psychological injury, or the risk thereof."*. Due to the undesirable nature of the outcome, identification of such an event should lead to further investigation of the situation. Ideally, sentinel events should occur infrequently. When they are recorded they should immediately alert the data analysts to the need to gather more information as to *why* or *how* the event happened. Examples of sentinel event indicators are morbidity and mortality values. Both are undesirable outcomes and the cause(s) contributing to these outcomes must be evaluated separately.

As POS was a new service, employing a new service model, all adverse patient occurrences were of interest to both clinicians and administrators, a sentinel event indicator was developed to monitor performance, and trigger investigation should it be warranted. (Refer to Chapter Four)

3.15.3 RATE BASED INDICATORS

JCAHO (1993) defines rate based indicators as the acceptable rate of an occurrence. This may be expressed as a whole number or as a ratio of the specific activity completion rate against the stated population. For example, a rate-based indicator may be used to describe the number of patients for whom a managed care plan is completed (as a proportion of the whole patient population managed by the service with a given diagnosis).

When the POS model of care was designed, there were elements of care that clinicians believed were important. It was agreed that they should be integral parts of the service delivery but there was no way of measuring that this occurred. A prime example of such an element was correspondence with the nominated medical officer. Anecdotally, POS clinicians had been advised that correspondence was something highly valued by the medical staff, both paediatric specialists and GP's. Processes were put in place in an attempt to respond to this need. At the time that this study was commenced, there were no measures in place to monitor performance against. Chapter Four will describe the development of the rate-based indicators for POS.

3.15.4 INDICATORS FOR THE COMMUNITY

Indicators to measure practice for community nurses are conspicuously absent from the New South Wales Australian Council of Health Service (ACHS) Guidelines. However, the Quality Improvement Council have addressed this issue and developed sets of service indicators to be used to measure the performance of various types of healthcare facilities that operate outside a hospital (Quality Management Systems, 1999). Whilst somewhat different to the ACHS indicators, this process of measuring a service is aligned with the former. What this meant for a new service like POS was that there were standardized measures against which the service could be benchmarked, that were specifically designed for use in the community setting, rather than contrive applicability of a document designed for in-hospital use. The researcher did not become aware of this document until after the development of POS-specific indicators, but it was interesting to note that there were a number of similarities in content between the two (Refer to Chapter Four).

3.16 THE EVALUATION PROCESS

Nield, Ecoff, Miller, Lozano, & Ward E. (1998) described evaluation as essential for service providers of any new service as it was the pre-determined evaluation criteria that would enable service providers to determine the degree to which the original service objectives had been achieved or where service improvement was required. That is, Nield et al., espoused the need for planned outcomes before the service or program was implemented so that after a determined period of time, data could be collected to assess whether these outcomes were achieved or whether they needed modification. This practice was supported by Jatulis et al (1990). However, Pearson and Theis (1991) observed that despite best practice of having pre-determined evaluative criteria, there are still many community programs that are set up with no evaluation plan initialised when the program begins.

Since 1998, health service planners and policy makers increasingly demanded evaluative data related to the efficacy and efficiency of POS in order that it's existence be continued. Pearson & Theis (1991) declared that evaluation of programs or services, whether newly developed or established for a long time, was required if service planners were to be able to ensure ongoing funding and sustainability . This was exactly the case for POS. The difficulty for POS service providers was the lack of an evaluative framework in the planning process – so they had no index against which to demonstrate their efficacy and efficiency.

Ingleton, Field & Clark (1997) high-lighted, the often competing, stakeholders. Financial planners, program staff, customers and managers all have a vested interest in the service being evaluated and each group will review the service from their own unique perspective. Even within each group there are likely to be varying views as individual's views will be influenced by their own experiences and what they expect the service to deliver for them. It is therefore important that an evaluation process defines the perspective it expects to reflect. One difficulty with programme evaluation is that in many circumstances, there are complexities in design and implementation that may not have been anticipated in the planning phase (Campbell, Fitzpatrick, Haines, Kinmonth, Sandercock, Spiegelhalter, &Tyrer 2000).

3.16.1 TYPES OF EVALUATION

Minichiello, Sullivan, Greenwood and Axford (1999:223-34) describe four types of health program evaluations. These are the:

- Needs assessment
- Process evaluation
- Impact and outcome evaluation, and
- Causal evaluation.

These types of evaluation can be performed sequentially as a service is planned and evaluated. Or they can be implemented at any time (without necessarily having worked through the sequence). In the current study, process evaluation was considered highly pertinent as the method of choice to underpin the research.

3.16.2 PROCESS EVALUATION

Process evaluation can occur any time after the implementation of a program or service. A strategy implemented in process evaluation to obtain data is the satisfaction survey. The methodology employed in the development of two client satisfaction survey tools (refer to Appendix Five and Seven) and their subsequent distribution will be described in detail in Chapter Four.

For POS, the procedure of process evaluation sought information about whether:

- all the activities of the program/service were implemented
- the program/service reached the target group
- the group was satisfied with the service
- the staff was satisfied with the service
- the service was being delivered as planned; and
- generally the quality and quantity of resources that were envisaged would be committed were actually provided (this included staff skill levels) (Minichiello et. al., 1999)

Nield et al (1998:34) asserted that in order to undertake evaluation there are three questions to address. Evaluator's should seek to answer the following:

- *Were the planned outcomes achieved?*
- *Were the users satisfied? ; and*
- *Does the delivery system need to be modified?*

These three broad questions seek to obtain similar information to the questions posed by Minichiello et. al. above.

The purpose of the evaluation process is to determine what is currently being done within or by a service and how this might be improved for service delivery in the future.

In order to evaluate a service, the opinions of and feedback from key participants should be sought (Nield et at 1998). Information may be sought using previously developed and validated tools or tools for the population and service being evaluated. Regardless of the tool used, it is true to say that the population being questioned should have an intimate and specific knowledge of the process/service being evaluated (Jack and Clark, 1998)

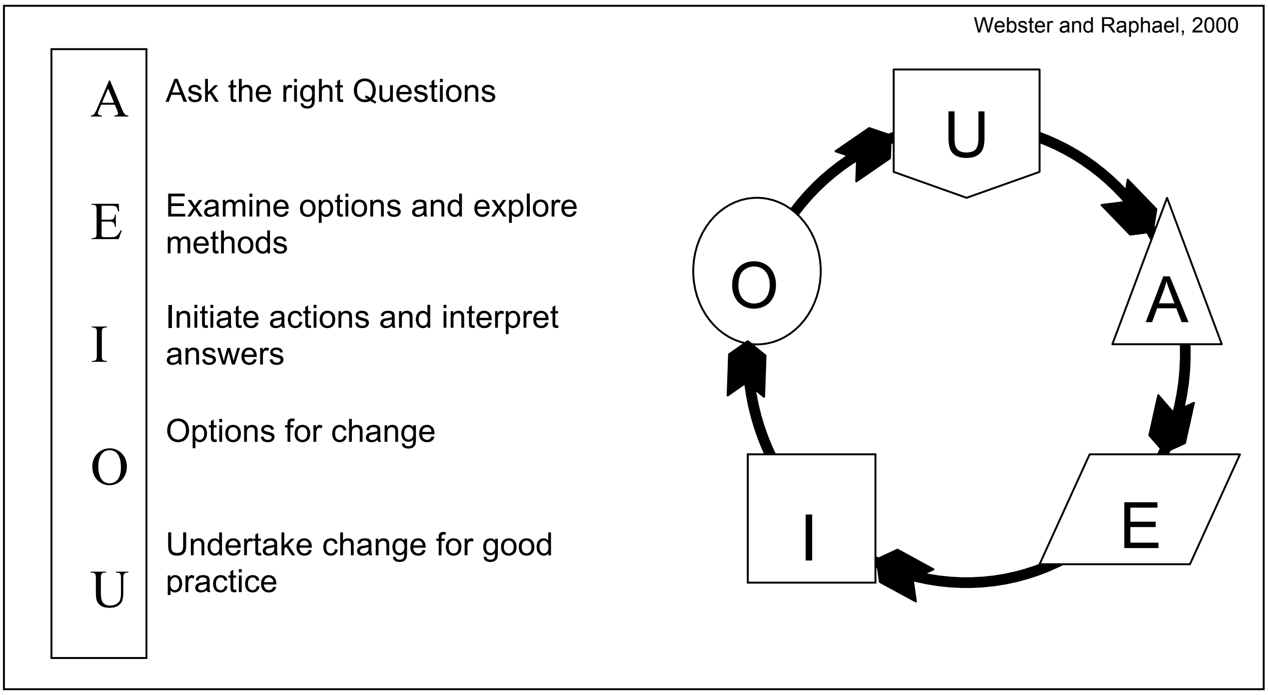


Fig 1: Webster and Raphael's AEIOU Model

Webster & Raphael (2000) describe the process of evaluation as a continuous cycle of asking questions, planning answers and then reviewing the outcomes.

They have based their discussions about the evaluation process on a model they call the "AEIOU Model" whereby each letter stands for a phase of the process (see Fig 1). This model has simplified a generally complex process into manageable tasks and Webster & Raphael describe, in detail, the steps inherent in each phase of the cyclical process.

Similar to authors already cited, Webster & Raphael also believe there are benefits to undertaking the evaluation process, and some of these are:

- [The ability to] build stronger relationships between those conducting the initiative, it's stakeholders and the community.
- [Ability to] clarify project purpose and desired outcomes
- Helps teams plan and achieve initiatives
- Achieves a higher level of accountability
- Continually improves strategies and actions to achieve better results

3.16.3 IMPACT AND OUTCOME EVALUATION

Once a process evaluation has been undertaken, the next step in the evaluation process is that of *impact/outcome evaluation.* This type of evaluation looks at the short-term and longer term results of a program service. Minechello et al (1999) described impact and outcome evaluations as processes used to determine whether a service has achieved what it set out to achieve. If this type of evaluation were being undertaken on a newly developed paediatric community nursing service, the purpose might be to see if the service reduced the length of stay for children; or reduced parental anxiety or saved money. One method to measure this is through the development of service indicators, collection of relevant data and analysis of the results.

3.16.4 CAUSAL EVALUATION

The fourth and final type of evaluation as defined previously by Minichiello (1999) is causal evaluation. Minichello differentiated this type of evaluation from previous types of evaluation as a process which measures whether behaviour, attitude or knowledge have changed as a result of the program or service provided. Causal evaluation is, in a sense, looking backwards through the service/process to date in order to marry the outcomes of the evaluation with the originally planned outcomes (Minichiello, 1999).

In evaluating a service, such as a new community-based paediatric nursing service, a causal evaluation might seek to discover the relationship between the new service and secondary outflows from the area it services. Another question to be addressed by causal evaluation might be whether there has been a change in the pattern of referral or the utilisation of the emergency department by families. As causal evaluation requires planned outcomes against which to assess the success (or lack there-of) of a service, it is necessary that such outcomes be determined in the planning process.

Within the first twelve months that the POS was operational, it became increasingly obvious to the author (who was also the service manager at the time), and others responsible for the functioning of the service, that there had been no clearly defined evaluation process developed whereby a systematic, objective review of the planned outcomes could be undertaken. As others (health services , New South Wales Department of Health) looked to POS for advice related to what worked and what didn't, the lack of evaluation criteria was more acutely high-lighted.

3.17 REFLECTION

Whilst there is a dearth of Australian literature pertinent to home-based nursing services, much of the international literature is relevant for consideration in the evaluation of the POS

It is important to understand that home-based paediatric nursing services can take on many appearances and be developed to meet many and varied service needs. Regardless of the service design, families need to be assured that the standard of care delivered at home is at least as good as that offered in hospital and they need to value the service that is offered

Additionally, referring agents and those services in the community providing care for children need to understand and value the function of the home-based nursing service. It is the responsibility of service planners and those implementing the service to meet these needs in order to subsequently ensure that consumer needs are addressed and met.

There are different measurements by which the success of a service can be assessed. These include, but not exclusively, customer satisfaction surveys and service indicators (both clinical and performance). No single measure will give a complete view of the functioning of the service. Campbell et al. (2000) assert that in order to evaluate complex services or projects, a use of quantitative in conjunction with qualitative research methods may be required to more completely develop a picture of the service/project under study.

Chapter four will describe the development of the study tools (two satisfaction surveys and also service indicators) for POS that were developed to collect both qualitative and quantitative measures of POS performance.

CHAPTER

FOUR

CHAPTER FOUR – METHODOLOGY

4.1 INTRODUCTION

This chapter will describe the project design including the process that led to the development of the study tools; the sample groups; the ethical considerations of this study; and method of data collection and analysis.

4.2 THE STUDY DESIGN

This study is underpinned by the principles of process evaluation (as described in Chapter Two). It utilizes both quantitative and qualitative methods of data collection and analysis to describe elements of service performance.

Evaluation methodologies are defined primarily by the purpose they serve. There are two methodological approaches to evaluation and they are *“summative”* or *“formative”*. Summative evaluation looks for cause and effect relationships whilst formative evaluation is more concerned with the social impact of service implementation (Ingleton, Field & Clark, 1997). Ingleton et al. 1997 explain further that formative evaluation is the methodology employed when the aim is to gather data to assist in service improvement. Such data is usually collected using a range of approaches.

Thus, it is a formative approach that will underpin data collection and analysis for this project in order to meet the study objectives: namely to determine the "elements of a Paediatric Outreach Service which satisfy the clients using the service" and the "indicators which provide measurement of successful service provision".

The *methodology* of the research refers to the approach utilized when addressing the research question(s). The "*method*" refers to the action taken to achieve the chosen methodology. In this study, the methodology is formative evaluation and the two methods drawn upon to achieve this are the customer satisfaction surveys and the development of service indicators.

Care must be taken when planning a research project that the methods chosen complement the chosen methodology. For this study, two satisfaction survey tools were developed to elicit information from the POS customers regarding their satisfaction with service. The service indicators were developed to monitor the quality of designated areas of clinical practice. How the service indicators were decided upon will be discussed in detail later in this Chapter. Both of these methods of data collection informed the evaluation process whereby service providers sought to determine whether POS met the needs of the customers it served.

4.2.1 THE SETTING

The setting for this study was a clinical healthcare setting at a metropolitan general hospital in Sydney, New South Wales, Australia. As previously described, the service being evaluated aimed to meet the paediatric health care needs of the child in their own home. The setting has been described in detail in Chapter One.

4.2.2 THE STUDY SAMPLE

The sample consists of two discrete groups of consumers: one is the group of health professionals who have referred patients to the POS and the other were the parents of children who had received care by the POS staff. Both groups received services from the POS during the period under study (that is, May 1998-Feb 1999). The sample was *"purposive"* (Burns and Grove, 1993:777) with the participants being selected from the service's "intake book". The "intake book" is a manual list containing demographic details related to each child referred to the service, including who referred them. All families referred to POS during the study period were included with the exception of a few families as described in section 4. 2. 2.1 below.

4.2.2.1 THE PARENTS OF PATIENTS

Families of children who received care by POS staff between May 1998 and January 31st, 1999 were surveyed. In total, there were 212 surveys distributed by mail. Exclusions to the mail-out included one family whose baby died during the year (terminal care referral) and those families who were known to have moved since care was provided and for whom POS had no contact details at the time of the survey mail-out. The reason for excluding the family of the baby who died (after approximately five months on POS) was because of the fact that there was not personal contact associated with the mail-out and the researcher decided that this was not appropriate. Had the contact been of a personal nature, this family may have been included in the sample.

4.2.2.2 THE REFERRERS

During the period under study, there were 16 referrers identified and they were all surveyed. This group included health-care providers (paediatricians, general practitioners, nurses, and allied health staff) who had referred children to POS for nursing care between May 1998 and January 31st, 1999. Fig 2 provides a breakdown of the health professionals represented in this group.

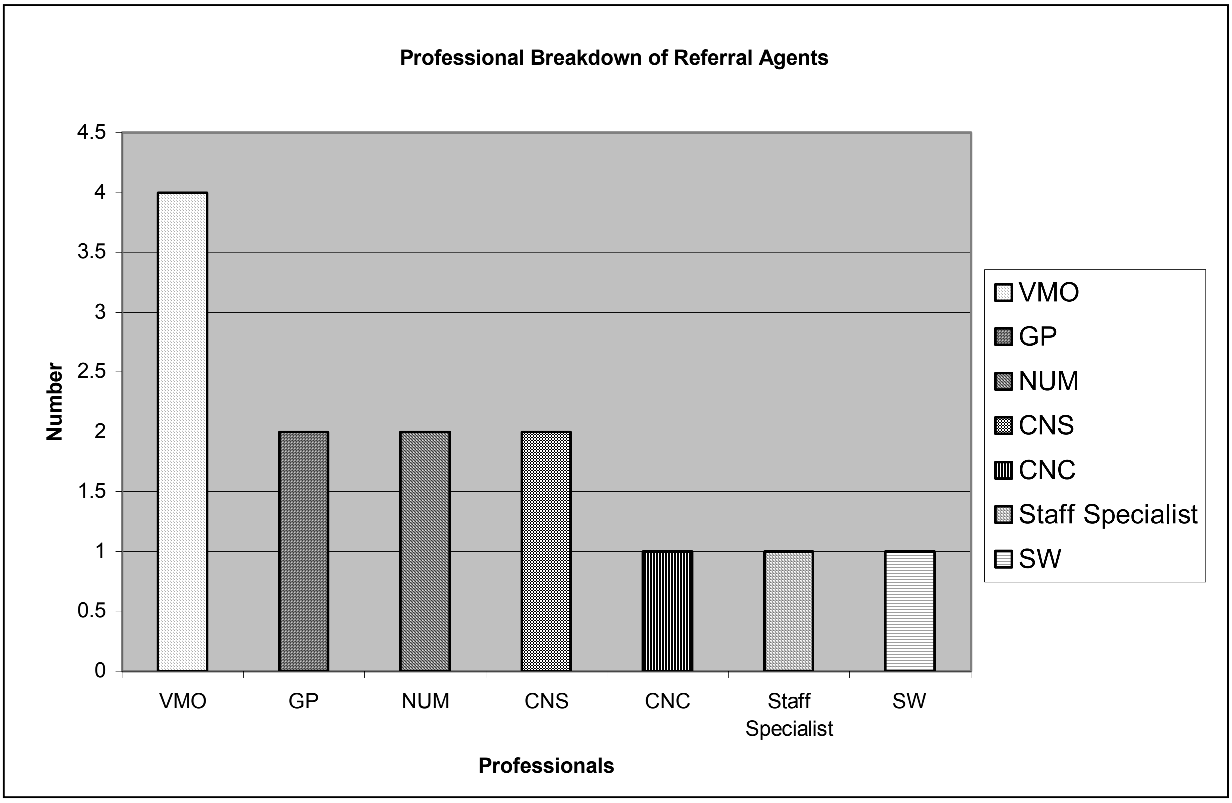


Fig 2: provides a breakdown of the health professionals represented in this group.

4.2.3 TIMING

Prior to conducting the actual satisfaction survey, a pilot was undertaken to facilitate fine-tuning of the tools that had been developed. The pilot study was conducted over a two week period. Once the findings of the pilot were analysed and incorporated into the final tool, the real study was conducted.

4.3 ETHICAL CONSIDERATIONS

Ethical approvals were sought and received from ACU (See Appendix One) and South Western Sydney Area Health Service (See Appendix Two) prior to the commencement of the study.

The ethical issues addressed in this study were participant anonymity and confidentiality, data storage, informed consent and researcher bias.

4.3.3 ANONYMITY AND CONFIDENTIALITY

The participants in a research project need to know that their responses will be anonymous in the published findings and that the confidentiality of their participation will be maintained.

The letter of introduction (See Appendix Three), sent out to all potential participants explained the purpose of the research project, assured participants that their involvement would be both confidential and anonymous. Participants were mailed a letter of invitation (see Appendix Four and Six) and a questionnaire (See Appendix Five and Seven). A return self-addressed envelope was included. There were no identifying features on the questionnaire, therefore there was no way to identify which of the potential participants had actually responded.

4.3.4 CONSENT

The ethical issue of informed consent was of paramount importance and one that needed to be addressed prior to commencing the project. Completion of the questionnaire, by participants, was voluntary. Thus, their completion of the questionnaire and it's return to the researcher were considered implied consent.

4.3.5 DATA STORAGE

The issue of participant anonymity and confidentiality of the data was further addressed in the method of data storage and security.

During the study, paper data was stored in a locked cabinet in the researchers home office where the researcher had the only key. Computer records were stored on a disc in a locked box to which the researcher has the only key. The list of respondents (as obtained from the POS Intake Book) was stored separately from the returned responses so that no correlation (actual or potential) could be made between the two sets of data.

Following completion of the study, data will be retained in a locked cabinet as above. After complying with the requirement to retain data for a minimum of 5 years, paper documents that are no longer required will be shredded and computer disks will be re-formatted to erase all data.

4.3.6 RESEARCHER BIAS

The researcher in this study frequently wore “two hats”. Concurrent with the study she was also the Clinical Nurse Consultant/Service Manager for the POS and provided the day-to-day clinical support to staff and families as required during the study period. In addition, the Clinical Nurse Consultant had a role in co-ordinating the service. There was, therefore, the potential for a conflict of interest for the researcher between the role of researcher and service provider

This issue was given considerable thought during the planning stages of the project to ensure that the researcher was very aware of the potential conflict. This consciousness, throughout the project, has ensured that the researcher’s care-giving role has not consciously influenced the data analysis, or contravened patient confidentiality. One strategy employed to assist the researcher to remain objective was to choose patients who had received care in the first nine months of the service’s operation as the sample. For most patients, this meant that they were no longer receiving nursing care and or monitoring from the staff of POS. Thus this eliminated the potential for undue influence on the patients related to their participation or decision not to participate in the study.

4.4 DATA COLLECTION

In order to collect data to answer the research questions of this study, tools needed to be developed and piloted to ensure they were sensitive to the data to be collected. The rest of this chapter is concerned with describing the process of development of the study tools and the process of data collection.

4.4.1 CONSTRUCTION OF THE SURVEYS

The two customer satisfaction surveys (See Appendix Five and Seven) were developed to elicit information from customers related to their satisfaction with the service provided.

Brady (1992:245) described the steps in the development of surveys. These steps include:

- *Determine the objectives of the questionnaire*
- *Develop the questionnaire after determining the appropriate format*
- *Check the validity of items (with an expert)*
- *Pilot the questionnaire using a small but representative sample. (The sample should have the same distribution of types as the final sample).*
- *Refine the items in the light of the pilot study.*

- *Administer the refined questionnaire to the whole sample (but do not include those who participated in the pilot study).*

The process of how these steps were met in conducting this study will be described later in this Chapter.

The survey method was chosen as the key data collection tool for several reasons. These included:

(1) input from a large number of people was required

(2) it is a cost-effective way to access many people

(3) it seeks to obtain anonymous responses (and it was hoped this aspect would encourage respondents to be as honest as possible)

The surveys were designed to collect quantitative and qualitative data from respondents. The quantitative data will be expressed as descriptive statistics and will describe the number of customers who have expressed a particular answer from the questions asked. These questions were designed as a mixture of tick boxes and Likert-type scales. The qualitative data was gathered from open-ended questions that asked customers to describe their thoughts and opinions about aspects of the service. The purpose of gathering data of both types was to give depth to the data.

Czaja and Blair (1996) describe three conditions that should be met when using a survey. These include that:

- *target audience must be clearly defined;*
- *a majority of respondents will know the information*

asked of them; and

- *the general focus of the analysis should be numerical.*

All three of these conditions have been met in this study. The target audience have been defined by the time period under investigation and also by the type of service they received (that is, care by POS). As the service was provided to the target audience, the respondents were in a clear position to answer the questions asked of them. Finally, much of the data collected will be converted to descriptive statistics for analysis.

Using a survey method provides the advantages described previously. In addition, Brady (1992:244) says that surveys are *"one of the best ways determine how a patient thinks and feels and why a person thinks and feels in that way."* There is a disadvantage in using surveys, that being the relatively set structure *"so the researcher must be very clear about the information that is being sought"* (Brady, 1992:244).

Surveys can be completed in person, or they can be posted out to respondents. In order to minimise the amount of time the researcher needed to spend obtaining data one-on-one, surveys were posted out for this study. This method has the advantage of maximising potential coverage of respondents. However, the distribution of surveys by mail has several disadvantages, one being the poor response rate. In order to maximise the response rate, the researcher mailed a reminder note out to all potential respondents two weeks after the original response deadline, requesting them to return the survey if they had not already done so. Moser and Kalton (1971) and Bell (1993) support this strategy in order to increase the response rate. Further, these authors believed that following up respondents in this way can increase the response rate by approximately 7%. The second mail-out did result in some further responses, however, of the nine extra responses, only two were completed whilst the remaining seven were marked “return to sender – not known at this address” and so, in all likelihood were totally unrelated to the reminder letters that had been sent out.

Another strategy that was employed to attempt to maximise the response rate was the inclusion of a reply-paid envelope with each survey sent out. It was envisaged that the fact that the envelope was provided so that the respondents did not need to purchase a stamp would encourage them to complete the survey and return it by the response deadline. Such a strategy has been recommended by Oppenheim (1992)

The two surveys were developed to address issues that the service manager/researcher thought were important. One disadvantage of using surveys to elicit responses about what aspects of a service are valued and what is not is that the questions generally focus on what the service operator or the researcher wants to know. For this reason, participants were also given some open-ended questions and invited to discuss issues that they wanted to. The topics chosen by the researcher to investigate were supported by Roland and Roland,1994. There were separate issues for each participant group and examples of these are given below.

Important issues covered in the Referrer Survey include the ease of referral, convenience of intake hours, confidence in the staff's ability, the standard of care delivered, and whether they would refer their patients to the service again. There were three open ended questions asking what referrers liked about the service, what they disliked, and what they suggested for the service to be improved.

Issues covered in the parent survey include length of wait for first visit and satisfaction with this, confidence in visiting nurses, parents feeling of being valued as carer, and whether parents believed staff were genuine Again, there were three open-ended questions asking what parents liked, what they disliked, and what they suggest as service improvements.

Once the surveys were developed, they were tested, prior to implementation for the main study, to assess their validity and reliability.

4.5 RELIABILITY AND VALIDITY

In order that the study findings have any credibility, it is important that the study methodology is strongly underpinned by validity and that reliability can be assured.

4.5.1 VALIDITY

Study validity *"is a measure of the truth or accuracy of the claim…questions of validity refer back to the propositions from which the study was developed"* Burns and Grove (1993:265). The validity of an instrument refers to how well it is able to answer the question being investigated. There are several types of validity, including content, predictive and construct.

In order to ensure content validity of the two survey tools developed by the researcher, they were given to an expert panel for review and comment.

4.5.1.1 THE EXPERT PANEL

In addition to submitting the two surveys to the Ethics committee of SWSAHS for approval (see Appendix Two), they were also submitted to the Quality Improvement Committee at Fairfield Health Service. This committee membership included the General Manager, Director of Nursing, Director of Community & Allied Health, Medical Superintendent, Quality Assurance Manager, the Business Manager (Community Health), the Business Manager (Hospital), the Quality Improvement Service Manager, and a representative from each of the following: nursing division, community health, General Practice and Medical Staff Council. Following a review of both surveys, the committee endorsed them for distribution to consumers of POS, with no alterations or corrections required.

4.5.2 RELIABILITY

Burns and Grove (1993) define reliability as a measurement that is concerned with how consistently the measurement technique measures the concept of interest. In the case of survey tools, it is important that the researcher know that the questions in the tool are not only understood by the participants but that the question means the same thing to each participant so that the answers received are comparable. To ensure the reliability of the questions in the study tools, each of the tools underwent pilot testing.

4.5.2.1 THE PILOT STUDY

In this study, pilot testing of the instruments helped to ensure that the final instrument was both valid and reliable. Treece EW and Treece JW (1986) describe the purpose of the pilot study as an opportunity to test a research tool to determine whether there are any flaws in the tool, so that they can be corrected before undertaking the primary study.

By undertaking the pilot study of the instruments, the researcher planned to refine them for use in the actual study. It also ensured that the data collected by the tool addressed the objectives set for the study. Piloting the instrument was a process undertaken by the researcher to ensure that the study instrument was the best that it could be and that it collected the data required to address the research question.

Following initial development of the Consumer Satisfaction Survey (refer to Appendix Seven) and the Referrer Satisfaction Survey (see Appendix Five), these tools were piloted to check the questions for ambiguity, clarity and user-friendliness.

4.5.2.2 THE CLIENT SATISFACTION SURVEY

The Client Satisfaction Survey (CSS) (refer to Appendix Seven) was developed to measure how effectively POS met customer needs and expectations The tool was piloted to ensure that parents could understand the questions being asked of them. In addition, the pilot was undertaken to ensure that the answers provided by parents would enable the researcher to meet the stated objectives for the study.

In order to pilot the CSS, a member of staff who was not working with POS during the study period was invited to pilot the instrument in the homes of parents whose child had received care by POS during the study period. This was done in an attempt to prevent a parent feeling they had to respond positively because the nurse who had provided their child's care was asking them to comment.

Five parents were telephoned and asked if they would agree to complete a CSS. They were informed that the process would take no more than 15 to 20 minutes and appointments were made at a time agreeable to the parents. To select parents to participate, the new staff member randomly chose names from the intake data-base where they were registered during the study period. Five participants were invited and all agreed to complete a CSS for the pilot study (verbal consent). This verbal consent was supported by the implied consent parents gave by actually completing the survey.

The staff member assigned to take the CSS to participants was given instructions by the researcher explaining how they should proceed. They were asked to sit with the parent whilst the parent completed CSS. The nurse was asked to document any problems parents encountered in answering the questions including If the parent sought clarification on any point If this occurred, the nurse was also asked to document their own response as well as any thoughts or feelings that were evoked at the time. Finally, the nurse was asked to record any general comments or problems each parent encountered.

The participant group comprised of four parents of children who had received care from POS and an adolescent patient who had received care by POS. All completed the written survey in less than the estimated 20 minutes

The cultural backgrounds of participants included: Armenian, Turkish, Australian, Assyrian and Vietnamese. Four participants spoke good English, although for three, English was their second language. One participant spoke reasonable conversational English. All the surveys were undertaken in English. In the pilot group, all the children who received care by POS were Australian born.

From analysis of the pilot study of the CSS, the flaws that were illuminated were:

(1) Q4 – Two out of five parents were unsure whether this question was meant to include the most recent illness (usually the one that saw them referred to POS) or whether it meant illnesses in addition to the current illness/condition.

(2) One parent qualified Q11 by indicating that the right number of visits were undertaken but they added: *"winter not enough visits"*.

(3) All five participants had difficulty with Q15E. This was most likely because of the choice of words chosen to ask the question.

(4) One participant voiced difficulty with the first possible answer to Q15 ie *"yes-usually"* as this gave participants two choices whilst all other alternatives had only single choices.

(5) The wording of the form was not appropriate for adolescent patients to self complete. This was because the document was designed for a parent to complete. The survey would have required considerable re-wording to be relevant for an adolescent to complete. The document was not re-worded.

(6) For the Non-English Speaking Background (NESB) participant for whom English was identified as somewhat of a problem, all questions up to Q15 were understood. However, the participant did have difficulty selecting an answer from the distractors provided. The participant wanted to answer in sentences instead.

As a result of the deficits identified by the five participants in completing the pilot CSS, the following alterations were made to the instrument:

(1) As less than fifty per cent of respondents had difficulty with question four, no changes were made to the question for the main study.

(2) Q11 - As this was a problem for only 20% of the pilot group, no changes were made

(3) Q15e - It is the researcher's belief that this is not so much a problem with the actual question as the fact that explanations about "rights and responsibilities" were not a direct feature of home visits. This means that whilst nurses negotiated with parents what was required

to provide care for the child at home, it was not explained using the term “rights and responsibilities”.

With regard to the option for answers to Q15, the first choice was changed to read: “occasionally” to ensure that all options offered only one response.

(4) Due to the inappropriate wording for adolescent participants to self-complete, participants in the main study were restricted to parents only. A separate adolescent tool has not been developed as the pool of adolescent patients is too small to warrant a separate tool being created.

(5) As only one respondent chose to disregard the available answers and answer in sentences no changes were made regarding this issue.

A potential limitation of the instrument, identified from the pilot study, was in relation to the language used. For financial reasons it was not possible to have the CSS translated into relevant community languages. However, many patients seen in the first nine months of the service for whom the spoken English word was difficult, reported to the researcher (via interpreters) that their English reading skills were better than their speaking skills. This does not necessarily apply to all families, but the cost of having the two survey tools translated into even two community languages was not possible for this study, due to the absence of research funding. Additionally, seeking cultural information, whilst undoubtedly important, was not the main focus of this study.

The other difficulty with having the CSS translated was that all the patient notes for the patients seen in this time would have to be physically recalled or data retrieved from the Community Health database to obtain the details related to interpreter needs and language spoken. This would have been very time-consuming and beyond the scope of this study.

4.5.2.3 THE REFERRER SATISFACTION SURVEY

The Referrer Satisfaction Survey (RSS) (see Appendix Five) was developed to measure how successfully POS met the referring agent's needs and expectations. The tool was piloted to ensure that the referrers could understand the questions being asked of them

As for the CSS pilot study, a pilot of the RSS was undertaken to ensure that the answers provided by referrers would enable the researcher to meet the stated objectives for the study.

RSS's were mailed out to referrers with a covering letter asking them to complete the survey (see Appendix Six). They were informed that it was expected that their involvement in the process would take no more than 15 to 20 minutes.

The participant group comprised of a sample of referring agents. However, as the number of agents who have referred to POS is quite a small group, the pilot test of the RSS was undertaken using referrers to another nursing service, which operates in a similar manner to POS, within the same Health Service. This strategy aimed to ensure that there was a maximum number of participants for the main study.

From testing this survey tool, no major flaws or limitations were identified. All questions that were asked were answered by the referrers. There were no questions directed to the researcher about the RSS. There were no questions left unanswered.

4.6 DEVELOPING THE SERVICE INDICATORS

Service indicators are measures against which a service's performance or clinical finesse can be considered. They have become important tools for administrators and clinicians alike in proving the value, benefit or cost (these can be finance, human or resource related) of providing a service.

Unlike it's hospital counterpart, POS had no indicators against which to measure the success of their service delivery. The hospital setting had extensive indicators provided by the Australian Commission of Health Standards (ACHS) to choose from that could reflect elements of service provision. POS could not simply "adopt" these indicators. Firstly because the indicators generally reflected elements of inpatient care; and secondly because if POS collected data against an indicator already collected by the hospital, there was a high probability of *"double-dipping"* ie collecting the same data twice (as it was related to the same population). Thus, the researcher looked at the types of indicators being collected by the paediatric inpatient unit, listened to the identified needs of some of the stakeholders and was cognizant of Department of Health reporting requirements. This lead to the development of 8 indicators against which the POS staff would measure service provision.

4.6.1 INTRODUCTION OF THE SERVICE INDICATORS

At the time when the clinical and performance indicators were developed as part of this thesis, Fairfield Health Sector became increasingly aware that few of the services offered by Community Health could be measured by parameters other than *occasions of service.* By comparison, their hospital counterparts were collecting measurement data to comply with ACHS requirements. All Community Health Service Managers were invited to develop indicators to measure their service from a clinical and/or performance perspective

4.6.2 DATA COLLECTION AND INTEGRITY PROCESS

In consultation with the Director of Community Health and the Chair of the Department of Paediatrics, it was agreed that the indicators developed by the researcher for this project could be implemented and tested as the measurements of several dimensions of service success for POS. In the initial testing period, during 1999-2000, it was decided that data should be collected for a total period of six months and then analysed. Analysis was the responsibility of the Sector Quality Committee, in conjunction with clinicians whenever clarification was needed. Recommendations were made to the clinicians re suggested changes/alterations/deletions for consideration and where there was agreement, implementation.

To attempt to ensure integrity of the data that would be collected, POS staff elected to collect data for two periods of three months each, with three months between the two periods of data collection. It was hoped that this would take account of diverse professional staff being involved in the delivery of care and documentation of data, as well as account for some likely seasonal fluctuation.

4.6.3 DESIGN OF THE SERVICE INDICATORS

The indicators initially designed were:

- Number of patients referred to POS with a diagnosis of asthma for whom a clinical pathway was completed

- The average number of home visits undertaken for a patient referred to POS with asthma
- Number of patients for whom a discharge letter was completed and sent to the nominated medical officer[s] within **24 hours** of discharge from POS
- Number of patients for whom an initial report was sent to the nominated medical officer[s] within **48hrs** of the child's initial visit.
- Number of patients referred to POS who were contacted within **24 hrs** of the receipt of the referral
- Number of patient's wounds that became infected during the period of management by POS that became infected after Day 3 post referral.
- Number of patients who experienced an adverse occurrence (morbidity or mortality)
- Number of POS patients who were re-referred for the same problem within 28 days of discharge from POS.

4.6.4 CONSTRUCTION OF THE SERVICE INDICATORS

The following pages provide the details of the construction of the service indicators. The format they take followed the standard format of the ACHS indicators that were already being collected by the hospital.

4.6.4.1 Paediatric Asthma

FAIRFIELD HEALTH SERVICE DATE: NOV. 99-00

Paediatric Outreach Service (POS) Clinical Indicator No. 8.3

INDICATOR TOPIC:	**Paediatric Asthma.** Asthma assessment and management in children
STANDARD (IF ANY)	Asthma is a common childhood condition; the severity & frequency may be decreased with careful planning.
RATIONALE:	PHN may be involved in outpatient management of the child. The condition affects approx. 20% of the paediatric population. Community management of a child's asthma should include evidence that parents understand how to manage their child's asthma, have the appropriate equipment & medications to do the same.
DEFINITION:	Assessment of a child's asthma management in the home should include clinical assessment of the respiratory system, including peak flow where it is ordered. Community assessment should ensure that scripts are filled. A child is defined as less that 15 years for the purpose monitoring this indicator.
TYPE OF INDICATOR:	Comparative rate based indicators addressing management of patient care.
NUMERATOR:	Pts. Referred to POS with a diagnosis of asthma for whom a documented clinical pathway is completed.
DENOMINATOR:	The total number of patients admitted to POS with a diagnosis of asthma, during the time period under study.
REPORTING:	

4.6.4.2 Initial Report

FAIRFIELD HEALTH SERVICE DATE: NOV. 99-00

Paediatric Outreach Service (POS) Performance Indicator No 8.1

INDICATOR TOPIC:	**Paediatric Outreach Service has a communication strategy with General Practitioner Divisions.**
STANDARD: (IF ANY)	
RATIONALE:	Paediatric Outreach nursing staff should provide regular written communication to patient's nominated GP &/or Paediatrician to facilitate seamless healthcare for the patient. Correspondence identifies to the medical officer the source of referral, assessment & management of the child & identifies any problems raised by the family, especially those requiring on-going medical management.
TYPE OF INDICATOR:	This is a comparative rate based indicator addressing patient management.
NUMERATOR:	An **initial report** for POS patients is forwarded to nominated GP/Paediatrician within 48 hours of initial visit.
DENOMINATOR:	The total number of patients managed by POS during the period under study.
REPORTING:	

COMMENTS: (Explanation of variances)

In January there were 2 patients for whom the first visit was after a period of 1 week or so. Additionally, there were 2 patients who would not nominate a GP and had no follow up with a paediatrician. A further 3 patients declined a visit after referral.

4.6.4.3 Discharge Report

FAIRFIELD HEALTH SERVICE DATE: NOV. 99-00

Paediatric Outreach Service (POS) Performance Indicator No. 8.2

INDICATOR TOPIC:	**Paediatric Outreach Service has a communication strategy with General Practitioner Divisions.**
STANDARD: (IF ANY)	
RATIONALE:	Paediatric Outreach nursing staff should provide regular written communication to patient's nominated GP &/or Paediatrician to facilitate seamless healthcare for the patient. Correspondence identifies to the medical officer the source of referral, assessment & management of the child & identifies any problems raised by the family, especially those requiring on-going medical management.
TYPE OF INDICATOR:	This is a comparative rate based indicator addressing patient management.
NUMERATOR:	A **discharge report** for POS patients is forwarded to nominated GP/Paediatrician within 24 hours of initial visit.
DENOMINATOR:	The total number of patients managed by POS during the period under study.
REPORTING:	

COMMENTS: (Explanation of variances)

In January there were 2 patients for whom the first visit was after a period of 1 week or so. Additionally, there were 2 patients who would not nominate a GP and had no follow up with paediatrician. A further 3 patients declined a visit after referral.

4.6.4.4 Morbidity and Mortality

FAIRFIELD HEALTH SERVICE DATE: NOV. 99-00

Paediatric Outreach Service (POS) Performance Indicator No. 8.3

INDICATOR TOPIC:	**MORBIDITY & MORTALITY ADVERSE PATIENT OCCURRENCE**
STANDARD: (IF ANY)	
RATIONALE:	Adverse pts. Occurrences are an undesirable outcome of patient care. Quality service provision should be to minimise the morbidity/mortality for patients. An increase in morbidity/mortality rates indicates a deterioration of service quality and needs to be investigated immediately.
DEFINITATION:	Threshold: 0% of patients will suffer morbidity/mortality related to the care delivered by POS staff.
TYPE OF INDICATOR:	This is a sentinel event indicator that measures a serious, undesirable and often avoidable process.
NUMERATOR:	The number of patients experiencing an adverse patient occurrence in the period under study.
DENOMINATOR:	The total number of patients referred to POS in the period under study.
REPORTING:	

COMMENTS: (Explanation of variances)

Nil

4.6.4.5 Re-Referral Rates

FAIRFIELD HEALTH SERVICE DATE: NOV. 99-00

Paediatric Outreach Service (POS) Clinical Indicator No. 8.5

INDICATOR TOPIC:	Re-referral to POS after discharge from POS.
STANDARD: (IF ANY)	
RATIONALE:	Any child who is re-referred to POS for the same problem within 28 days of discharge. The aim of POS is to empower parents to competently and confidently take care of their child at home, re-referral in such a short time-frame may indicate failure to meet the service aim.
DEFINITATION:	
TYPE OF INDICATOR:	Comparative rate based indicators addressing patient's management (prevention) and process outcomes.
NUMERATOR:	Patients referred to POS who are re-referred for the same problem within 28 days of discharge from POS.
DENOMINATOR:	The total number of patients discharged from POS during the time period under study.
REPORTING:	

COMMENTS: (Explanation of variances)

Nil

4.6.4.6 WOUND INFECTION RATES

FAIRFIELD HEALTH SERVICE DATE: NOV. 99-00

Paediatric Outreach Service (POS) Clinical Indicator No. 8.1

INDICATOR TOPIC:	Community paediatric patient having evidence of wound infection on/after the third day following referral to POS (this excludes patients who are day 5 or less post-surgery or post-injury).
STANDARD: (IF ANY)	
RATIONALE:	Infection in clean wounds is avoidable. In a contaminated wound, infection may be kept to a minimum through appropriate antibiotic prophylaxis.
DEFINITION:	Wound Infection: A wound from which purulent material drains or is obtained. Microbiological confirmation is not necessary for the purposes of this indicator.
TYPE OF INDICATOR:	Comparative rate based indicators addressing outcomes of patient care.
NUMERATOR:	Number of wounds with infection managed by POS that occur after Day 3 post referral.
DENOMINATOR:	Total number patients with wounds referred to POS with a length of stay greater than three days.
REPORTING:	

COMMENTS: (Explanation of variances)

Nil

4.6.4.7 Timeliness to First Visit

FAIRFIELD HEALTH SERVICE DATE: NOV. 99-00

Paediatric Outreach Service (POS) Performance Indicator No. 8.4

INDICATOR TOPIC:	Timely home visit after referral to POS.
STANDARD: (IF ANY)	Threshold 95% of patients will be contacted within 24 hrs of referral to POS.
RATIONALE:	One purpose of a Paediatric Community Nursing Service is to prevent a hospital admission where possible. An integral component of this is the provision of a nursing home visit within a reasonable timeframe to meet patient needs.
DEFINITION:	
TYPE OF INDICATOR:	This is a comparative rate based indicator addressing patient management (quality measure).
NUMERATOR:	All patients referred to POS who are contacted within 24 hours of receipt of referral.
DENOMINATOR:	The total number of patients discharged from POS during the time period under study.
REPORTING:	

COMMENTS: (Explanation of variances)

Nil

4.7 SUMMARY ON DEVELOPMENT OF THE SERVICE INDICATORS

These indicators were chosen as they reflected stake-holder's concerns. They also reflected the Department of Health reporting requirements, whilst not collecting duplicated data with the hospital environment. The application of these indicators in the clinical setting will be discussed in Chapter Nine.

4.8 DATA COLLECTION AND ANALYSIS

The processes of data collection and analysis are integral to the research process and subsequently the discussion of the research findings. Table 1 below summarises both data collection and analyses.

TABLE 1: summary of data collection and analyses

OBJECTIVES	METHOD OF DATA COLLECTION	DATA ANALYSIS
Develop evaluation tools to evaluate POS after 9 months of operation	♦ Client Satisfaction Survey ♦ Referrer Satisfaction Survey	♦ Descriptive statistics-collate results of surveys Report in % if > 75% return rate or in actual numbers if <75% ♦ Analyse for content derived from open ended questions
Identify clinical indicators for POS	♦ Review accreditation processes examples of clinical indicators for community health ♦ Literature review of articles that describe/discuss clinical indicators	♦ Select the types of indicators that could be used to measure POS ♦ Test indicators in the clinical setting and review data collected.

4.9 DATA ANALYSIS

The process chosen for data analysis was descriptive statistics. *"Descriptive statistics allow the researcher to organise data in ways that give meaning and facilitate insight, to examine a phenomena from a* *variety of angles in order to understand more clearly what is being seen"* (Burns and Grove, 1993:473). Burns and Grove add that data analysis for any study involving quantitative data, and even some studies concerned with qualititative data collection where the data is numerical, begin with descriptive statistics. Further, that for some studies, descriptive statistics will be the only approach to analysis of the data. Such is the case for this study. Findings from responses will be reported as whole numbers or percentages of the whole.

4.10 REFLECTION

A lack of evaluation tools in the literature meant that in order to be able to determine indicators of satisfaction and success for the POS, tools needed to be created and tested. The satisfaction tools (surveys) were piloted on a subset of the population and refined prior to use. The success tools (indicators) were tested within the clinical environment and refined prior to endorsement for use by the Sector Quality Committee.

Descriptive statistics were chosen as the method of anaylsing and reporting the findings from the satisfaction surveys, as most of the information collected was numerical in nature.

Data from the service indicators were presented numerically also with the frequency of the event measured by the indicator statement being measured as a proportion of the overall population being measured.

The following chapters will provide details of the findings from each process of data collection. This will be followed by discussion and analysis of the results.

CHAPTER

FIVE

CHAPTER FIVE -FINDINGS- Referrer Satisfaction Survey

5.1 INTRODUCTION

This chapter will present the findings from the Referrer Satisfaction Survey (See Appendix Five). In order to provide a context against which the survey data was collected, this chapter will first introduce details about the clinical statistical information gathered by the POS staff, and then provide answers to the closed- and open-ended questions asked of referring agents.

5.1.1 A PAEDIATRIC OUTREACH SERVICE

There really is no standard definition of what a paediatric outreach service is or what one should do/provide. The scope of service provision appears to vary from site to site. Lack of definition then makes it difficult to determine if a service provides what it is expected to. In July 2001, in response to a need to be able to describe to others what POS staff did and provided, the staff of POS and Members of the Department of Paediatrics and Adolescence prepared a description of the paediatric outreach service.

Defining characteristics include:

- A paediatric & adolescent nursing referral service which interfaces with primary, secondary and tertiary health care in the hospital and the community
- Targeting medical and nursing requirements suitable for home environment, and therefore providing management in cases that would otherwise mandate hospital care
- Standard of care at home must be consistent with that which would be obtained in hospital
- Care can be provide in several domiciliary sites, depending on the family arrangements
- Criteria of competent paediatric nurse apply to all staff
- Paediatric and adolescent services provided as close as possible to home
- Transfers back to local care; either long-term or interim between episodes of tertiary care
- Home management of the disabled and chronically ill
- Skilling carers
- Real-time communication
- Expedite home management
- Reduce complications
- Reduce re-admissions
- Reverse secondary outflows
- Enable seamless delivery of benchmark level of care
- Promote consumers as partners of care
- Promote partners initiating home management
- Legitimize and initiate the concept of self-care

5.2 BACKGROUND INFORMATION RELATED TO POS

Since POS began, basic demographic and clinical information was recorded by the POS staff to enable them to build a profile of the types and numbers of patients who have been referred to the service.

5.2.1 OCCASIONS OF SERVICE (TARGET & ACTUAL) FOR POS

An "*occasion of service*" is defined as any event that results in a direct episode of patient care (NSW Health Circular 98/57). This may include a home visit or a telephone call that is directly related to the patient's care and results in documentation in the patient notes. With regard to POS, the patient is the child but in most circumstances the education and support are provided to the parent(s). However, as the care is related to the child, the documented occasion of service *must* relate to the specific care the nurse provided for the child and/or the education provided to enable a parent to provide ongoing care for the child at home.

Occasions of service, as well as being a very crude measure of productivity, also inform the process of budget allocations. Therefore, ideally, the POS team needed to perform as close to the target occasions of service as possible because falling short was likely to see a budget cut in the following year. In contrast, significantly overshooting the target would mean a budget over-run. The implications of this requirement for the POS nurses relates to the need for nurses to be aware of the budget because if the budget is reduced, or reached prior to the end of the financial year, nurses may be asked to deny service provision based on resource deficits. Clearly this would not be in the best interests of the patients, and inability to provide an alternative to inpatient care means that POS had failed to meet one of the prime objectives it was designed to address.

Each financial year all patient care departments within Fairfield Health Service were required to make a projection regarding their expected occasions of service delivery for the coming year. Occasions of service are usually based on the previous year's episodes of care delivered. As POS was a new service, there were no previous targets to build upon. In addition, there were also no services similar to POS's on which to base projections. The first year's projection of 835 patient services was a very rough estimate made by the Clinical Nurse Consultant, in conjunction with the Director of Community Health and the Community Paediatrician. This estimate grossly underestimated the actual occasions of service which totalled approximately 1800.

FIG 5. 1 illustrates the occasions of service (both the target and actual numbers) delivered to children by the POS team in the first nine months of operation.

There is a significant reduction in target numbers for the months over spring and summer. This was in keeping with expected seasonal fluctuations. The actual numbers of patients seen over the period under study did not reflect the expected seasonal variations. Postulated explanations for this will be described in the discussion chapters.

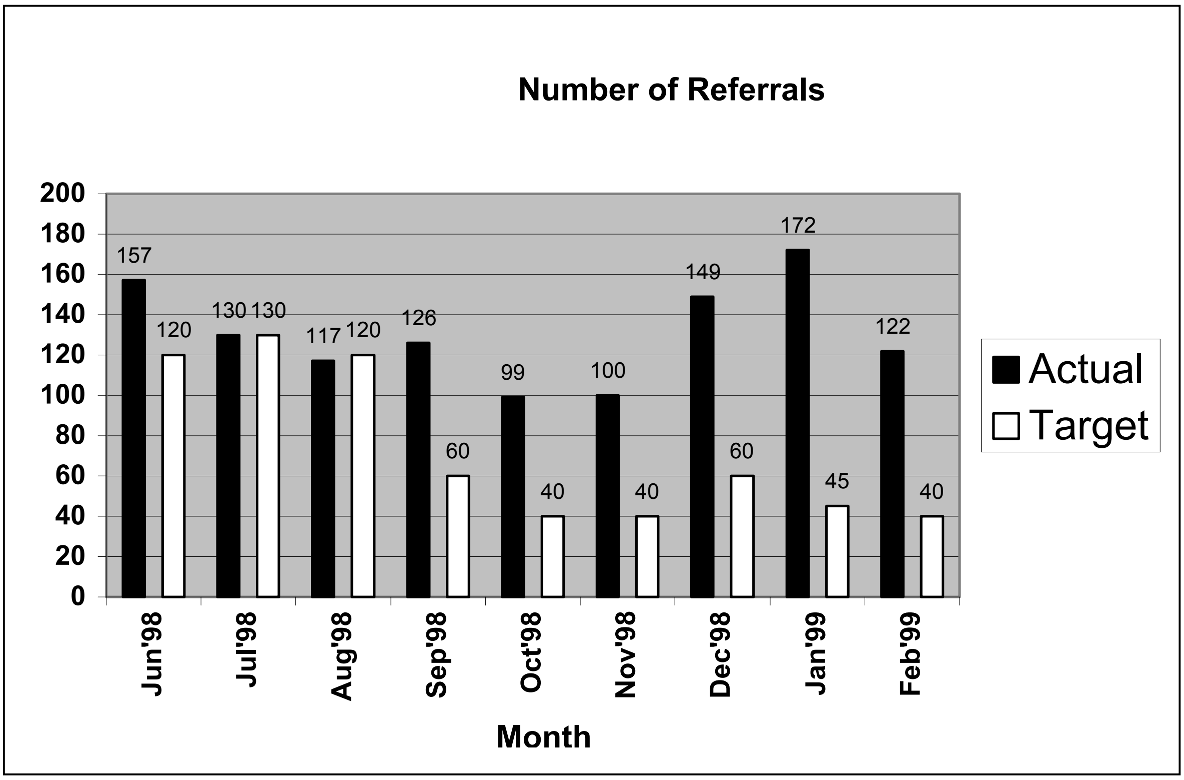


Fig 5. 1 Target and Actual Occasions of Service Provided by POS in the First Nine Months of Operation.

5.2.2 NUMBERS OF REFERRALS

Each month POS staff were required to keep a record of the numbers of patients referred to them for care. It was vital that this number reflected only the referrals that accepted home-based nursing care (that is, referrals which were excluded were those who declined any home-based nursing intervention or who lived outside of the defined geographical region) in order to reflect the true workload of the nurses. Fig 5. 2 displays the number of the patients referred to POS by month over the first 9 months of operation.

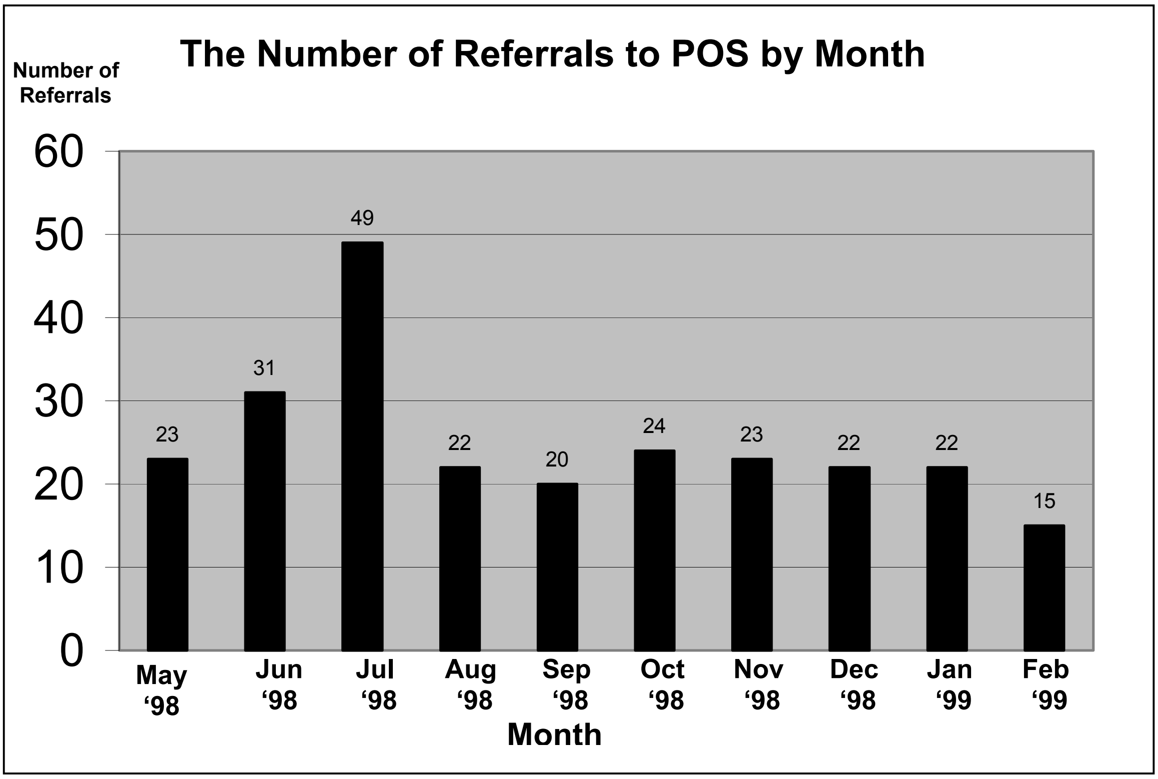


Fig 5. 2 The Number of Referrals to POS by Month

5. 2. 3 REASONS FOR REFERRAL

Upon commencement, POS staff set very few limitations on the types of conditions warranting referral to POS. Limitation criteria was predominantly related to two groups of patients: the first was well babies where the presenting problem was related to parenting issues; and the second group of patients was those whose medical condition was not amenable to home management. This resulted in the broad range of conditions referred to POS within its first nine months of operation, as can be seen from Fig 5.3. The greatest populations referred were infants and children with respiratory conditions (n=104)

Fig 5.3 (p125) displays the numbers of children referred to POS and the reasons for those referrals during the first nine months that the service was operational.

5. 2. 4 SOURCES OF REFERRAL

The following diagram (Fig 5.3) illustrates the sources of referral of patients for POS. POS provides care only for children living in the Fairfield Local Government Area (FLGA). However, not all children receive their medical care within the local government area (LGA) that is, they may travel to see their general practitioner or specialist. Consequently, referrals to POS may come from a variety of sources, both within and external to FLGA Referrers can be professionals (eg doctors, nurses, allied health, Department of Community Services, Centrecare) or non-professional (eg family member or friend).

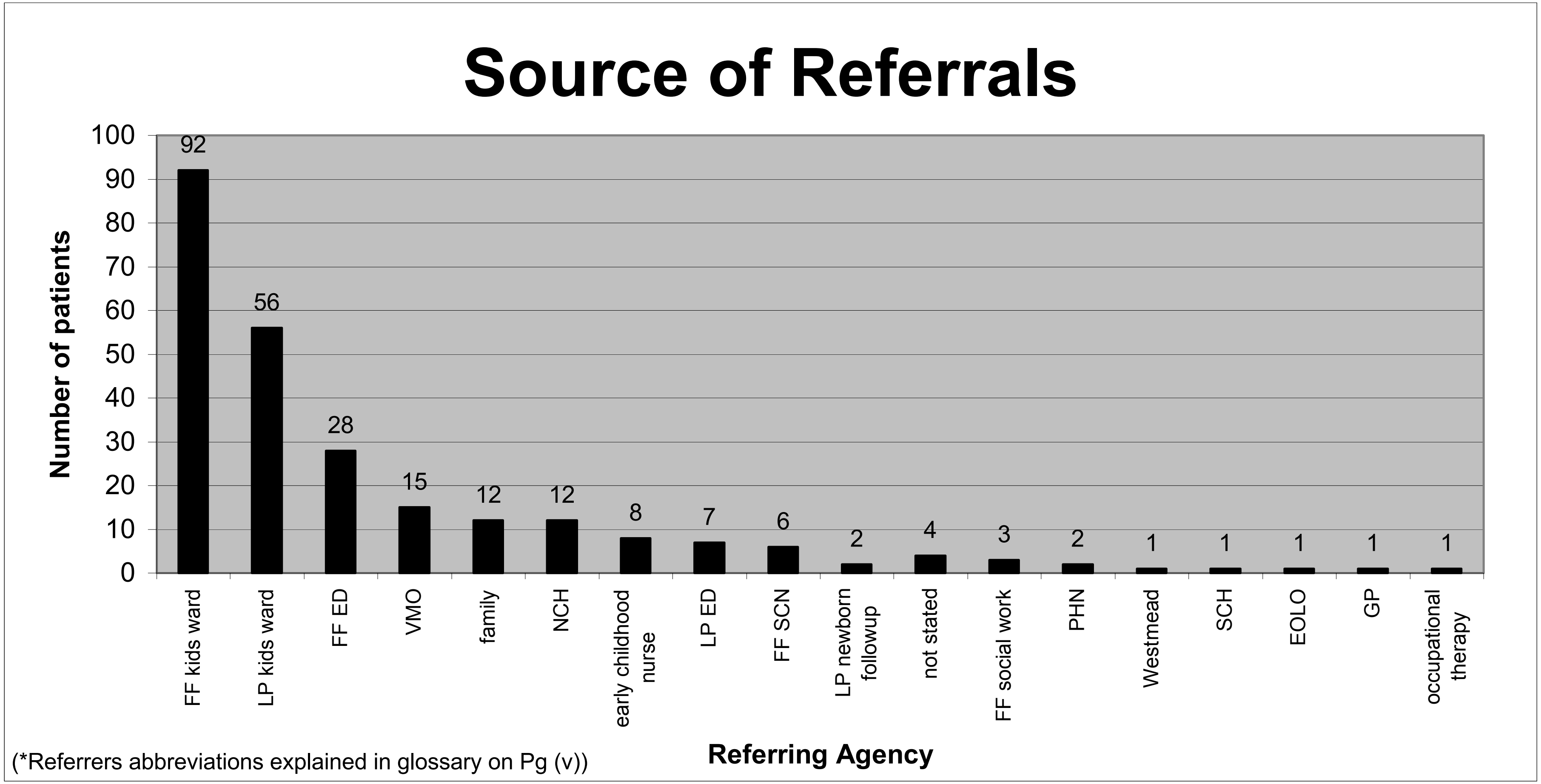
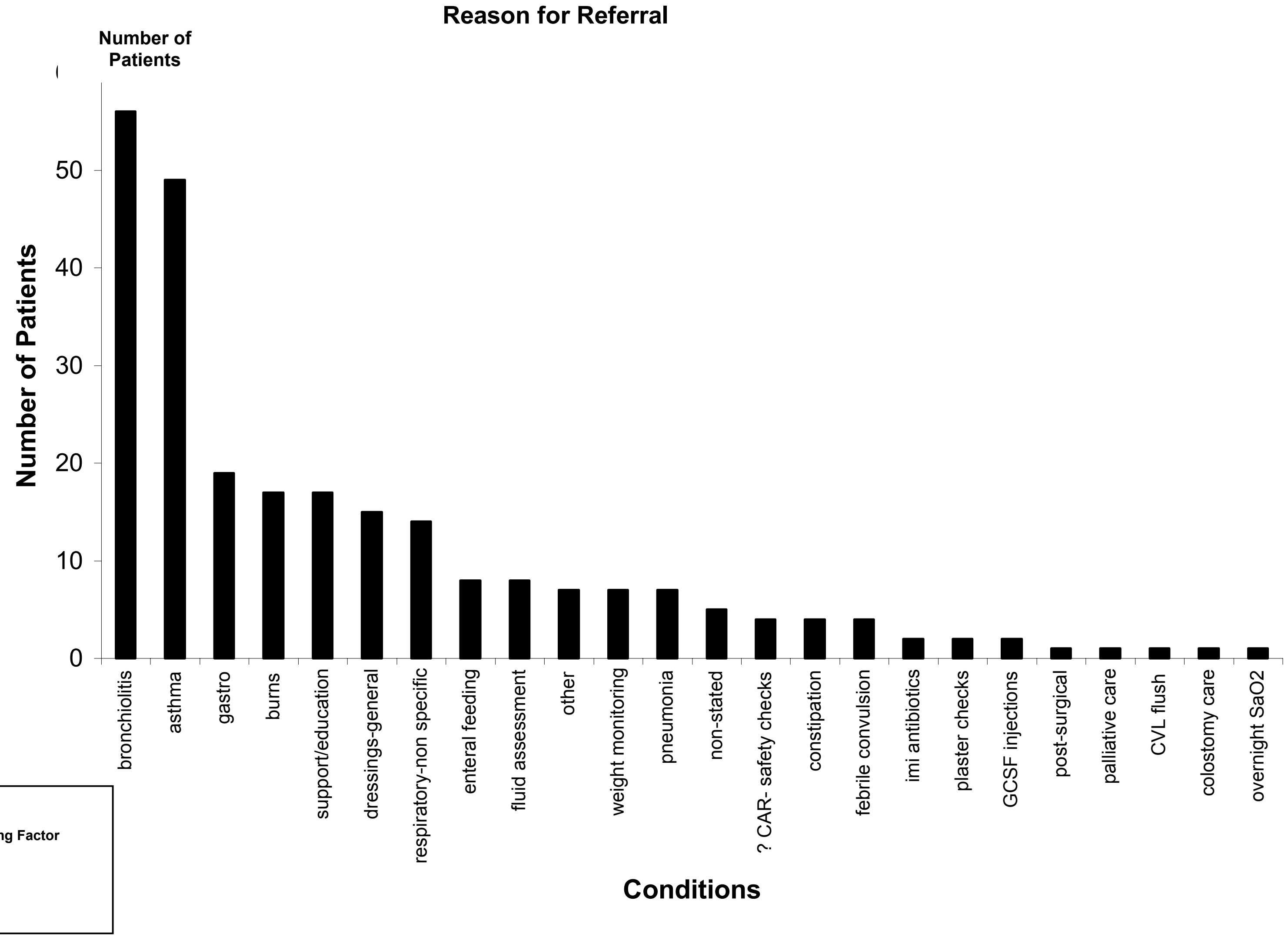


Fig 5. 4 The Sources of Referral for POS Patients

Fig 5.3 The Number of Children Referred to POS and the Conditions For Which They Were Referred.



Note:
CAR=Child At Risk
GCSF= Granulocyte Colony Stimulating Factor
IMI=intramuscular
CVL=Central Vascular Line
Sa02= Oxymetry

5.3 REFERRER SATISFACTION SURVEYS – FINDINGS

There was a 75% return rate on this group of surveys. Generally, responses from referring agents were very positive It has been previously stated that family/friends can make referrals to POS, however, for the purposes of this study and as previously stated, only professional referrers received a Referrer Survey. The professions of respondents is displayed in the Fig 5.5.

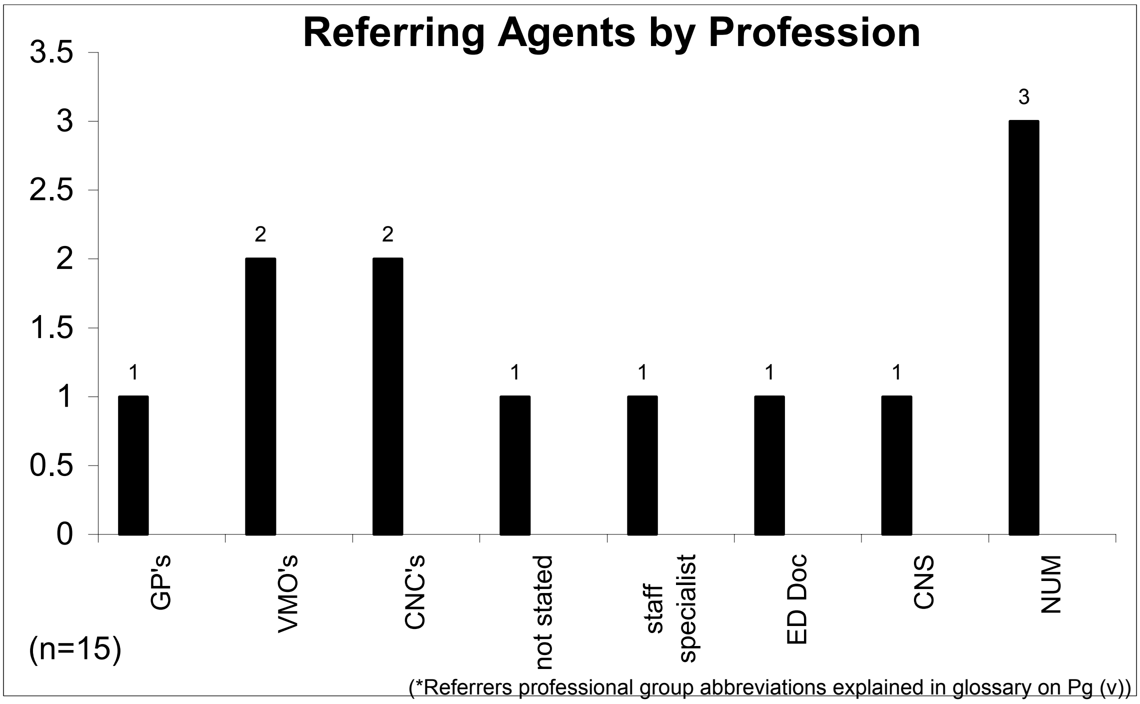


Fig 5. 5 Referring Agents By Profession

5.2.3 CONVENIENCE OF INTAKE

One hundred per cent of referring agents concurred that the POS intake process was convenient to their practice

For one respondent, they valued the fact that referrals could be made,

“ *in person, by fax or by phone”* (Paediatrician)

and another commented that,

“*it is very convenient to be able to fax and communicate referrals”* (CNC)

5.3.2 ACCESS TO POS STAFF

One hundred per cent of the referrers said that POS staff were easy to reach to discuss their patients. It is important in order to maintain open lines of communication between care providers to sustain the care continuum. One respondent commented that

> *“phone contact was available at any time”* (GP)

5.3.3 CONTINUITY OF REFERRALS

All respondents concurred that they will continue to refer to POS. One respondent commented that:

> “*the service provides continuum of care”* (Paediatrician)

5. 3. 4 CONFIDENCE IN POS STAFF'S SKILLS

Again, there was consensus between referring agents and one hundred per cent of respondents expressed confidence that the POS staff possessed the necessary skills to meet their patients' needs.

5.3.5 REGULARITY OF REFERRAL

Fig 5. 6 displays referring agents regularity of referral. When asked if they refer to POS regularly, 64% responded yes. The remaining 34% said that they did not refer regularly. Reasons for this will be explored later in the Discussion Chapter (Chapter 7). Comments made in support of their answer included the fact that their practice is outside of the FLGA, that many of the patients referred from one service require mother-craft follow-up rather than paediatric nursing care/support and a third comment was that many patients actually get referred from POS to their service, rather than to POS.

5.3.6 RECEIPT OF FEEDBACK

The question concerning feedback from POS staff to referring agents asked respondents to indicate whether or not the feedback was timely. POS nurses are supposed to provide written feedback to the nominated medical officer (GP or Paediatrician) but this is not necessarily to the actual referring agent. However, POS staff are required to advise referring agents when the referral cannot be accepted. In most cases, where the referring agent was not a medical officer overseeing the child's care, the referring agent commented that feedback related to the care that was delivered was not provided, but was available if required. Seventy five per cent of respondents answered that they did receive feedback, whilst twenty five per cent responded that they did not. One comment made by a respondent who indicated they did not receive feedback was:

> *"should I need feedback it is available" [sic]* (ED DOC)

5.3.7 STANDARD OF CARE

Respondents were asked to rate the standard of care they believed was delivered by POS. One hundred per cent (100%) of referrers rated the service as above average (67%) or excellent (33%)

5.3.8 REFERRING AGENT RESPONSES TO THE OPEN-ENDED QUESTIONS

In addition to the closed-ended questions, there were three open-ended questions in which respondents were invited to provide comment concerning what they liked about POS, what they disliked about POS and what they thought should be improved upon by POS (See Appendix Five). Not every respondent chose to answer any or all of the open-ended questions. However, in the responses to the open-ended questions, several issues were identified. These will now be depicted.

5.3.8.1 POSITIVE PERCEPTIONS OF POS

There were four issues identified by respondents in relation to POS:

- Communication
- Quality and Standard of Care
- Access to POS Staff
- POS Staff Expertise

Each of these will now be described in more detail, and use respondent direct quotes to highlight the issue.

5.3.8.1.1 COMMUNICATION

The first issue identified by parents was in relation to communication. In order that excellent care can be provided to the children and their families and that the care continuum is maintained, communication needs to be provided in two directions.

There were two facets to the issue of communication. The first was in relation to improved communication with the referring agent related to the care given to the patient. Comments to support this include:

"*good communication – like the fax reports especially as these* *don't interrupt my day and I can still keep in touch if needed"* (Paediatrician)

"*excellent referral form which identifies a variety of issues"* (CNS)

and

"*feedback is better"* (Paediatrician).

The second aspect associated with communication concerned the timeliness of feedback whereby POS staff are said to have:

"*always responded in a timely manner"* (Paediatrician)

5.3.8.1.2 QUALITY AND STANDARD OF CARE

In addition to answering the question about the standard of service provision in the closed-ended questions (see Appendix Five), some respondents made further comment on both the standard of care delivered:

"*providing an equivalent standard of care to hospital admission"* (Paediatrician) and concerning the quality of the service another author expressed it like this:

"*it is excellent service – I had feedback from the families that they are very satisfied with the service"[sic].* (GP)

5.3.8.1.3 ACCESS TO POS STAFF

In order for referrers to make their referrals to a service, staff availability is an important factor of service provision. Respondents commented on the availability of POS nurses,

"*…readily available in hours*" (ED DOC)

and

"*…staff are easy to contact…*" (GP)

5.3.8.1.4 POS STAFF EXPERTISE

Another issue that was of importance to the referring agents and was the most commonly repeated issue in responses was in relation to the qualifications of the POS nurses – having specialist nurses provide care to the children in the community was valued by referrers, "*you are aware that patients are being seen by a team of clinically competent staff*" (Paediatrician)

"I like the idea of having paediatric nurses caring for the children in the community I feel more confident referring patients to this service" (CNS)

and

"*I have great confidence in referring infants to a service with specific paediatric nursing skills…*" (NUM)

5.3.8.2 IDEAS FOR IMPROVEMENT

The referring agents also made comments on things they didn't like or thought should be improved. These issues include service restriction and resource allocation; and they will now be described in greater detail.

5.3.8.2.1 SERVICE RESTRICTION

The most consistently expressed idea here was in relation to service restriction. This was expressed in terms of the disadvantages in the fact that the

"*program is limited to one sector*" (Paediatrician)

and the fact that it was thought that it should be *"[made] an area service"* (ED DOC)

and

"POS should be allowed to enter other areas" (CNS).

In relation to the model of service delivery provided by POS within FLGA, one respondent said,

"*when I refer a particularly complex paediatric patient in other areas I always wish the family lived in the Fairfield Area…"* (CNS)

5.3.8.2.2 RESOURCE ALLOCATION

An issue raised by one respondent is in relation to resource usage. There has been ongoing discussion since before POS began about whether a service like POS was *"more of the same or something different"* (Waterlow, 1995). The following comment illustrates the fact that this debate still persists,

"…*some people have made the criticism that your service like the one at Liverpool over-services the clients and that resources could be better spent elsewhere"* (Paediatrician)

5. 9 REFLECTION

The high response rate for this survey is indicative of the interest that referring agents have in influencing the formation and operation of the paedaitric home-based nursing service. In general terms, the respondants feedback was favourable. These findings will be discussed in detail in Chapter Eight. The next Chapter will detail the findings from the parent satisfaction survey.

CHAPTER

SIX

CHAPTER SIX- FINDINGS - PARENT SATISFACTION SURVEYS

6.1 INTRODUCTION

This chapter will present the findings from the Parent Satisfaction Survey (See Appendix Seven). In particular, it describes the profile of children referred to POS (including reason for referral, source of referral and parental perceptions about the quality and standard of care delivered). In addition to a series of close-ended questions, parents were given three open-ended questions and asked to more fully document their opinions on the home-based nursing experience they were exposed to.

6. 2 THE PARENTAL RESPONSE RATE

From the total of 212 surveys that were posted out, only 29 surveys were completed and returned. This gave a response rate of just 13% from the parent consumers. In addition, there were a further 17 (8%) survey's returned to the researcher marked "not known at this address" or "return to sender". This means that in total, 21% of the mailed out surveys could be accounted for. This response is, in fact, one of the limitations of the study and will be discussed in detail in Chapter Nine of this thesis.

Parents were asked to respond to a series of closed-ended questions and then they were given three open-ended questions and invited to share their opinions related to what they liked and disliked about the service and what they thought needed to be improved (like the referrers).

6.3 THE SURVEY RESPONSES

The following pages detail the responses parents gave to the questions in the Client Satisfaction Survey.

6. 3. 1 DEMOGRAPHIC DATA

The first three questions that were asked had the purpose of gathering demographic data about the children who had been seen by POS. The first question was related to where (within the LGA) the child lived. This was denoted by postcode (Fig 6. 1)

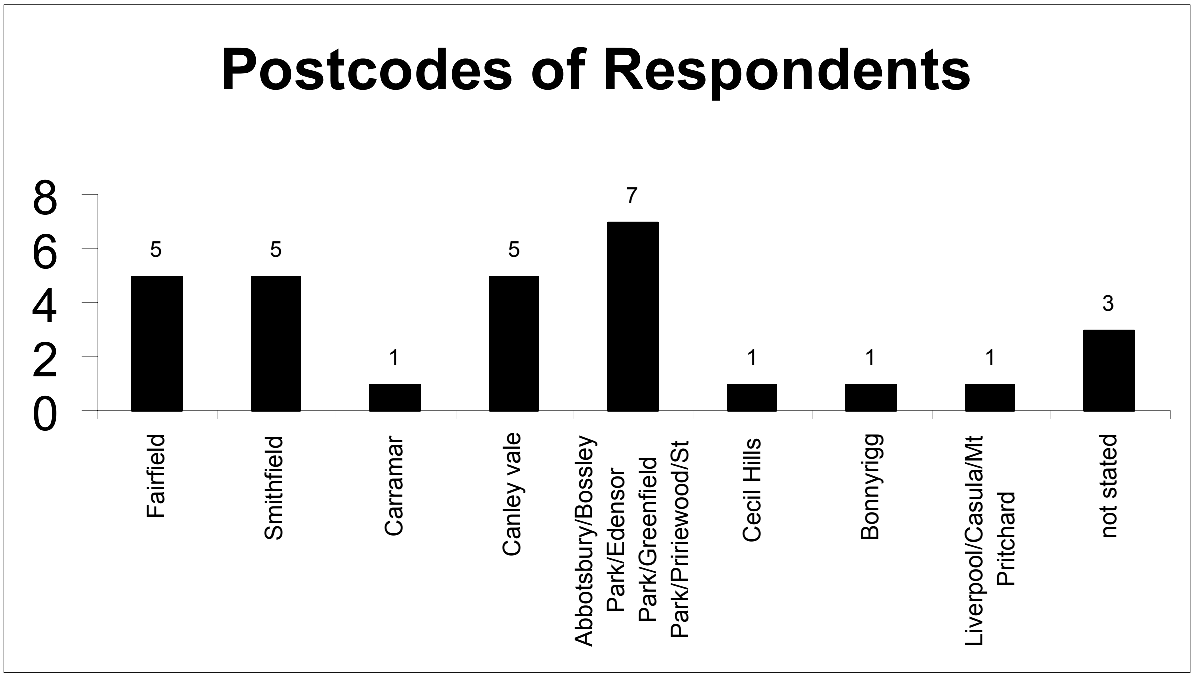


Fig 6. 1 Graph Depicting Residential Address by Postcode

Also of interest to the researcher was the child's country of birth and the language spoken at home (Fig 6. 3). More than 95% of the children seen by POS were born in Australia. This is to be expected in a population of children.

More than 90% of respondents listed English as the language spoken at home. This is somewhat surprising because statistically, South Western Sydney Area Health Service boasts a population where approximately 133 cultures speak 50 different languages (Fairfield City Council stats www. ffcity. com ,2000)

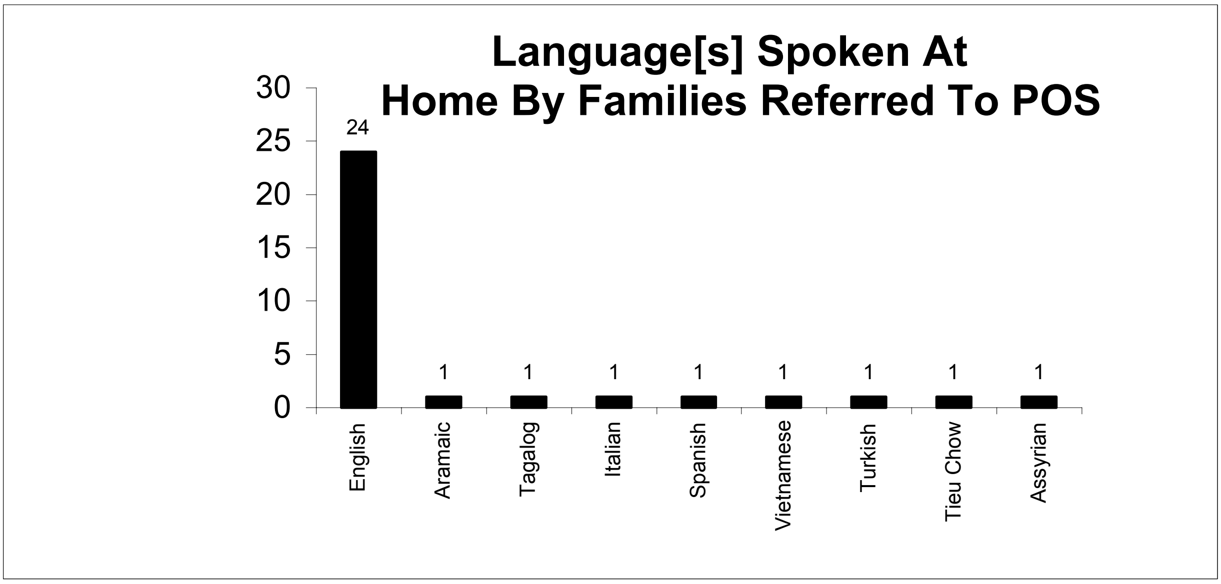


Fig 6.2 Graph showing the Language(s) Spoken at Home by Families Seen by POS

The totals in this graph add up to greater than 100% because there were several parents who indicated that there was more than one language spoken in their home. Seventy-six per cent of all respondents indicated that English is the language spoken within the family home.

6.3.2 FREQUENCY OF PREVIOUS ILLNESS IN CHILDREN REFERRED TO POS

Parents were asked to recall how many times their child had been sick in the previous six months. Approximately forty per cent of children had experienced 3 or more episodes of illness in the stated period and a total of almost two thirds of children had had 2 or 3 episodes of illness.

6.3.3 HEALTH CARE PROFESSIONALS WHO REVIEWED THE CHILD

Parents listed a variety of health care professionals when asked to indicate whose assistance they had sought in relation to their child's health. By far, the greatest number of parents sought the opinion and assistance of their Local Medical Officer when their child was ill (almost twice as often as all other health care professionals).

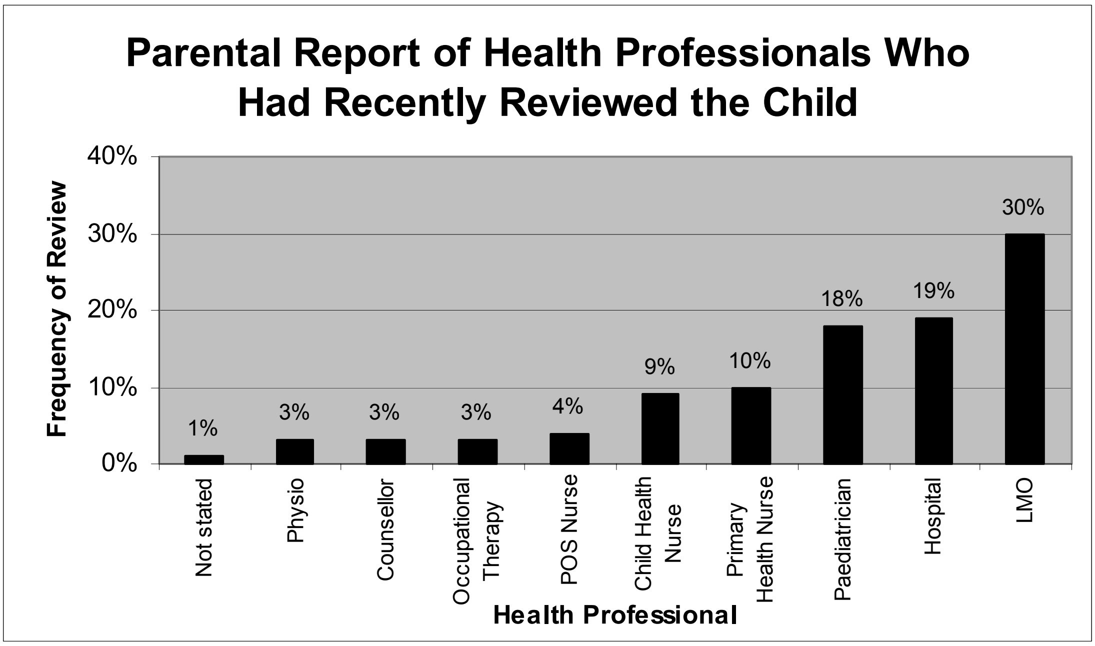
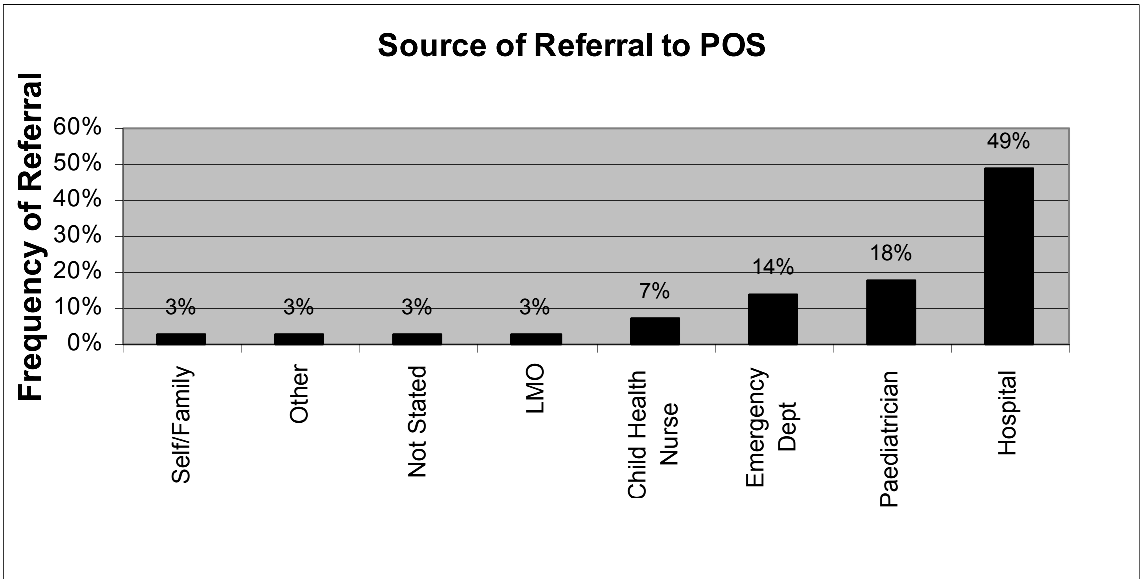


Fig 6.3 Graph Depicting Health Professionals Who Have Reviewed the Child Recently

6.3.4 SOURCE OF REFERRAL

Parents were asked to indicate who referred their child to POS. Fig 6.6 illustrates the sources of referral for respondents' children.

Fig 6.4 Graph Displaying Parental Recall Related to the Source of Their Child's Referral to POS



6.3.5 REASON FOR REFERRAL

Consistent with statistics gathered by Hanson RAHC 1990, the greatest cause of illness in the referred children was respiratory system related. Bronchiolitis was the most common reason for referrals, followed by asthma, non-specific respiratory illness and pneumonia. Cumulatively, respiratory illness accounts for a little over 50% of all referrals

Fig 6.5 shows that children were referred to POS for a wide variety of reasons (including physical nursing care, support, and resource provision). Parents often identified that the child and family had more than one health need. The category of "*other*" includes conditions such as eczema, toilet training, pneumonia, convulsion, cough/cold, burns and general advice. These were specific reasons that parents documented independently, rather than tick one of the given illnesses.

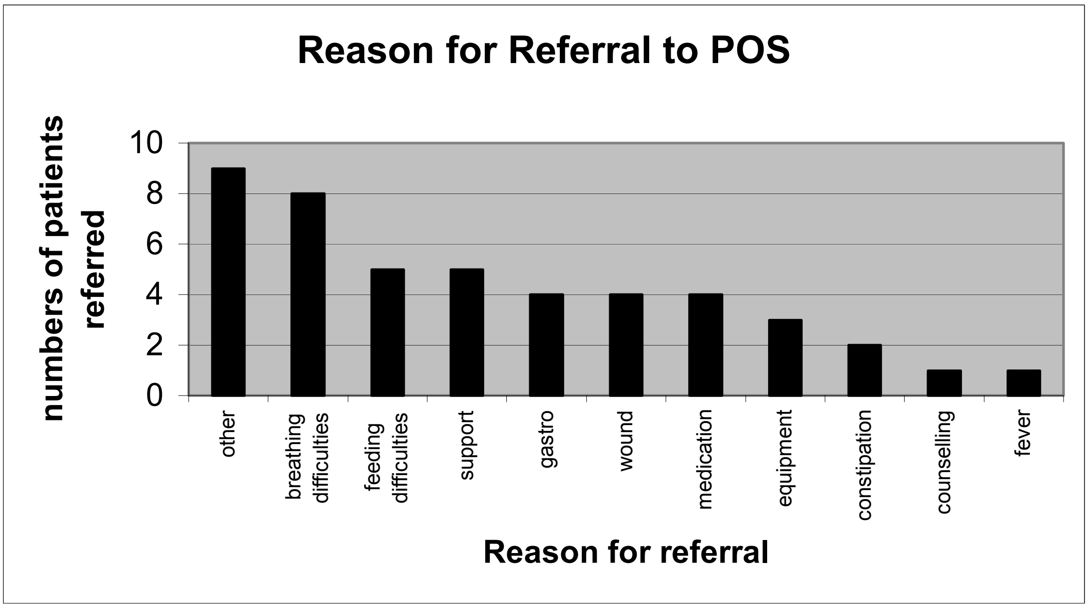


Fig 6.5 Reasons for Referral to POS

6.3.6 TIMELINESS TO HOME VISIT

Almost 50% of patients received their first visit within the first 24 hours. A further 30% received their first visit within two days. Fig 6.6 demonstrates the parental responses about the length of time they waited for a visit from POS.

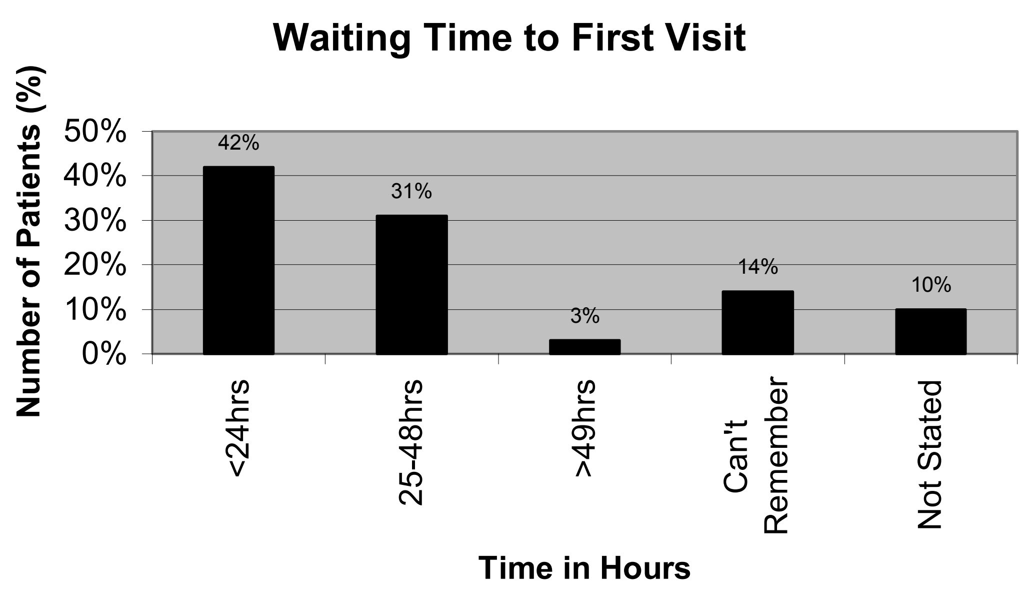


Fig 6.6 Graph Depicting Time to First Visit

6.3.7 SATISFACTION WITH WAITING PERIOD

When asked about their satisfaction with the period of time they had to wait for their child to be seen by POS, 93% of parents stated that they were satisfied.

6.3.8 SATISFACTION WITH NUMBER OF VISITS RECEIVED

Parents were asked to recall how many times their child was visited by POS staff (Fig 6.7) and then to state their satisfaction with the number of visits provided.

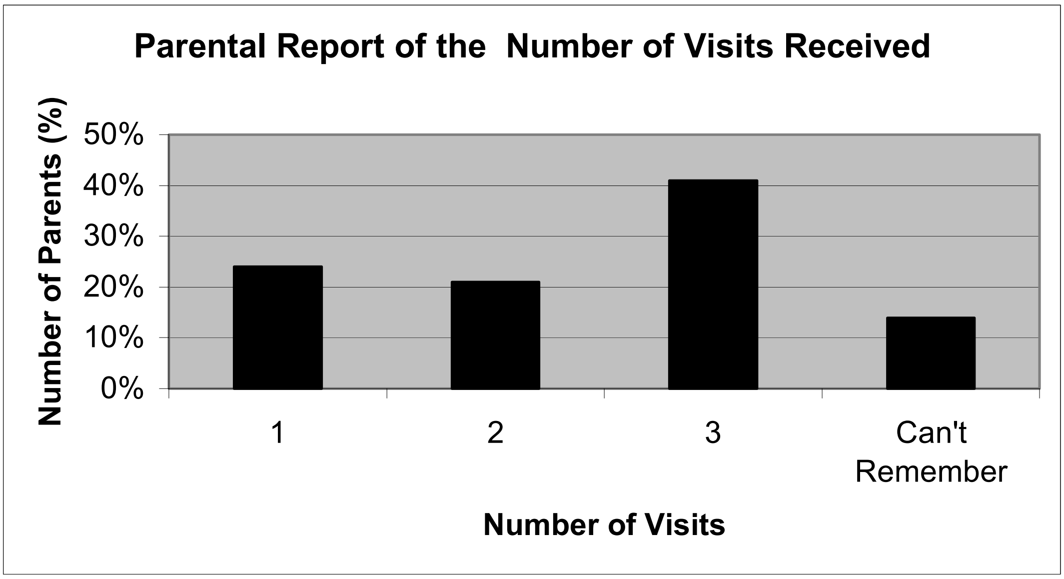


Fig 6.7 Number of Visits Received

Forty one per cent of parents indicated their child received three or more visits.

Regarding parental satisfaction with the number of visits provided, 97% of parents were satisfied that their child had received “the right number of visits”.

6.3.9 PARENTAL PERCEPTION OF SERVICE QUALITY

Parents were asked to rate the quality of the home-visiting nursing service they received. Fig 6.8 shows that seventy per cent of parents rated the quality of the service provision as excellent with a further twenty-four describing it as above average.

Fig 6.8 Graph displaying Parental Opinion Related to The Quality of Service Provided by POS

6.3.10 PARENTAL SATISFCATION WITH HOURS OF OPERATION

Parents were asked whether they thought the current hours of operation were adequate. Fig 6.9 shows that almost ninety per cent of respondents said they thought the hours off operation were adequate. One parent who answered “no” said the service should operate between 8pm-12mn because:

"children always get sick in the night".

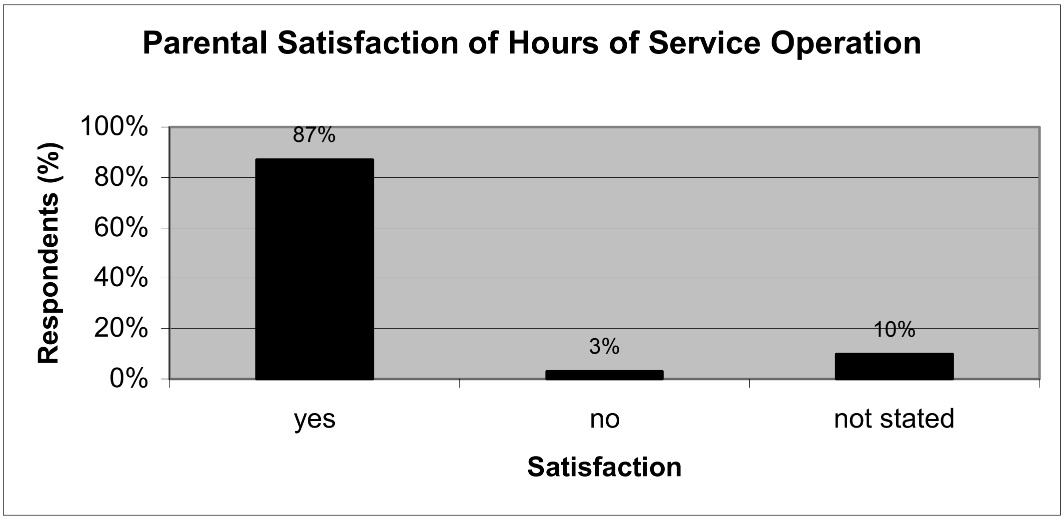


Fig 6.9 Graph depicting Parental Opinion Related to the adequacy of Service Hours

One parent, who did not answer the question, identified that her assistance had been via the phone and so, she was not sure of POS hours.

6.3.11 RECEIVED INFORMATION ABOUT THEIR CHILD'S CONDITION

Eighty seven percent of parents said they usually received information about their child's condition, with a further seven percent of respondents indicating they sometimes received information. This left only six percent of parents who felt they didn't really get much information.

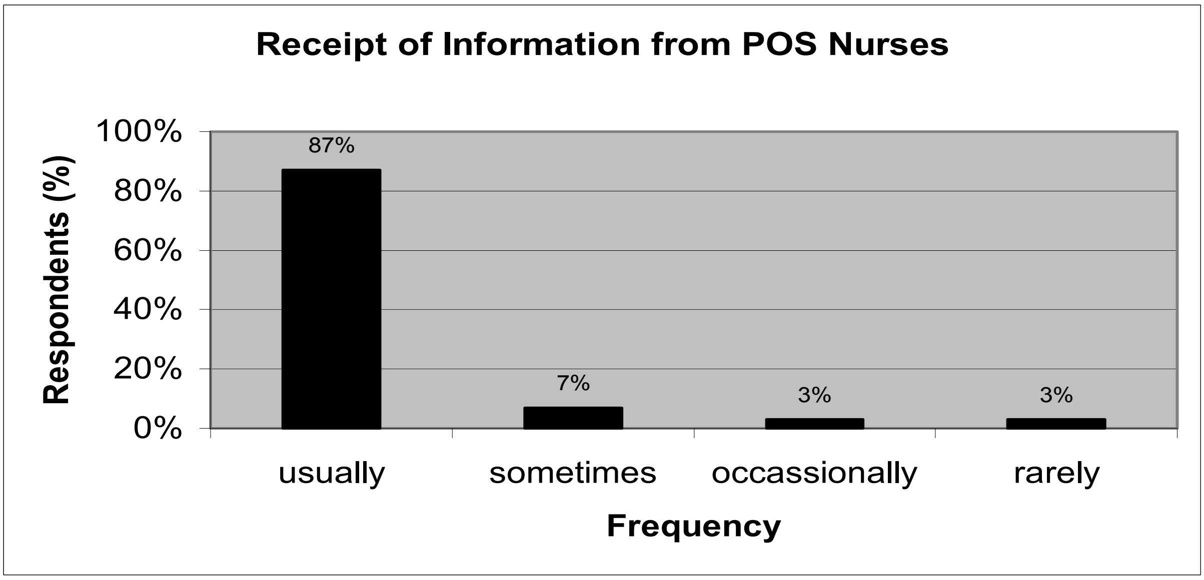
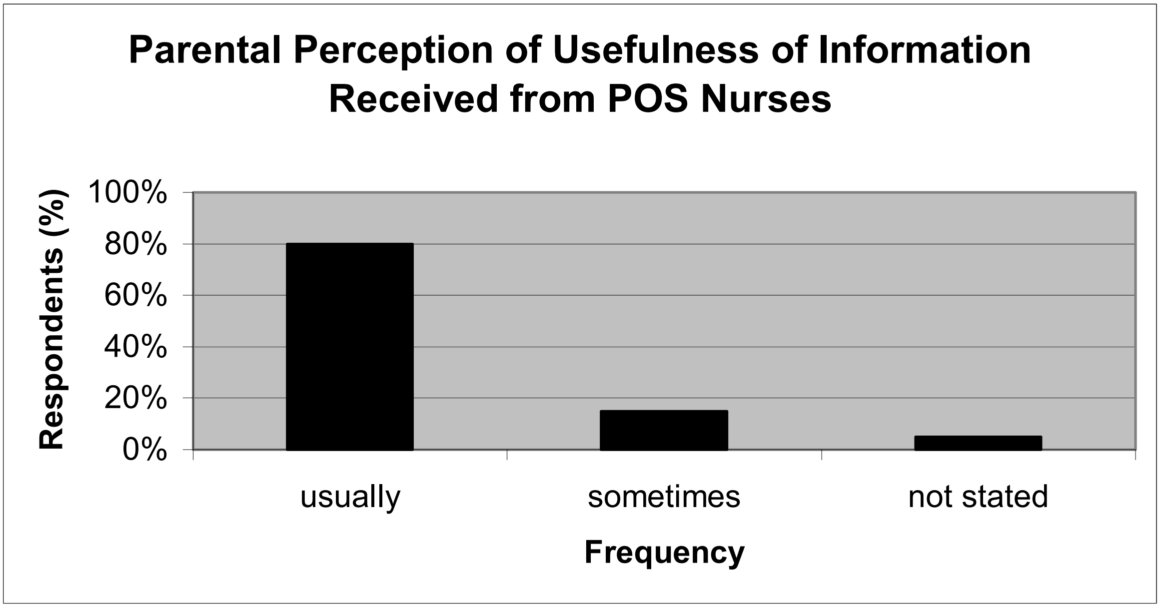


Fig 6. 10 Graph depicting Parental Opinion Related to the information they received from the POS Nurses

6.3.12 PARENTAL PERCEPTION OF THE USEFULNESS OF THE INFORMATION RECEIVED

Parents were then asked to comment on the usefulness of the information they received. Ninety-seven per cent of parents usually or occasionally found the information to be useful. Three per cent of respondents did not answer this question.

Fig 6. 11 Graph depicting Parental Opinion Related to the usefulness of the information they received



6.3.13 PARENTAL CONFIDENCE IN NURSES SKILLS

Eighty five percent of parents indicated that they were usually confident in the skill level of the nursing staff who were taking care of their child. Seven percent were sometimes confident, four percent were occasionally confident and four percent of respondents were rarely confident. (See Fig 6.12)

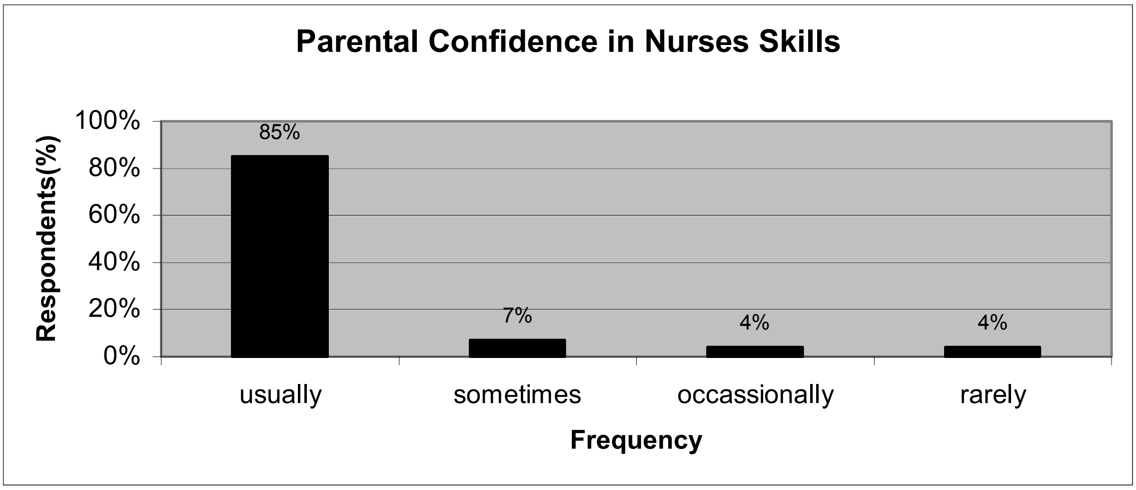


Fig 6.12 Graph Displaying Parental Confidence in the Skills of the Nurses Taking Care of Their Child

6.3.14 PARENTAL CONFIDENCE IN NURSES KNOWLEDGE

Parents had a similar response when asked about their confidence in the nurse’s knowledge with eighty five percent of parents indicating they were usually confident in the nurses’ knowledge. (See Fig 6.13)

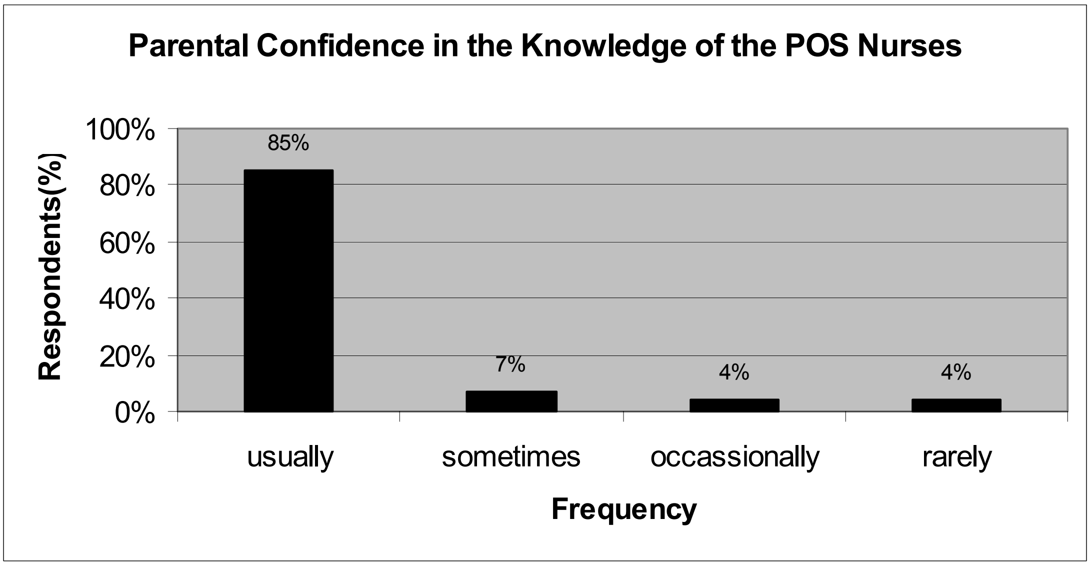


Fig 6.13 Graph Displaying Parental Confidence in the Knowledge of the Nurses Taking Care of Their Child

6.3.15 PARENTAL INVOLVEMENT IN CARE PLANNING

POS nurses provide intermittent nursing care through home-visiting. In the absence of the nurse, parents are required to continue to provide health care for their child. In light of this, it is somewhat alarming that only forty nine percent of parents felt they were involved in care planning, whilst thirty one percent of parents only occasionally or rarely felt involved in the planning of their child’s care.

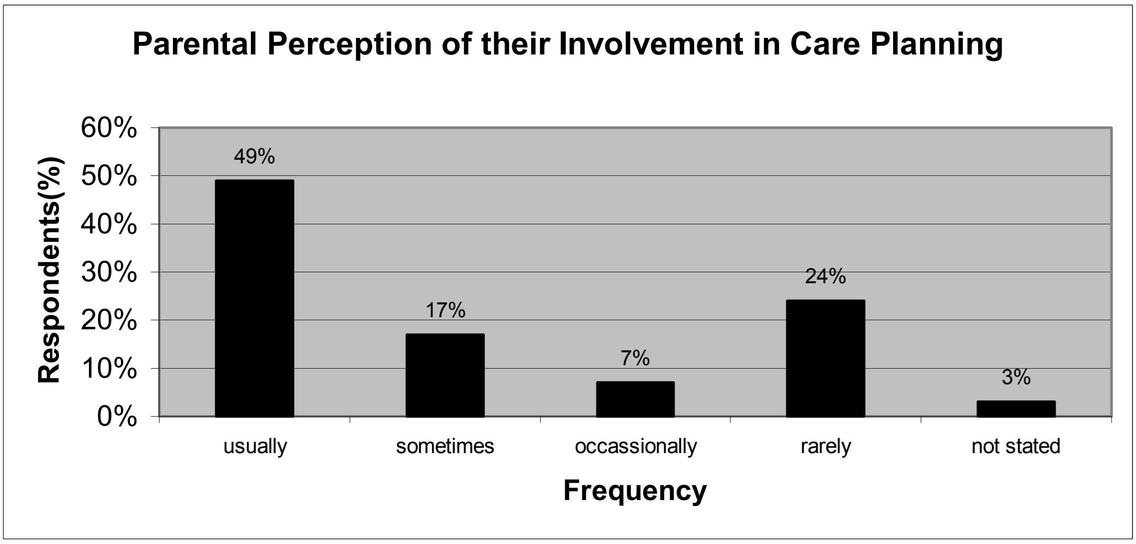


Fig 6.14 Graph Displaying Parental Perceptions of Their Involvement in Care Planning for Their Child

6.3.16 PARENTAL AWARENESS OF THEIR RIGHTS AND RESPONSIBILITIES

Within a partnership each party has rights and responsibilities. Only sixty three percent of respondents felt that the nurse usually explained their rights and responsibilities to them. A further thirteen percent said that they sometimes or occasionally had their rights and responsibilities explained. It is alarming that seventeen percent of parents indicated that they were rarely told of their rights and responsibilities as consumers of the POS.

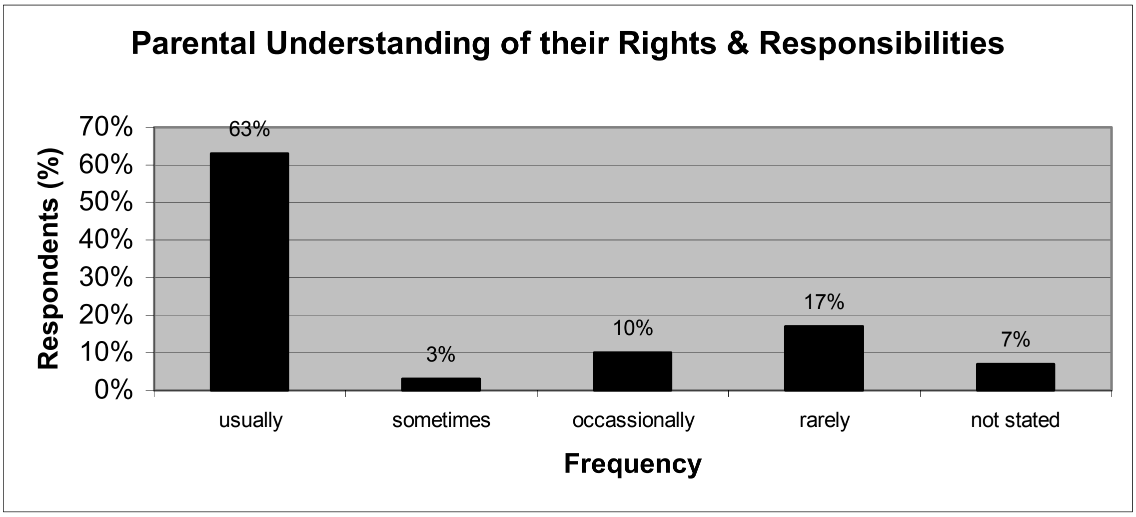


Fig 6.15 Graph Displaying Parental Understanding of their rights and responsibilities

6.3.17 CONTRACTING THE NUMBER OF HOME VISITS REQUIRED

When asked if the nurse discussed with them the approximate number of visits required to treat their child's condition, only sixty two percent of parents said this usually happened. A further seven per cent said this occurred sometimes. For almost thirty per cent of parents, involvement in contracting home visits did not occur (see Fig 6.16)

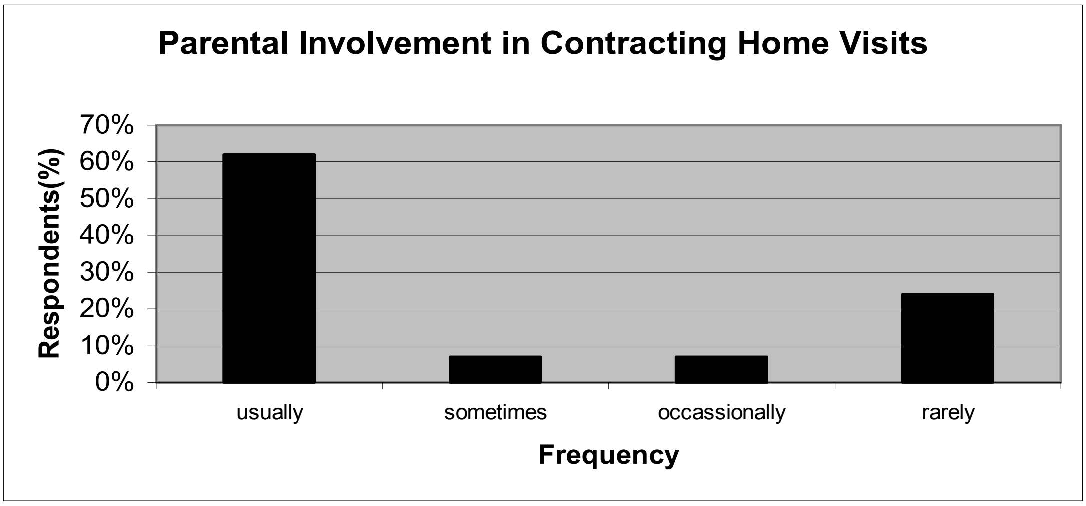


Fig 6. 16 Graph Displaying Parental Perception Regarding Their Involvement in Contracting Home Visits

6.3.17 KNOWLEDGE OF THE TREATING NURSES NAME

Seventy six percent of parents indicated that they generally knew the name of the nurses who visited their child at home. Seventeen percent said they sometimes or occasionally knew the nurses names. Seven percent of respondents did not answer this question

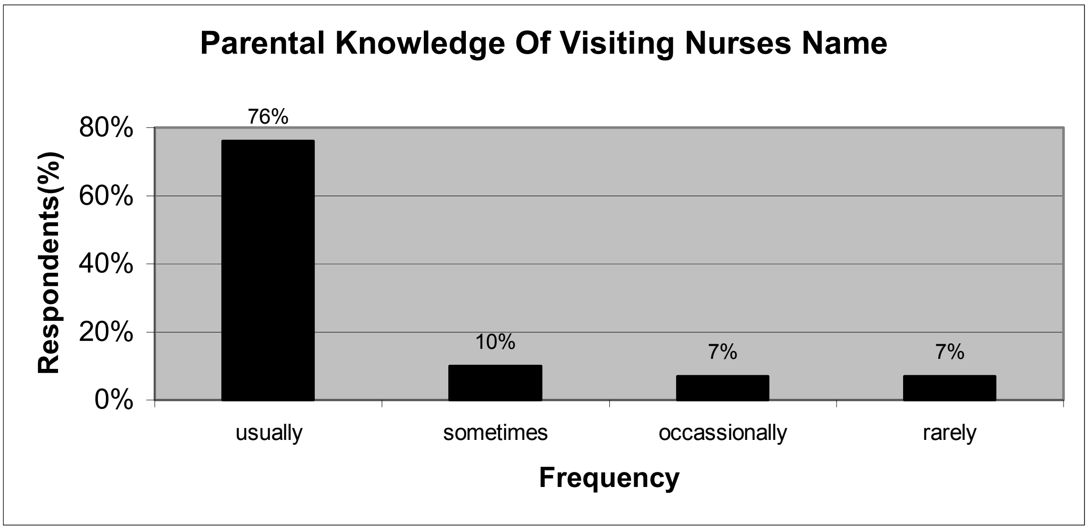


Fig 6. 17 Graph displaying parental awareness of the name of the nurse taking care of their child

6.3.18 GENUINENESS

Two other questions were asked of parents that impacted upon the personalised nature of their relationship with the nurse. The first was in regard to whether parents believed the nurse was genuinely concerned about their child. Genuineness was usually perceived by forty seven percent of respondents with a further forty five percent saying they sometimes believed the nurse was genuine.

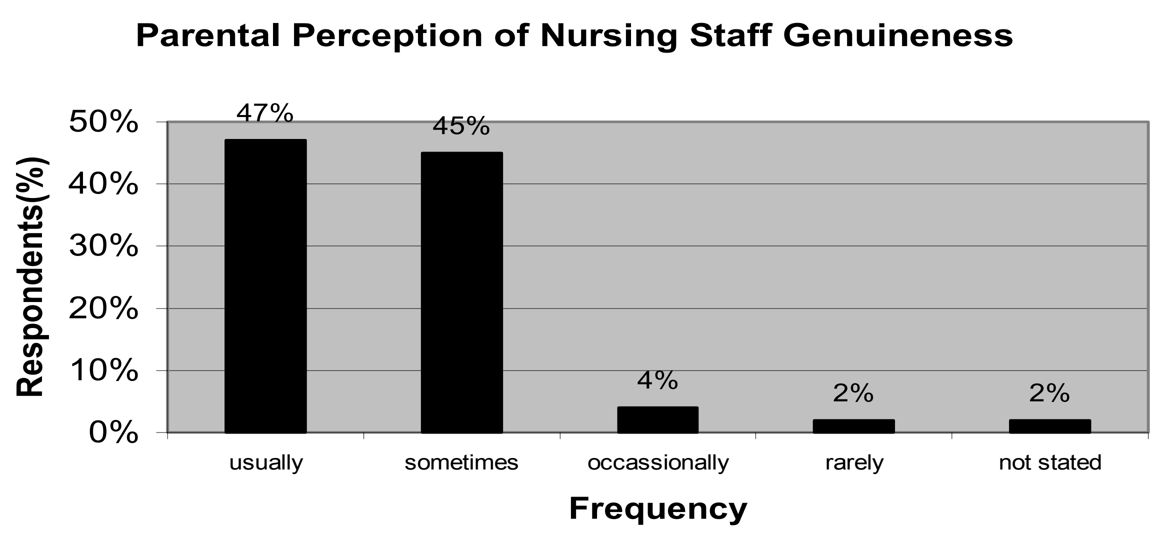


Fig 6.18 Graph Displaying Parental Beliefs Related to Nurses Genuineness

6.3.19 PARENTAL PERCEPTION OF THEIR ROLE AS CARER

The second question that impacted upon the personalised nature of their relationship with the nurse was about whether parents felt that their role of carer was valued. It is reassuring that almost 90% of respondents felt valued in their carers role.

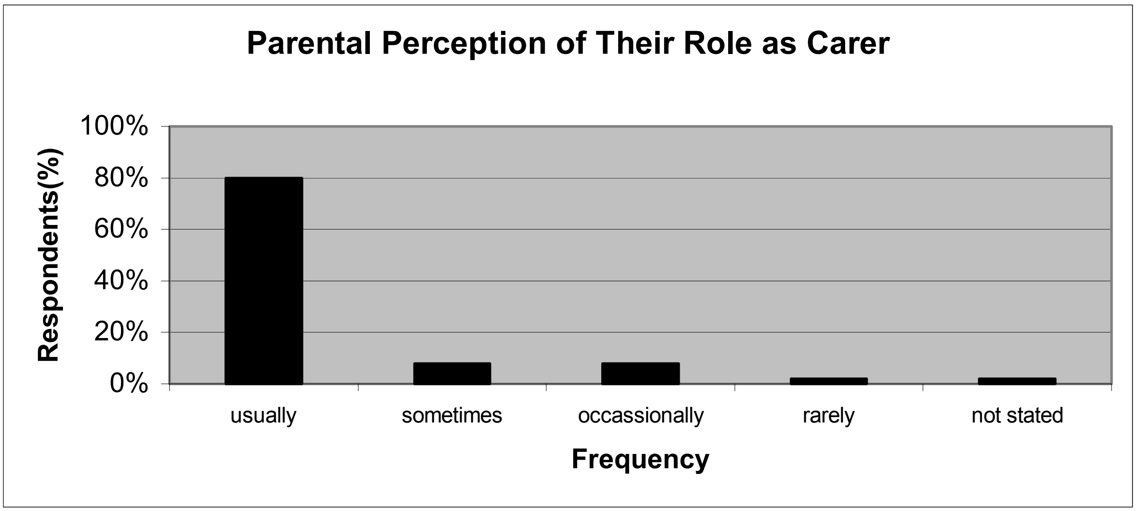


Fig 6.19 Graph Displaying Parental Beliefs About The Value of Their Role as Carer

6. 3. 21 PARENTAL AWARENESS OF COMPLAINT PROCESS

When asked if they had been made aware of how to make a complaint, almost 60% of parents indicated that they were really not aware of this process. (See Fig 6.20)

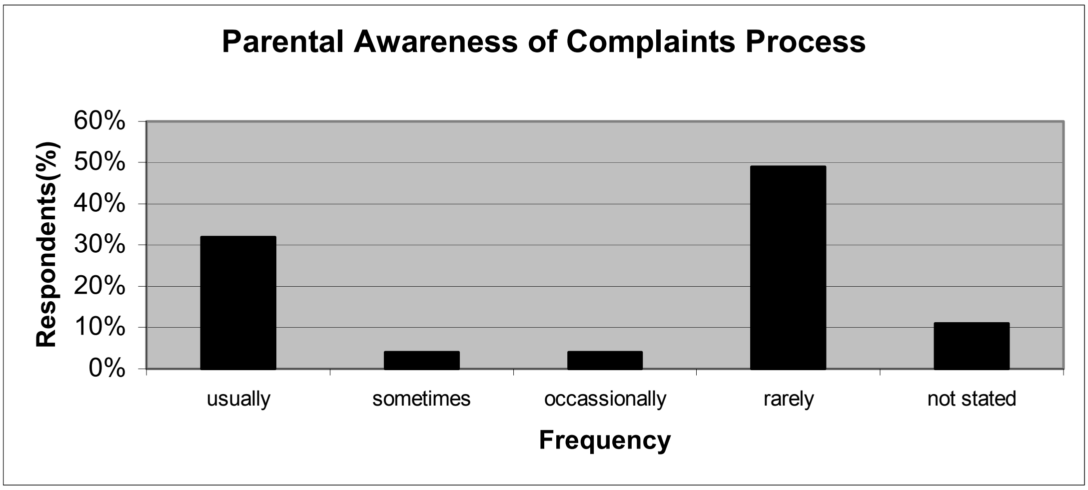


Fig 6.20 Graph Displaying Parental Awareness of How to Make a Complaint

6. 3. 22 CARE PLAN & LIFESTYLE CONGRUENCE

Parents were asked to indicate whether the plan of care suited their lifestyle. Eighty five percent of parents indicated that the care plan usually fitted in with the family’s lifestyle. A further eight percent said it sometimes fitted.

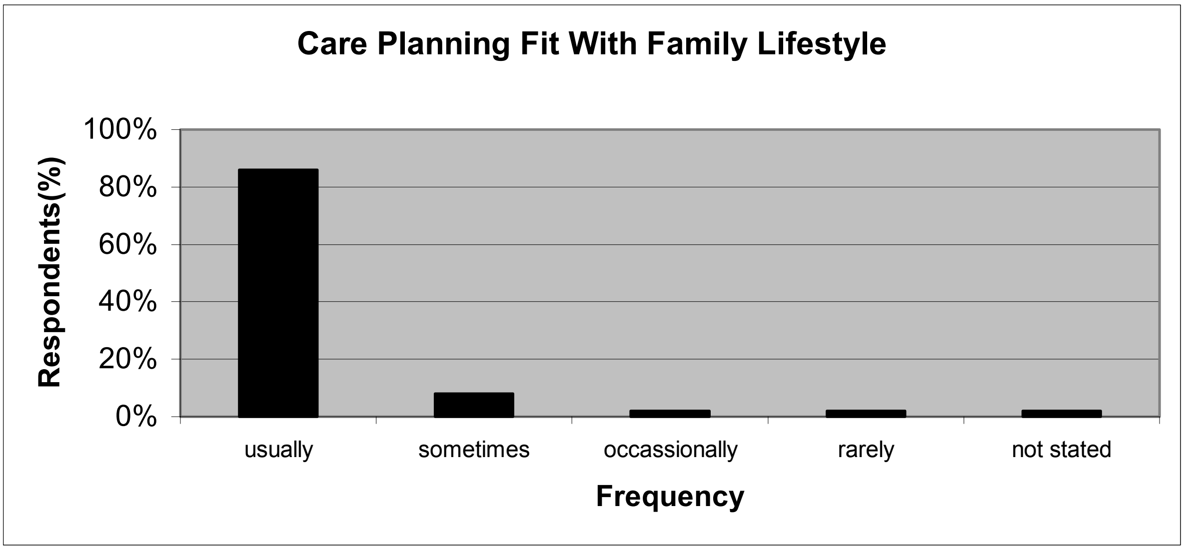


Fig 6.21 Graph Showing Parental Beliefs of How the Medical Care Plan Fit with Their Family's Lifestyle

6.4 ANSWERS TO THE OPEN-ENDED QUESTION

In addition to the closed-ended questions, there were three open-ended questions asked. Parents were asked to describe what they liked about the service, what they disliked and what they believed could be improved.

6.4.1 THE THINGS PARENTS VALUED

There were a number of issues identified that parents valued about POS These included:

6.4.1.1 NURSING STAFF ATTRIBUTES

Personal attributes of the nurses that were valued include the fact that nurses were perceived as caring, considerate, friendly and punctual.

> *"it was generally a friendly and supportive visit…"*

> *"the nurses were all lovely, helpful and caring towards me and my son"*

> *"…nothing was too much trouble…"*

> *"…and they really cared about my son. I liked the way they would ring me and tell when they would be coming and…they would be exactly on time"*

6.4.1.2 NURSES KNOWLEDGE

Parents valued the fact that the nurses knew what was wrong with their child and about the treatment required to return their child to optimal health.

> *"the person who came out to visit was brilliant and gave very valuable information"*

“. . explained how to and showed how to bandage and treat eczema…”[sic]

6.4.1.3 REASSURANCE

Parents need to know that they are doing the very best that they can for their children Having a nurse come to the house to see them and their child(ren) in their own home is important to parents They have the opportunity to learn and ask questions in the security of their own home.

“…and took the time to explain to me and my wife about reflux…”

“ …nurses coming to your house when you needed to talk to somebody so the nurse can see first hand the problems…”

“…at both times I looked forward to the nurse calling me I appreciated her opion and felt reassured after each call”[sic]

“ it gave me peace of mind…”

6.4.1.4 STANDARD OF CARE

In order that parents will accept an alternative to hospital care, they need to know that the choice they make for their sick child is not for an inferior service. Therefore POS needs to be able to offer parents a service of as good or better quality as they could receive at the hospital. One parent described this as:

> *"… being able to stay at home and having the same monitoring as if we were in hospital"*

6.4.15 EARLIER DISCHARGE

It was interesting that one of the issues raised by parents as a positive aspect of POS, was about a shortened length of stay in hospital for their child because of the POS intervention. It appeared that parents equated being sent home supported (by a visiting nurse) with a shorter length of stay. They said:

> *"…my child was able to get out of hospital quicker and return to home environment, which made her happier…"[sic]*

> *"…what I liked about the service I received was that my sick child was cared for by professional nurses in his own environment and monitored, thus his recovery was much speedier than him been in hospital with total strangers…" [sic]*

> *"…not having to stay in hospital for the extended time. Freedom to get life back to as normal or as close to as soon as possible"*

> *"…being at home and its surrounds was better than hospital environment…"*

6.4.2 PARENTAL DISLIKES

The most consistent parent complaint was related to lack of phone follow-up once the child had been discharged from POS. This was also given as a suggestion for service improvement. Parents said:

> *"…follow-up on sick children would be appreciated now and again…"*

> *"…telephone call would be nice to check how my son was doing at least I know you also cared…"*

> *"… regular calls to the parents to make sure the child is doing well…"*

6.4.3 PARENTAL IDEAS FOR SERVICE IMPROVEMENT

The most consistent idea for service improvement was in relation to disseminating information about the service more widely. Regarding service improvement, parents most commonly commented on the need for an increase in community knowledge about the service. Respondents said:

> *"…expand what already exists so that all parents have the opportunity of using this service…"*

> *"…should be more around. Other areas would benefit…"*

> *"…perhaps making your services known to local hospitals…"*

> *"…advertising your service and informing more parents about your service better. At present most parents are hearing about the service from a few staff members at the emergency unit of the hospital…"*

6.5 REFLECTION

As the response rate from this group was small, it is difficult to determine whether these results are indicative of the broader population. However, even this small number of responses provided POS staff with opportunities for service improvement. How these findings were applied will be discussed in detail in Chapter Nine.

CHAPTER

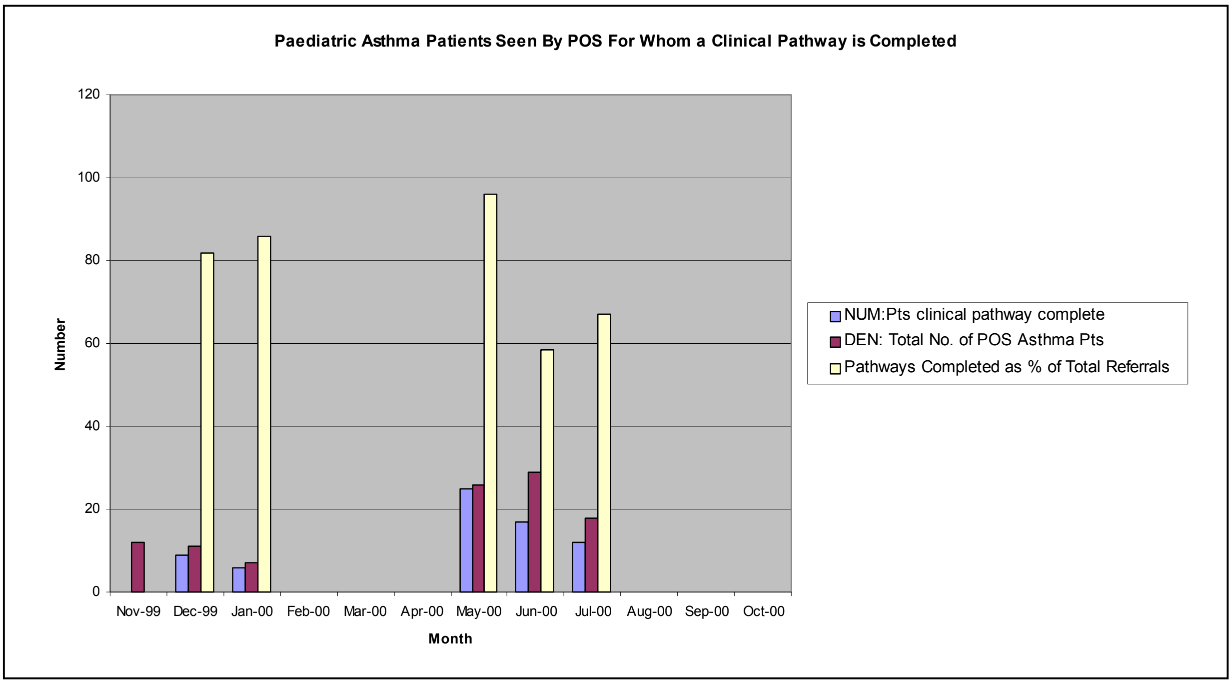
SEVEN

7.1 INTRODUCTION

This chapter will present the findings of data collection against the service indicators that were developed. Data was collected for 2 periods each of three months duration to test whether the indicators could collect the information they were designed for.

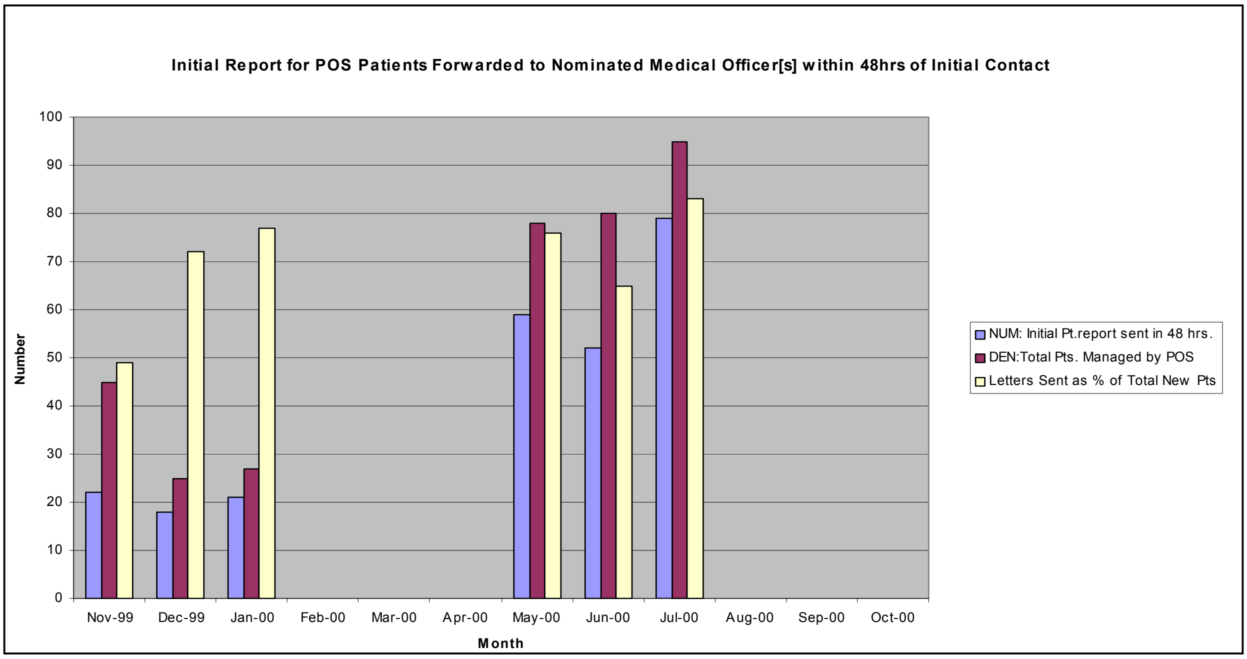
7.1.1 PAEDIATRIC ASTHMA

MONTH	Nov 99	Dec 99	Jan 00	Feb 00	Mar 00	Apr 00	May 00	Jun 00	Jul 00	Aug 00	Sep 00	Oct 00
NUM: Pts clinical pathway complete.	0	9	6				25	17	12			
DEN: Total No.of POS Asthma Pts.	12	11	7				26	29	18			
Pathways Completed as % of Total.	0	82	86				96	58.6	67			



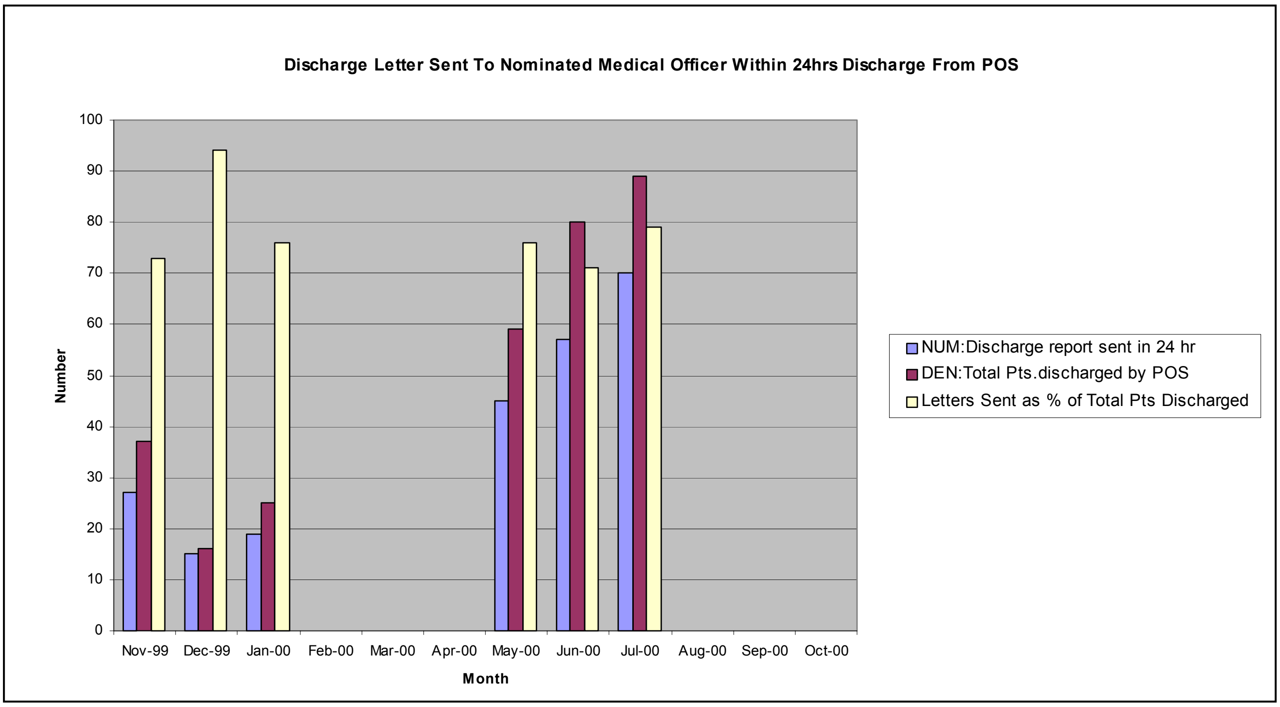
7.2 INITIAL REPORT

MONTH	**Nov 99**	**Dec 99**	**Jan 00**	**Feb 00**	**Mar 00**	**Apr 00**	**May 00**	**Jun 00**	**Jul 00**	**Aug 00**	**Sep 00**	**Oct 00**
NUM: Initial Pt. Report sent in 48 hrs.	22	18	21				59	52	79			
DEN: Total Pts. Managed by POS.	45	25	27				78	80	95			
Letters Sent as % of Total New Pts	49	72	7				76	65	83			


Initial Report for POS Patients Forwarded to Nominated Medical Officer[s] within 48hrs of Initial Contact

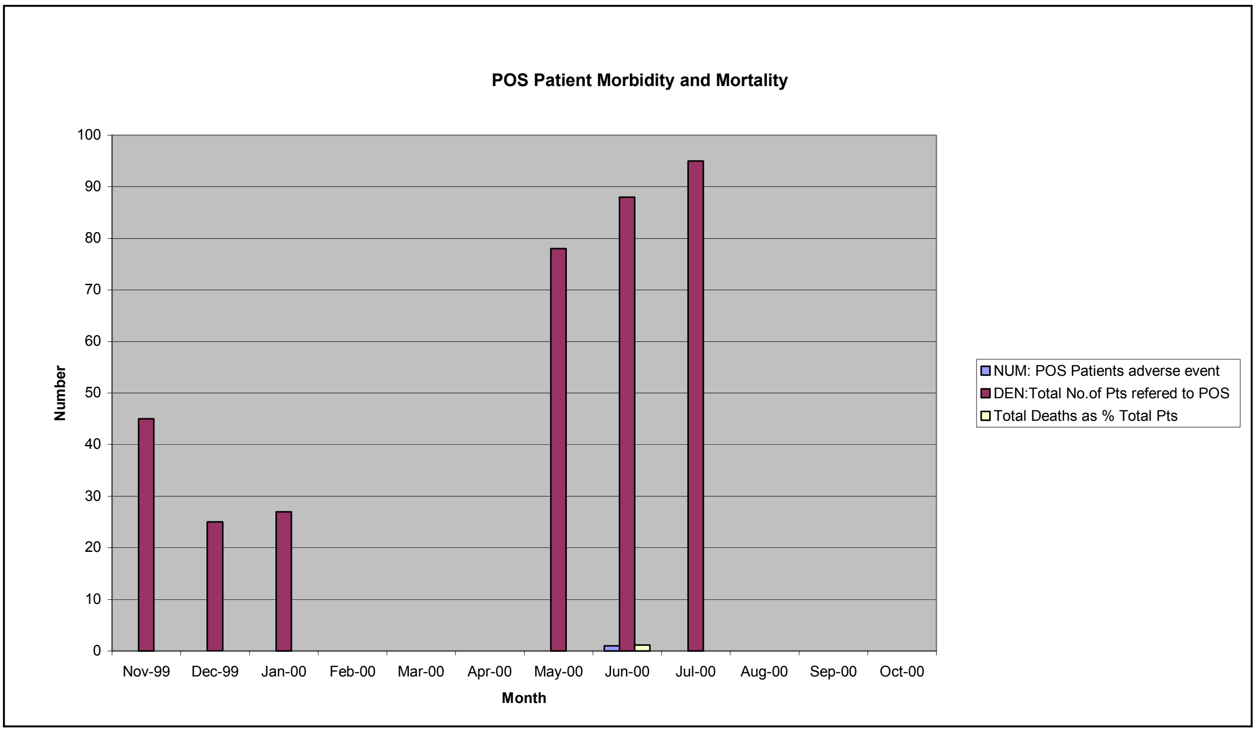
7.3 DISCHARGE REPORT

MONTH	Nov 99	Dec 99	Jan 00	Feb 00	Mar 00	Apr 00	May 00	Jun 00	Jul 00	Aug 00	Sep 00	Oct 00
NUM: Discharge report sent in 24 hrs.	27	15	19				45	57	70			
DEN: Total Pts. discharged by POS.	37	16	25				59	80	89			
Letters Sent as % of Total New Pts.	73	94	76				76	71	79			



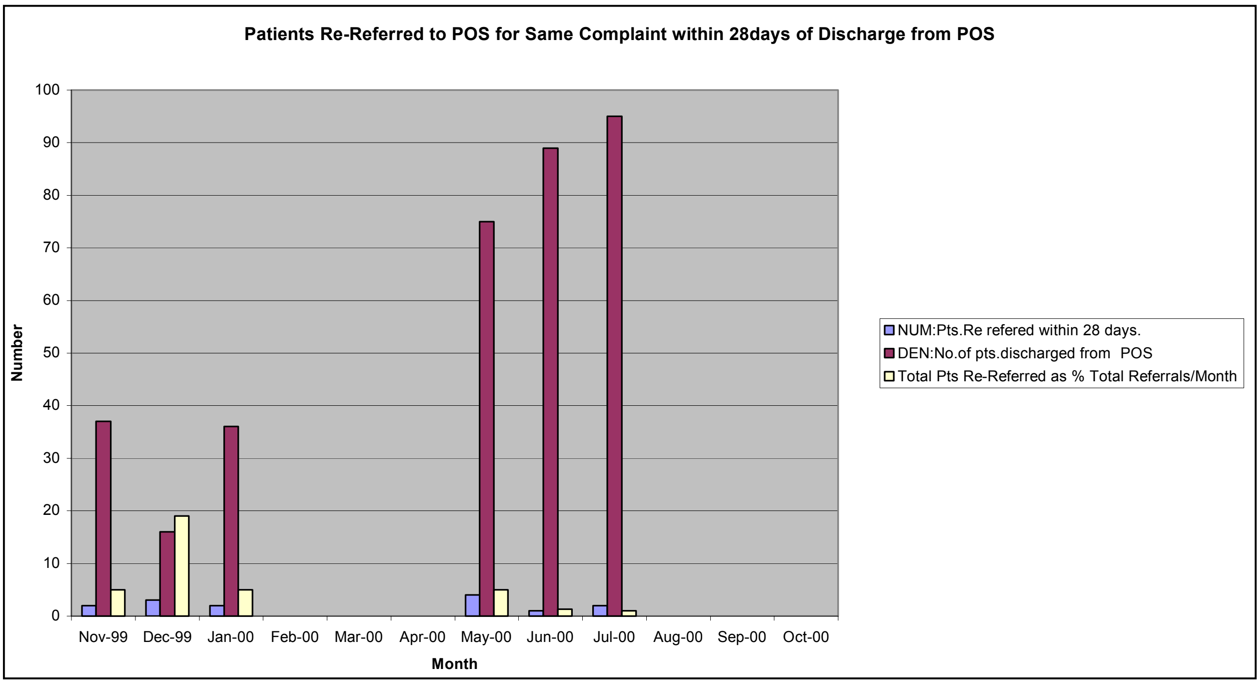
7.4 MORBIDITY AND MORTALITY

MONTH	**Nov 99**	**Dec 99**	**Jan 00**	**Feb 00**	**Mar 00**	**Apr 00**	**May 00**	**Jun 00**	**Jul 00**	**Aug 00**	**Sep 00**	**Oct 00**
NUM: POS patients adverse event.	0	0	0				0	1	0			
DEN: Total Pts. referred to POS.	45	25	27				78	88	95			
Total Deaths as % Total pts.	0	0	0				0	1.13	0			



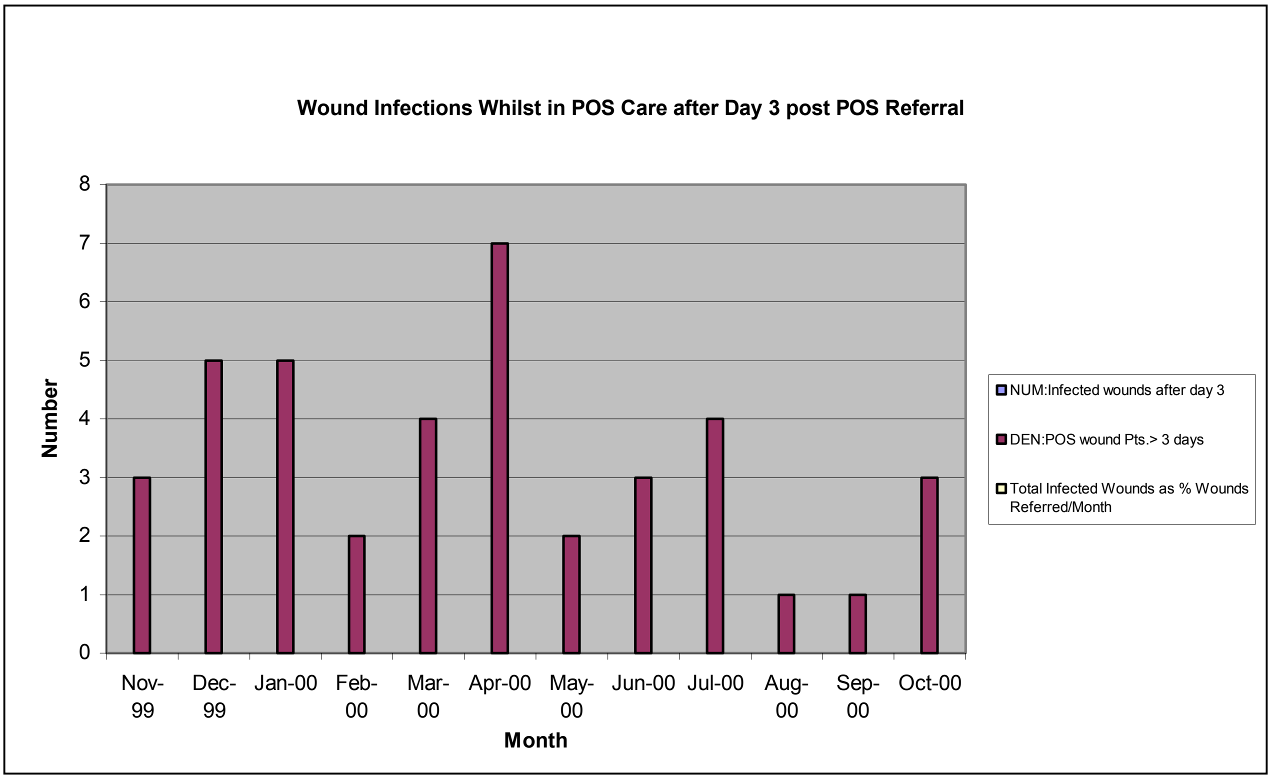
7.5 RE-REFERRAL RATES

MONTH	**Nov 99**	**Dec 99**	**Jan 00**	**Feb 00**	**Mar 00**	**Apr 00**	**May 00**	**Jun 00**	**Jul 00**	**Aug 00**	**Sep 00**	**Oct 00**
NUM: Pts. Re-referred within 28 days.	2	3	2				4	1	2			
DEN: No. of pts discharged from POS.	37	16	36				75	89	95			
Total Pts re-referred as % Total ref.	5	19	5				5	1.3	1			



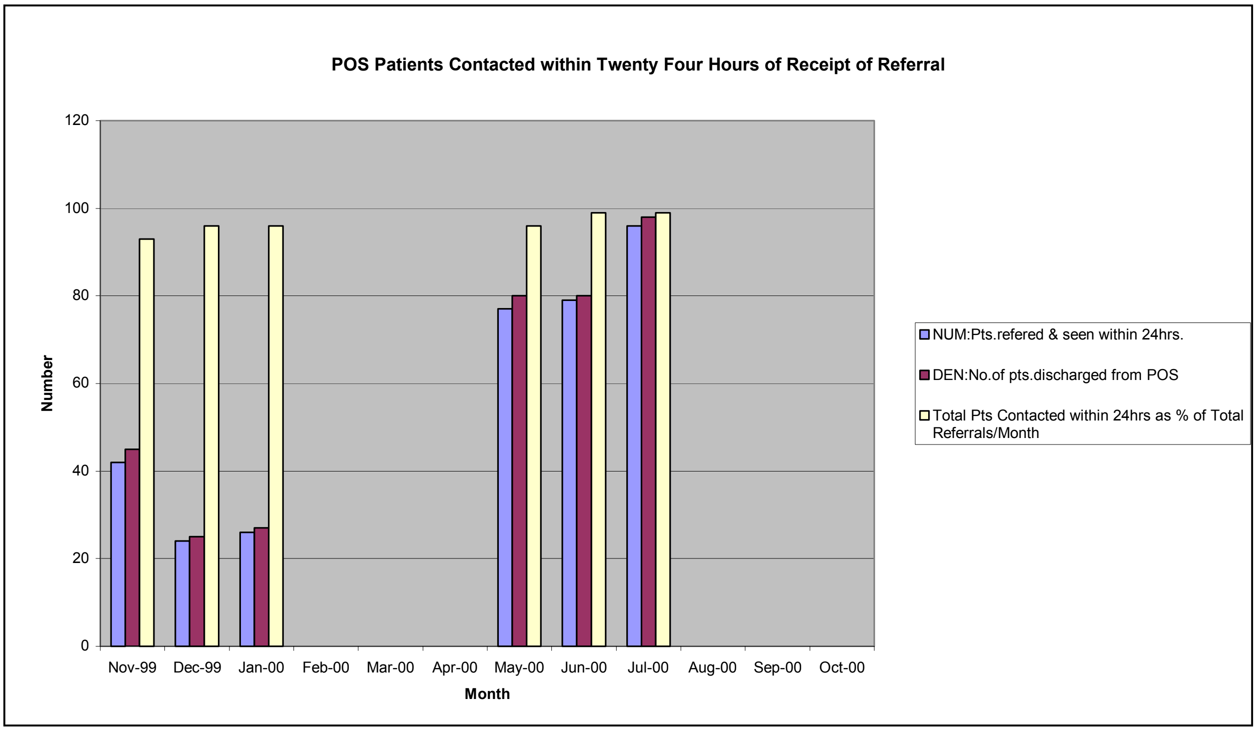
7.6 WOUND INFECTION RATES

MONTH	**Nov 99**	**Dec 99**	**Jan 00**	**Feb 00**	**Mar 00**	**Apr 00**	**May 00**	**Jun 00**	**Jul 00**	**Aug 00**	**Sep 00**	**Oct 00**
NUM: Infected wounds after day 3.	0	0	0	0	0	0	0	0	0	0	0	0
DEN: POS wounds Pts.>3 days.	3	5	5	2	4	7	2	3	4	1	1	3
Total Infected Wounds as % Wounds	0	0	0	0	0	0	0	0	0	0	0	0



7.7 TIMELINESS TO FIRST VISIT

MONTH	Nov 99	Dec 99	Jan 00	Feb 00	Mar 00	Apr 00	May 00	Jun 00	Jul 00	Aug 00	Sep 00	Oct 00
NUM: Pts.referred & seen within 24 hrs	42	24	26				77	79	96			
DEN: No.of pts discharged from POS.	45	25	27				80	80	98			
Total Pts Contacted within 24 hrs.	93	96	96				96	99	99			



CHAPTER

EIGHT

CHAPTER EIGHT-DISCUSSION

8. 1 INTRODUCTION

"Mirror Mirror on the Wall
Who's the Fairest of them all?"

From Snow White(Disney, 1937)

When Snow White's vain stepmother, the Queen, looked into her mirror she wanted to know who was the most beautiful woman in the region, or more specifically, she wanted to know that *she* was the fairest in all the world. For POS providers, the evaluation process was the mirror and when staff looked at that, they wanted to know that they were the fairest of them all, or more plainly, staff wanted to know that the service provided was the best it could be.

When the Queen looked into her mirror, she wanted to know that all her hours invested in beauty therapies were evident. When POS providers looked into the evaluation mirror, they wanted to see where the hours spent developing the service were evident. Where beauty was in the eye of the beholder for the Queen, it was in the eye of the consumer for POS. Thus, it was important to seek the opinions of consumers in order to evaluate what was beautiful (good) about current practice, what was ugly (not valid) and what could be improved.

To continue this metaphor of the evaluation process as a mirror, looking at service provision, is like being in a room full of mirrors. Each phase of the evaluation process (as described in Chapter 2), is like a separate mirror, each reflecting a different component of the evaluation process. In order to ascertain consumer opinion on paediatric outreach as a service for this thesis, two “mirrors” were developed in the form of customer satisfaction surveys. Questions were developed by the researcher to elicit information that would address issues of concern and interest to the researcher. Once the surveys were developed, each mirror was polished in the pilot process, in the hope that the mirrors presented to the consumers would be as clear as possible and free of any smears or scratches. The service indicators, too, provided mirrors for POS staff to review their service in.

This chapter will discuss the research findings in order to draw meaning from them. The findings will be discussed in the context of clinical practice and finally, conclusions will be drawn and recommendations for future research made.

8.1.1 THE SURVEYS

Separating the findings of this project from the workplace events has been a difficult task. It might seem that they are two separate entities and as such easily segregated. However, the Paediatric Outreach Service has been, and continues to be, a very dynamic service. It has been responsive to the feedback of patients' families and referrers on a one-to-one basis, day-to-day, as needs have been identified by customers.

The data for this study was elicited from service users from the first 9 months of the POS's existence. The survey tools were developed with the intention to gather information about the POS, to aid further service development. However, concurrent with data collection, service changes were occurring. The survey tools were constructed 12 months into the service development. It was decided to collect data from the first 9 months of service for two reasons; firstly to enable a full period of data collection and secondly, because the Organization was planning to conduct an area wide survey of the whole of their Services, and this researcher did not want to be competing for return responses within the sample group.

8.2 THE REFERRER SURVEY

It was essential that the Paediatric Outreach Service providers understood what their impact was on the families of the children who received care from the Paediatric Outreach Service. It was equally important to understand whether the service being provided met referrer expectations and needs.

8.2.1 REFERRER RESPONSES

The next pages of this chapter will discuss individual components of the referrers responses.

8.2.1.1 INTAKE PROCESSES

When the POS was developed, several changes were made to the intake process for the Paediatric Outreach Service that made it different to the already established Community Health intake processes. The POS intake became the centralised point for paediatric referrals on a dedicated and secure facsimile machine. In addition, the traditional limited intake hours were extended to make it possible for referrers to send referrals 24 hours a day, 7 days a week. These decisions regarding the POS intake were based on anecdotal feedback from the community about the hours and methods of the traditional intake process. Asking the questions about access to staff, the service hours and the intake procedure was really seeking validation of the decisions made based on the anecdotal feedback. From the referrer responses, it would seem that referrers did in fact value both the ease of making referrals and access to POS staff to discuss their patients; additionally, referrers found the open hours for referral convenient to their practice. The overwhelming positive responses in relation to these questions suggest that in listening to, and subsequently actioning stakeholder discussion about their needs, the POS met referrer expectations in these respects.

8.2.1.2 FEEDBACK

Another service-related expectation that referrers held (and had been anecdotally reported) was the need to receive feedback about their patients. The lack of timeliness related to the receipt of discharge summaries following a hospital admission, by primary carers and paediatricians, has been a long-standing issue. The seamlessness of the care continuum is dependent on all parties being aware of what is going on, with regard to the patient's care. In turn, this awareness can only be achieved through timely and meaningful communication.

There is some variation in the responses from the referring agents with regard to receiving feedback. This is thought to be due to the fact that POS staff had an undertaking to provide feedback to the nominated GP and/or paediatrician. However, as stated by the referrers from the Emergency Department, they knew that they could get feedback, should they need or want it. The staff from the Neonatal Intensive Care Unit (NICU) indicated that they would really appreciate some feedback related to the progress of the infants they referred, following discharge. This need was not really related to maintaining the care continuum, as much as it was about validating the cares they had provided whilst the baby was in their care. Having been made aware of this issue, POS staff made an effort to provide some verbal feedback to the staff of NICU, as well as other referring agents who previously would not have received direct feedback.

8.2.1.3 CONTINUITY OF REFERRAL

Regularity of referral seemed to be related, perhaps not unreasonably, to the geographical location of the referrer to POS. There are two dimensions to this idea. Firstly, referrers located in the LGA, wanting their patients to receive ongoing care locally, readily made referrals. The other group of referrers was those located outside the local LGA who needed their patients to continue receiving care close to home. However, there was some variation in this group based on the referrers proximity, with those located further from POS's LGA being more likely to refer.

8.2.1.4 CONFIDENCE IN POS STAFF

Generally, confidence in a product will influence consumers' willingness to purchase or engage. Accessing a service such as POS is no different. In order that referrers use the service, a level of confidence in what the service can deliver is integral. Referrers need to have confidence in the skills of the POS nursing staff, particularly as they are engaging a service to continue the delivery of care that they might otherwise have provided themselves. The fact that referrers will delegate this responsibility, and unanimously agree that they have confidence in the POS nursing staff is very encouraging.

In reality, a service like POS cannot function without referrals. A lack of confidence in the service and subsequent decisions not to refer patients would ultimately lead to the demise of the service. The decision about continuing to refer to the service was also unanimously supported by all referrers. This fact, in itself is an indicator that POS offered a service valued by the stakeholders it was designed to support.

8.2.1.5 STANDARD OF CARE

It is in the question related to service quality that perhaps all the other survey questions culminate. All referrers rated the service as above average or excellent. For this group of referrers, it seems that POS met it's objective: that being, to provide a service that was meaningful and valued.

Having said this, POS can not afford to rest on the laurels of these successes. Over time, different referrers with different needs may require something different of POS. The staff of POS need to remain open to hearing the needs of stakeholders and continue to adapt service provision, within reasonable limits, to meet their needs, and then, by extension, their patient's needs.

8.2.2 SUGGESTIONS FOR SERVICE IMPROVEMENT

In the open-ended questions, the most common idea expressed for service improvement was about extending service boundaries. Referrers found it difficult knowing that in one LGA they could get home-based nursing support and in the very next LGA such a service was not available. Services need to have boundaries, both in terms of geographical cover, and core business in order that they can function effectively and efficiently. Fairfield Health Service had endorsed and implemented a POS in response to a set of demands (as discussed in Chapter Two) and predominantly on an inherent belief that such a service could dramatically improve patient care. However, the lack of strong empiric data and the fact that POS was, in a sense, a service model to be tested, other health sectors waited to establish similar services until some data demonstrated benefits (cost and/or patient-related).

8.3.3 POSITIVE OPEN-ENDED RESPONSES

The positive aspects of the service that referrers chose to provide individual comment on were related to communication, access to staff, staff expertise and standards of care. These issues are all inter-related and the result is the fourth listed issue here.

8.2.3.1 COMMUNICATION

As already discussed, the role of communication is pivotal to maintenance of the care continuum. Referrers do not always know what the capacity of a service is when they want to make a referral. Easy access to POS staff for a referrer to be able to discuss their referral for appropriateness or urgency or to discuss the social determinants impacting on a child's health is really important. To facilitate this process, staff carried mobile phones throughout the advertised service hours; both the mobile phones and land-line had answering machines so as to not miss any calls when staff were on the phone or involved in a patient care procedure; and there was twenty four hour fax access that referrers could utilize to provide referral details and request a phone-back to discuss the case. This combination of communication modes meant that referral data could be provided at any time of the day, seven days per week and that POS staff were able to respond to referrers in a timely manner.

The fax machine was used to provide patient information to nominated medical officers. In one case, where the referring agent was also the nominated medical officer, they indicated that faxed information was very useful as they did not need to be interrupted during patient consultations and could review the faxed information at their convenience, and follow-up with POS staff if/when it was required.

Mobile phones carried by the nursing staff also facilitated timely communication with the nominated medical staff when the POS nursing staff identified deviations from the child's expected recovery or care-plan. This element of service provision was also highly valued by referrers.

8.2.3.2 STAFF EXPERTISE

The issue of confidence in staff expertise was a question in the closed-ended question section. However, three referrers chose to address this issue specifically in the open-ended questions. Each respondent expressly commented upon the paediatric qualifications of the POS staff being the thing that they valued most. These comments by referring staff are particularly interesting in the context of the specialist versus generalist debate, discussed in Chapter Three. Services such as POS were an emerging specialty. Previously, community based services had been provided by generalist (primary health) nurses; most of which had little or no paediatric qualifications. It is the paediatric nursing expertise that these respondents have deliberately commented and expanded upon, in this case, lending weight to the “specialist” argument.

8.2.3.3 QUALITY OF SERVICE PROVISION

As it was important for parents to know that they were choosing an equivalent standard of care when deciding between hospital and home-based care (as was discussed in Chapter Six), it was also important to the referring agents to know that this was what they were choosing for their patients. Referrers gained their impressions both from their contact with

POS service providers, and from feedback from the families they referred to POS.

8. 3 THE CLIENT SATISFACTION SURVEY

The next section of the thesis will discuss the significant findings illuminated by the answers of the parental respondents.

8.3.1 INTRODUCTION

Parents were invited to provide written comment concerning many key nursing aspects of the outreach service provided to meet the health care needs of their child (see Appendix Seven). The next section of the thesis discusses major findings illuminated from answers provided by parental respondents (n=15).

8.3.2 COUNTRY OF BIRTH

This question was designed to elicit information about the cultural background of the children referred to the nursing outreach service. However, it was found that this question was not very useful for the purpose for which it was designed because it addressed ethnicity, rather than culture. *"Ethnicity"* refers to the country a person comes from; and their race. From the findings, a much more complex concept was that of *"culture" ;* where culture was defined as the *"values, norms, beliefs and* *practices of a particular group that are learned and shared and guide thinking, decisions and actions in a patterned way [it] is seen as a pervasive element that is present in all human actions and therefore influences interactions"* (Chalanda,1995:20). To this end, a patient's culture cannot be ignored. Every family had their own culture, whether they were fourth generation Australian, or newly arrived immigrants.

In this study, culture influenced all aspects of family life. When they sought health care or health maintenance, they did not discard the influence of their culture; instead, they brought their culture with them to every clinical situation. When they accessed the health system for their child, they brought with them all their diversity. They also brought with them their life experiences, beliefs, fears, and their expectations. These factors framed the cultural identity of the families and determined how closely families adhered to a care plan.

When paediatric nurses fail to gather data about the "life-world" of their patient, they may fail to deliver meaningful care. It is possibly even more important for these nurses delivering home-based care (than a hospital-based nurse) to understand the impact of culture on the child and their family as the nurse is entering the family's home and asking the family to become involved in providing the majority of health care activities, in between visits from the nurse. This plan of care must be congruent with the culture and lifestyle of the child and their family, or it will fail.

One limitation of this study is that research questions one and two (refer to Appendix Seven) gathered only information about ethnicity, rather than the cultural aspects influencing the care relationship, thus limiting the researcher's ability to derive significance of this aspect of the patient's and family's identity on the plan of care, and it's congruence with their life experiences, beliefs, fears, and their expectations

In future surveys, these questions need to be redeveloped to seek information about the family's culture, and their perception of the cultural sensitivity of the nurses entering their home.

8.3.3 LANGUAGE SPOKEN

Despite the fact that ninety seven per cent of the children referred to the nursing outreach service were born in Australia, about seven languages were identified as spoken in these family's homes. This is an important factor for nurses to consider when planning home-visits and individual care plans, because it is the parents who will provide most of the care for the child during their episode of illness. When delivering home-based care, the paediatric nurses need to be able to discuss the specific care that is required, how it needs to be implemented, and ways to monitor and evaluate the care provided. Language is integral to this process. Nurses need to know how to access both telephone or face-to-face interpreters and the benefits of using a professional, rather than a family member, to conduct interviews and provide education within each family.

From the findings, utilisation of an interpreter is crucial to minimising the impact of a language barrier. Another limitation of this study is the lack of a question to parents concerning their access to interpreters and the value of this process in assisting them meet their child's health care needs.

On reflection of the question regarding the language spoken, an oversight in question design was identified. This lead the researcher to conclude that for future surveys this question needs to be redesigned to elicit detailed information about parental evaluation of the communication process with the nurses, including ease of dialogue and understanding of the care required.

8.3.4 PATIENTS' POSTCODES

From the literature, there is a wealth of information concerning the relationship between patient's health and socio-economic conditions (Nossar 1992). The purpose of this question was to determine if the services of the nursing outreach service was concentrated in a particular location within the Area Health Service, as there exists a broad range of socio-economic conditions across the Local Government Area (Refer to Ch 2)

Findings from question three (see Appendix Seven) illustrated that the most patients referred to the nursing outreach service came from postcode 2176. This is an area of socio-economic deprivation, identified by the Families First Interagency Committee in 2001 as a vulnerable area within the Local Government Area.

Where people have less grasp of the language of the country in which they live, they are less likely to access health care services. Added to this, many of the residents of the 2176 postcode were unemployed and living in poverty. Awareness of the socio-economic vulnerability of this part of the area health service was important for the POS nurses. The nurses needed to be mindful to organize interpreters to assist them assess their patient and implement the management plan as ordered. This also meant that generally, the POS nurses needed to allow more time to conduct their home visit. The reason for this was twofold. Firstly, time was required to present information and then for the interpreter to repeat it and then for the parents to answer and the interpreter to repeat their answer. Secondly, where families access health care later, the child was more likely to be sicker at the time of presentation. This in turn meant that POS nurses needed to spend more time explaining the implementation of the care plan and sometimes, on health education.

8.3.5 ILLNESS HISTORY OF THE CHILD

This question was designed to determine if parents had any recent previous experiences regarding their child's illness/health. The researcher anticipated that the parents of children who had had multiple recent episodes of illness would be influenced by the experience. This has the potential to positively, or negatively affect their ability to learn about, and participate in, the provision of care for the most recent illness episode. Some parents may be very tired due to many nights being awake with a sick child. This may compromise their ability to comprehend and/or remember key aspects of the care plan. In other circumstances, parents' previous exposure to health services and care providers may mean they come with definite expectation about what they want/demand from the care relationship related to their child's most recent episode of illness.

It may have proved useful and interesting to have asked the parents whether the diagnosis of the most recent illness was the same or different to their previous illness. This would have allowed the POS nurses to assess the parents' ability to apply previous learning. Such knowledge may be useful for future researcher's to understand because one of the functions of POS was to build capacity within families. This may strengthen their ability to recognize and treat their child's illness, and to reduce representations and readmissions to the hospital, especially related to late presentation during the episode of illness.

8.3.6 ACCESS TO HEALTH PROFESSIONALS

Parents were asked to identify the health professionals whose help they had sought regarding their child's illness. The response to this question has only interest value in it's current state. The question could have been more useful if the sequence of seeking review had also been identified, as well as the number of times each type of professional was accessed. As it currently stands, this question adds little to the researcher's understanding of the indicators of service success. Another way to phrase the question may have been in terms of unexpected follow-up for the child but as this was a retrospective study, recall of such detail may have been difficult for parents.

8.3.7 SOURCE OF REFERRAL TO POS

In this study, children were initially referred to the nursing outreach service from a range of diverse sources. Predominantly, these children were referred from the two local inpatient units, to complete their episode of care. This is significant, when compared with later service statistics that demonstrated a move away from inpatient referrals to an increase directly from the Emergency Department and local General Practitioners.

This shift, over time, in the source of referrals is significant and goes part-way to addressing the question raised in Chapter 2 whether POS provided services that were “more of the same, or something new”.

Where patients are referred to complete their episode of care, the benchmark length of stay needs to be considered in the equation. Home-based care is only a more economic model of care when the home component is provided as a substitution for inpatient care, not an addition to it.

When the referrals were from the inpatient units, it was mainly seen by critics of the service to be adding to the cost and overall involvement of healthcare providers, regardless of whether the extended length of care improved outcomes for the child and their family. Critics of home-based services argue that where care is provided over and above the benchmark length of stay, it is over-servicing.

This however does not appear to be an opinion shared by parents. Where parents had an opportunity to make comment about the service in the three open-ended questions, they indicated that the opportunity to receive education and review of their child in their own home was beneficial; with one parent stating:

> *“what I liked about the service I received was that my sick child was cared for by professional nurses in his own environment and monitored, thus his recovery was much speedier than him been in hospital with total strangers” [sic]*

Once there was a shift in the referral source so that patients who may have once been treated in hospital were referred to POS, thus avoiding a hospital admission, POS was seen to offer something new; a different way of delivering healthcare. This was an important shift in acceptance of the service, particularly by funding agencies such as the Department of Health, who used substitution of inpatient care as a determinant of service success (GWCHN Minutes, 2002).

8.3.6 REASONS FOR CHILDREN'S REFERRAL

The reasons for referral were many and varied. Parental responses to this question high-lighted the scope of service delivered. This information was important to the researcher as there was a list of possible reasons for referrals detailed when the service was developed, but no one actually knew what the potential for service delivery could be.

At a conference presentation in Beijing in September 2000, a paper about POS was entitled "The POS – Abilities", implying that there was much POS could offer, and in addition it's scope of practice was not fully realised. Initially, it was anticipated that the service would provide acute and post-acute care. What became increasingly evident was the need to provide care for children with chronic and acute conditions also. This realisation brought with it certain realities with regard to resource distribution for POS. Patients with chronic or complex conditions often required more equipment, or more expensive equipment such as nasogastric tubes and enteral feed pumps. Home visits often took longer, thus being more time intensive for the human resources. Care of children with chronic or complex conditions was sometimes more demanding on the nurses, requiring that their home-visits were alternated amongst staff to ensure that all staff knew the family and the plan of care and also in an attempt to protect nursing staff from over-involvement and burnout.

In the document about POS, developed at the time of it's inception to describe it to key service providers, perhaps the most significant statement regarding referrals was that which asked referrers to call and discuss any potential referral with POS staff. This was particularly so when it was for an aspect of nursing care, not indicated on the potential, but not exhaustive, list of referrals.

In not being absolutely prescriptive of the types of referrals it would accept, POS certainly remained flexible to the "POS – Abilities", and in doing so, remained flexible to meeting a broad range of nursing care needs for paediatric patients living in the local government area.

8.3.8 WAIT TO FIRST VISIT AND SATISFACTION TO TIME OF FIRST VISIT

This was a significant question for the researcher. For help to be considered useful by a person, it generally needs to be provided in a timely manner to when the need for help is identified. POS was modeled within an acute-care framework and as such, waiting lists would have indicated a failure to address a central tenet (that being responsiveness to a request for help). To monitor this tenet, the clinical indicator related to delay between time of receipt of referral and first contact was developed. Parental response to this question indicates that they were almost all satisfied with the time to the first home visit.

This question could have been further clarified had it also sought to determine when the first contact with the family had been, and whether there had been negotiation about the timing of the first visit. For example, this data is not able to show whether the nurses called the family on the day of receiving the referral and there was agreement that the visit should occur the next day; or whether the family were discharged from the hospital but the referral request asked for a visit in 48hrs or later (eg, for a dressing).

Whilst the responses related to the time to first visit fall outside the acceptable range for the clinical indicator, parental satisfaction with this period suggested that it was still reasonable, thereby indicating that POS was addressing the needs of the family at the time they believed they were in need of help.

8.3.9 NUMBER OF VISITS AND SATISFACTION WITH NUMBER OF VISITS

The question of the “right number “ of visits is somewhat like the question, “how long is a piece of string?” In clinical practice, the nursing staff of POS said that it was not possible to say that a particular presenting condition requires a certain number of visits. The number of home visits required by any family was dependent on many variables. These may include, but are not limited to:

- the support systems the family had access to;
- previous experience with managing the same or similar health problem;
- parental confidence in their own monitoring and management ability;
- parental willingness and/or ability to learn, monitor and implement the medical and nursing care plan;
- financial security; or
- parent-child interactions

For any family there may be one or multiple variables in play that will affect the number of home visits required.

Parental satisfaction with the number of visits required will be influenced by the nurse’s assessment of the family, and the congruence of this assessment with the family’s perceptions of themselves and their needs. Where both assessments and perceptions are congruent, parental satisfaction will be higher.

It is important that the POS nurses were able to determine the “right” number of visits for each patient because under-servicing may impact negatively on parental satisfaction with service delivery. On the other hand, over-servicing may have caused parental dependence on the POS nurses, creating conflict between the service aim (to empower families) and the practice. Over-servicing would also have cost implications for the service in that the nurses have a finite capacity for delivery of home-based services and the provision of unnecessary visits to one family may mean that a family in need do not receive the level of service they require.

Another factor that created a dilemma for the managers and administrators overseeing the POS service was the provision of care to children with chronic and complex needs. This has been a challenge faced by all the paediatric home-based nursing services that have been established in Sydney, subsequent to POS (personal communication, 2003). It is not a feature specific to Paediatrics. Adult community based services have also identified different care needs between patients with acute and chronic or complex conditions, and have stranded accordingly (personal communication, 2003). In Middlemore in New Zealand, to address this dilemma, service providers developed two separate nursing teams to meet the discrete needs of these two groups. POS did not go as far as to create two separate teams, but the impact of meeting the care needs for families of children with chronic or complex needs was acknowledged by the service manager and rostering was altered to allow staff more time to work with these families, without disadvantaging the families of children with acute care needs.

The disease or disability of children with chronic or complex conditions did not follow a set course or duration. Thus it was not possible to assign the number of visits that would be required to address their needs. Even defining a period of time over which visits would be conducted (rather than the actual number of visits), with a predicted date of discharge, was also less possible for this group of patients.

Patients with acute care needs were somewhat easier to estimate the number of visits required, but even within this group, unless the referral request was really specific, for example *"give x7 days GCSF" or "give enema x 3 days"* patient variables meant that determining the "right" number of visits was still based on best "guesstimate". "*Guesstimates*" were dependent on patient related factors that the staff could not always account for, for example wound healing is affected by factors such as hygiene, compliance with medications, nutrition, activity levels, or infection Where influencing factors negatively impacted upon wound healing, the patient group would fall outside the predicted number of visits.

As a service provider, the researcher defines the "right" number of visits as the number of visits required to meet the child and family's needs. Application of this definition within the context of the parental rate of satisfaction (97%) it would seem that this definition promotes congruence with parental perceptions of need.

8.3.10 PARENTAL UNDERSTANDING OF INFORMATION PROVIDED AND PERCEPTIONS OF ITS USEFULNESS

In order that POS was successful in keeping children out of hospital, it was important that parents understood what they were told about their child's illness and the plan of care required to facilitate recovery. POS nurses attended the patient's house for only a small part of the day, and their assessment of the child was based on a snap-shot of the child which included what they could see during the home-visit and what was reported by the parent. Service success was contingent on the family's ability to monitor the child's condition against a set of agreed criteria and to follow the care-plan described by the nurse.

The provision of information was not the only important criteria. The information provided to parents also needed to be useful to them. Parental failure to apply the information that was provided by the POS nurses may have led to readmission of the child. During the period of data collection for the clinical indicators, the readmission rate for children with the same condition was very small (see page 207 for a discussion of readmission rates).

A significant challenge for the nurses was ensuring that families of non-English speaking backgrounds also received information that was useful. It is difficult to know from the survey results whether this occurred as surveys were only provided in English. In an attempt to try and meet the needs of non-English speaking families, POS nurses accessed the interpreter service whenever it was required. This had implications on the budget as well as the time management of the nurses. Use of an interpreter often doubled the time required to conduct a home visit as everything needed to be said twice. Face to face interpreters were often not readily available and so interpreter access via the telephone was utilised. So as not to impose upon the family's resources, the nurses used their mobile phone. This added costs to the service for both the phone call and the interpreter's service. However, it appears the costs were well justified as, reviewing the readmission rates, this population was no more represented than any others.

8.3.11 STANDARD OF CARE, PARENTAL CONFIDENCE IN NURSING STAFF SKILL AND KNOWLEDGE

Parents accepting home-based care for their child needed to know that they were not choosing an inferior service model. It was thought that an integral component of a successful service was related to the calibre of the nursing staff employed to deliver nursing care.

In developing POS, clinicians were committed to ensuring that the service delivered at home was safe, effective, efficient and high quality. Essentially, these qualities were directly related to the nursing staff providing the care.

Delivery of care at home is not simply a matter of moving the environment where care is provided. In the home environment the nurse is, at the time, a sole practitioner – the observations and analysis they make of the child and their family during the period of the home visit is what the plan of care will be based on and maintained or changed.

By comparison, in the ward environment, if one nurse does not detect a change in the patient's condition, there are many other care providers moving through the environment and it is likely that someone else will detect the change. Without the other possibilities of surveillance, it was essential that the nurses employed to work in POS had excellent nursing skills, as well as interpersonal and critical thinking skills.

When the POS nurses were employed, criteria that was considered important was related to their nursing experience, not just the length of time they'd been employed but also the breadth of their experience (either that they had worked in several different institutions, or that they had worked across several subspecialty areas). There was some challenge in getting Community Health Nurse Managers to agree to allow recruitment to be based on paediatric qualifications, rather than experience in community health. This is consistent with the debate, discussed in Chapter 3, Section 3.12 about generalist versus specialist nurses in the provision of home-based paediatric nursing care. The high level of parental confidence in both the skills and knowledge of the paediatric nurses providing support to their child and family is reassuring. The consensus between both participant groups on the high standard of care delivered by the paediatric nurses is also encouraging.

One hypothesis for the high parental regard for the quality of the nursing service provided is the fact that the care they experienced at home was based on a one-to-one relationship; their needs were met when they wanted them to be so: they were not competing with a number of other families for the attention of the nurse (as they would need to in the hospital setting). Additionally, parents could be comfortable that what they chose to discuss with the nurse could not be overheard by others (as is usually the case in a hospital setting, unless hospital accommodation is in a single room).

If a measure of good quality care by experienced, knowledgeable nurses is readmission rates for the same condition, then it may be postulated that the care provided by the POS nurses was excellent as the readmission rates for the group of patients captured with the clinical indicators (see page 158) is very small. Another clinical indicator that can be used to reflect nursing staff skill and knowledge could be wound infection rates. During the period of data collection, the zero infection rate demonstrates the nurses compliance with quality practices to meet infection control standards.

Another hypothesis for the high level of agreement related to the skill and knowledge of the POS nursing staff is the level of consensus and consistency amongst the nurses. In the clinical setting, differences between the practices or explanations of the staff may be perceived by the parents as a lack of ability in an individual (or even the group as a whole). The POS nurses were very committed to the continuum of care and to ensuring that what they did or discussed with a family was shared with the nurse providing the next home-visit. This was reflected in the POS nurses' commitment to completion of the clinical pathways that were introduced by the Area Health Service. The provision of seamless nursing care, regardless of which nurse attended the home-visit, enhanced the parental perception of the nurses skills and knowledge.

8.3.12 HOURS OF OPERATION AND SATISFACTION WITH OPERATING HOURS

In planning to commence service delivery for POS, there was discussion between the clinicians and the managers about what the hours of operation ought to be. When POS was being launched, the adult-equivalent service in community health only worked routine business hours, ceasing operation at 5pm.

The notion of providing a service that only operated in business hours posed some difficulties for those planning the service in terms of being able to meet the needs of families. Some of the issues that were identified were in relation to school-aged children and access to them with minimal, if any, impact on their schooling. If they did not get home until about 4pm, no complex procedure or education would be able to be addressed as the staff needed to be back at the centre before 5pm to avoid overtime costs etc.

Another group whose needs were considered were those where one or both parents worked but needed to be able to discuss their child's care with the nurse. A service that closed at 5pm meant that either parents needed to take time off work, or not have access to the nursing staff to discuss their child's care (other than over the phone).

A third group for whom it was believed extended service hours were needed were patients with a respiratory condition. Often, respiratory conditions are exacerbated by night-fall and the associated drop in temperature. A service with extended operating hours would allow for the conduct of respiratory assessments later in the evening and allow the nurses to gain a better appreciation of the child's likelihood of coping through the night at home.

Whether POS needed to offer a weekend service was another consideration for the service planners with regard to hours of operation. When POS commenced, few other services offered weekend coverage. A major influencing factor in deliberating weekend hours was the impact on the budget, due to the penalty rates applicable. However, it was argued that failing to offer a seven day service may mean that care plans would be compromised, simply to fit with the hours of operation; for example how would the needs of a patient requiring daily dressings and wound review be met?

Continuity of care was agreed upon as an underpinning principle of the service. In order to meet this principle, the hours of service were negotiated against the staffing profile available. The finally agreed upon hours were from 8.30am to 8pm Monday to Friday and 8.30-12.30 on Saturday and Sunday. There was a little flexibility particularly associated with the weekend hours. The nurses negotiated home-visit times the previous day wherever possible, and it may have been that the four hour shift started at 9am to meet families requests. In winter, some weekend days were extended up to six or eight hour shifts to accommodate the increased demands for respiratory review and burns dressings (related to increased exposure of children to hot drinks and heaters).

For some families, Sundays posed a problem due to the family's needs to meet competing demands between their religious practices and the health-care needs of their child. Again, the nurses needed some flexibility in planning for the child's healthcare needs. In such circumstances, they would negotiate a plan of care with the children's ward at Fairfield Hospital whereby the family were asked to contact the ward in the afternoon after their religious service was completed and the ward staff would advise when it was convenient for the family to bring the child to the ward to have their agreed treatment administered. The ward staff would document the episode of care and leave for the POS staff for the next day.

The fact that the nurses were able to provide their services at times that met the needs of the family led to parental confirmation that the hours of operation were essentially suitable for the needs of the population being serviced. In the open-ended questions, one parent indicated that it would have been better if the nurses were available during the night, due to the difficulty of having to go out to seek medical review and assistance for a sick child in the middle of the night, particularly when there are other children involved.

Whilst appreciating the difficulty experienced by families needing assistance with a sick child during the night, there were reasons that a twenty-four hour service was not provided. The most important reason was related to the service referral criteria that required the child be seen by a medical officer and have a medical plan of care for the nurses to implement, prior to involvement of the POS nurses. There were also safety issues associated with having the nurses out in the middle of the night, particularly for families that were not already known to the POS nurses. Many of the on-call general practitioner services in the area had a pre-requisite that the patients they reviewed overnight were patients of the service. One service in the United Kingdom tried to address the safety issue for the nurses overnight by having them accompanied by a security officer from the hospital, saying that the call-out rate was low. Neither the POS budget nor the hospital's security staff profile lent itself to such a solution for POS. In addition, there was a school of thought amongst the clinicians and the managers that suggested if the children were sick enough to need a medical review during the night, they really ought to be seen by a medical officer. There was consensus on this and so, the hours of service were maintained as developed.

8.3.13 PARENTAL INVOLVEMENT IN CARE PLANNING; THE VALUE PLACED ON THE PARENT'S ROLE AS CARER; CONTRACTING HOME VISITS AND THE EFFECT ON CARE PLANNING AND LIFESTYLE

With a parents-in-partnership model of care underpinning the POS nursing care, it is disconcerting that almost thirty per cent of parents felt that they were not involved in care planning for their child. In contrast, almost ninety percent of parents indicated that they believed that the POS nurses valued them and their role as carer. A reason to explain these parental responses may be related to the difference in how parents perceive their relationship with the nurses in relation to their child's health care needs in comparison to their general parenting role. Parents may have felt that they did not have the skills or knowledge to participate in planning care for their child, in terms of determining treatment choices. Only approximately seventy per cent of parents indicated that they were involved in contracting the number of home visits that would be required to address the identified health needs of their child. However, almost ninety four per cent of parents indicated that the plan of care fit the family's lifestyle.

Again there appears to be some incongruity in how parents responded to the questions. This may have been related to the terminology used. It is highly unlikely that the POS nurses always suggested a plan of care that coincidently fit with the family's lifestyle. The negotiations that inevitably occurred to enable the POS nurses to deliver the care required, allowing the family to meet the rest of their commitments, was in fact care-planning and contracting. As discussed in section 8.3.12, *Hours of Operation and Satisfaction with Operating Hours* (see page 186), POS staff did offer flexibility in order to ensure that the family's lifestyle demands generally had little or no impact upon the child's care-plan.

8.3.14 PARENTAL UNDERSTANDING OF RIGHTS AND RESPONSIBILITIES AND THE COMPLAINTS PROCESS

From the survey results, it appears that this was the weakest aspect of care provided by the POS nurses. The nurses recognised that for families to be truly empowered, they needed to know what was expected of them, what they could expect of the nursing service, and how to complain when their expectations were not met satisfactorily. The nurses had believed that they described these concepts to families using dialogue such as "when I come to visit tomorrow, I need you to do….." (ie a responsibility – something they are expected to do); "whilst providing care for Johnny, I will call to organise a time that suits you" (ie a right – something they can expect of the nurse). The fact that the parents could not identify this meant that either the nurses were not doing it well, or the survey question was framed using terminology that the nurses themselves did not use. The POS nurses believed the reason to be the latter. Following analysis of these survey results, the POS nurses made some alterations to their practice to address this deficit.

The POS nurses identified that the Community Health Services had developed a *Rights and Responsibilities* brochure that explained these concepts, and included advice about how to make a complaint within the health service. The information was service-generic in that it did not describe any one particular community-based health service. The POS nurses agreed that they believed it met the needs of their patient population and agreed to include it in their introduction of the service to new patients. In addition to providing the brochure, the nurses agreed to take a few minutes to highlight the relevant parts of the brochure.

The nurses anticipated that their change in practice and their deliberate use of the term *Rights and Responsibilities* in discussion with families meant that when the survey was repeated, the parental response rate would be much more positive in indicating that they had been advised of these important components of health care.

8.3.15 KNOWLEDGE OF THE NURSE'S NAME AND PERCEPTION OF THE NURSE'S GENUINENESS

For parents to truly value the relationship with the nurse coming to their house and treating their child, the researcher believed that these two elements were important in establishing rapport in order to be invited back into the home. There was a high level of affirmative response for both of these dimensions of care. Waterlow (1999:1) discussed the notion of the POS nurse as a visitor, saying that *“the home visit component of the Service is that simple yet profound process where a professional enters the home of a client, courteously, and with informed consent”.* In practice Waterlow said that it was the second visit that indicated success – that is, when the nurse was invited back to the house was evidence that they had offered something valued by the family (it could have been direct care, information, support).

8.4 THE OPEN-ENDED QUESTIONS

Parents were then invited to answer 3 open ended questions which were related to the factors that parents enjoyed about the service provided, factors that they disliked, and the areas they believed could be improved upon.

8.4.1 WHAT THE PARENTS LIKED

Parents took the opportunity to describe many of the factors that they liked about the service Most of the comments were associated with nursing staff-related attributes. These included such traits as caring, consideration, friendliness, reassurance, and punctuality. These were seen to be relevant and related to the nurse's knowledge and in turn, the ability for their child to be discharged from hospital early, to complete their recuperation at home. It was important to parents that the nurses visiting their house turned up when they said they would, delivered a high standard of care so that they did not feel like they had been discharged too early, nor that they had been abandoned. This parental assessment of the service they perceived they had received supported several of the objectives on the activity cascade (Waterlow, 2001) namely *"reduced length of stay in hospital"; "early return to home management"; "enhance client/carer satisfaction"; and "promote consumers as partners of care".*

This was particularly encouraging for the POS nurses as well as other staff with a keen interest in the actual service delivery of POS. Parental confirmation that POS was achieving a number of the activities that had been penned out in 2001 (3 years after the service commenced operation) describing service functions was encouragement that the path being taken by the POS nurses in the development of the service was correct for the needs of the group that they were servicing.

Parental feedback was not all positive however, and parents indicated the aspects they did not like and also where they saw room for improvement.

8.4.2 WHAT THE PARENTS DISLIKED

The biggest complaint received from the parents was related to the fact that POS nursing staff did not provide long-term telephone follow-up “to see how the children were going”. Parents somehow saw the lack of telephone follow-up as indicative of a lack of caring on the part of the nurses. This was a particularly useful piece of information gained from the survey and enabled the POS nurses to change the way they disengaged from families at the end of an episode of care. From a purely logistical point of view, it would not be possible for the POS nurses to simply telephone every family ever referred to the service to see how the children were progressing .

Once this expectation was high-lighted by several of the respondent families, it provided POS nurses with an opportunity to change their practices and set up expectations for the families. This change in practice was reflected in the disengagement dialogue that informed parents that the POS nurses believed that the child’s condition had resolved. If parents agreed with this and indicated that they no longer needed to see the nurse, then parents were given another set of contact details (in case they had lost the ones given at the first visit) and advised that POS staff would not contact them again but should they need the services of POS staff at some point in the future, they should feel free to call.

8.4.3 ROOM FOR IMPROVEMENT

Parental comments about room for improvement regarding service provision gave POS nurses the opportunity to review the processes of marketing for the service. The issue several parents identified was related to the way the service was offered to consumers. They advised that this process was not uniform across health services and appeared to be clinician dependent. The other issue that appeared to be highlighted in the parental comments was the fact that access to POS was not uniformly offered. The inference was that POS was only offered to families that health professionals believed might need support – access was not based on a family's self identified need. This was problematic. POS staff wanted their service to be able to be used by any family that wanted support. Thus, the challenge for POS nurses was to develop strategies to advertise the service widely enough so that consumers would know about it and be able to request referral when they wanted it.

8.5 THE SERVICE INDICATORS

Each of the service indicators will be discussed in detail, with the problems and successes of each of the indicators described.

8.5.1 NUMBER OF PATIENTS REFERRED TO POS WITH A DIAGNOSIS OF ASTHMA FOR WHOM A CLINICAL PATHWAY WAS COMPLETED

The principle supporting the use of a clinical pathway was the mapping the of the patient's movement through the health system (or a part of it) in order that the care delivered was standardised and based on best practice ideals. It was considered highly important for POS nursing staff to provide care in this way for a number of reasons. Firstly, the fact that the staff worked a rotating roster meant that there was the possibility for staff to undertake the assessment and education processes differently and that their rotation meant that families may have missed crucial care information. The use of a care pathway that documented all the activities (skills and education) that staff needed to provide on a per visit basis meant that the nurses had in fact, an instruction list concerning what they needed to plan and implement. When this process was carried out differently compared to the care pathway, the nurses could document these changes on the pathway.

In essence, the documented care-path acted as a prompt for nurses. Thus, care provision was streamlined and theoretically was more comprehensive and meaningful for the children and their families when delivered in accordance with the pathway. A measurement of the success of the pathway might be the re-referral rate of paediatric patients with asthma to POS (re-referral rates will be discussed in detail in Chapter 8, page 207).

The flip-side of the benefits that the care-path afforded to these nurses, was the time it sometimes took in documenting the nursing activities provided, using the pathway. When time was short, such as when the nurses were short-staffed, the nurses were sometimes less than diligent in completing the tool. This was quite obvious over the peak winter months of June and July 2000 where completion rates fell to fifty-eight and sixty-seven per cent respectively. In comparison, the traditionally quieter clinical months of December and January had completion rates of eighty-two and eighty-six per cent respectively. It is also possible that sometimes staff completed the tool, but forgot to document this against the patient's details in the allocation book (which was used to collate data for the indicators). A retrospective chart review was not undertaken to check for the presence /absence of a pathway in the patient's note. Thus, if it was not recorded as completed in the allocation book, it was assumed to be missing.

To undertake a chart review to obtain this data would have been very time consuming. To address the issue of missing data, the service manager (who was also the researcher) discussed the matter with the POS nurses during a team meeting where the importance of data entry was emphasised and the joint team responsibility to ensure this occurred was emphasised. This indicator was a measure of staff performance and as such, failure to complete data recording reflected on their professional conduct. The nurses accepted this explanation for the need to record the data and the expectation of this as part of their role. However, there would always be limitations placed on their time by external pressures that would affect their ability to comply with this expectation

8.5.2 THE AVERAGE NUMBER OF HOME VISITS UNDERTAKEN FOR A PATIENT REFERRED TO POS WITH ASTHMA

It was initially thought that this variable may be a useful indicator of service provision. However, it quickly become evident to the nursing staff that as an overarching indicator, it was quite useless, as it did not take into consideration any of the variables impacting on this situation, such as previous education received, the degree of sickness experienced by the child during this episode of illness, other support systems (eg GP). A family referred to POS following their child's first asthma presentation may require three or four daily visits to provide sufficient assessment and education to empower a family to manage the child's condition in the future. A family of a child with long standing asthma may only require one or two visits to check that they were able and willing to implement the education and asthma plan previously provided. Or this same family may have little insight into the inherent dangers associated with asthma and it's treatments and requires lots of supervision, support and reinforcement, despite repeated presentations. Consequently, the nurse researcher recognised that this indicator was flawed because trying to equate the number of visits provided with the quality of service provided or as an indicator of a family's needs, is impossible

This recognition was echoed by the Hospital's Quality Committee when they reviewed the POS indicators following six months of data collection.

They determined that this measure did not provide any useful information to assist with service improvement and was subsequently dropped from the list of future indicators for collection by POS staff.

The nurse researcher was very much in agreement with their decision. On reflection, when this indicator was first proposed, it was purely a number thing, similar to the collection of *occasion of service* statistics that were already collected by the Community Health Services. As already stated, there was a recognition that the number of home visits could not reflect the quality of the service, or its need due to a broad range of variables influencing the family's needs.

8.5.3 NUMBER OF PATIENTS FOR WHOM AN INITIAL REPORT WAS SENT TO THE NOMINATED MEDICAL OFFICER[S] WITHIN 48HRS OF THE INITIAL VISIT.

This indicator was developed in response to stakeholder feedback, particularly from local general practitioners, as they were often unaware that their patients had even been admitted to hospital; or were often unaware of health-related activities by hospital staff which involved their patients.

Dispatch of a health document within forty-eight hours of the initial patient visit was designed to address this issue. The letter identified what the source of referral was, what the request to POS was, and the observations POS nursing staff had made and the nature of the care delivered. The letter was designed to include all the issues the general practitioners had identified as lacking in many circumstances when the child represented to them for a follow-up review.

The mode of dispatch of such correspondence was the topic of much debate amongst staff in the Department of Paediatrics, as well as more broadly with Health Service staff. Historically, discharge letters had either been posted to the general practitioners, or sometimes handed to the child's parent to hand-deliver at the follow-up review visit. Both of these systems were flawed. Sometimes, relying on the postal system meant that the child had represented at the general practitioners rooms before the discharge documentation arrived; sometimes parents who had been relied upon to hand-deliver the document forgot or lost the document POS nurses were keen to investigate other possibilities to try and eliminate the barriers to general practitioners receiving meaningful information in a timely manner. The use of fax machines seemed a logical choice.

The Division of General Practitioners for Fairfield was approached to determine the availability of fax machines within individual practices. The contact list that was made available for POS staff for all general practitioners registered with the Division, indicated that a large proportion of general practitioners in fact, had a fax machine. All paediatricians within the Fairfield and Liverpool (adjoining Health Service, and providing care for a number of patients from the Fairfield Local Government Area) also had a fax machine located with their service. It was decided by the

Department of Paediatrics that wherever possible, information would be faxed to the general practitioner. Where a fax could not be sent, or a fax number was not available, conventional postal services would be used. If it was urgent that the general practitioner receive the information prior to a child's booked review, the telephone may also need to be used to communicate the necessary information.

However, telephone alone was not acceptable as a communication strategy. Documentation was required to form part of the child's medical record with the nominated medical officer[s]. As a safety measure for staff to ensure there was a record that the fax had been sent and was received by the correct fax machine, the fax machine utility of generating a report with every fax sent was employed. The fax-machine generated report was included in the patient record, with the original (if faxed) or copy (if posted) summary letter for the nominated medical staff.

At the time when the letter was sent, the patient may have been seen/contacted just once, or many times. Ideally, this report should have been generated for one hundred per cent of patients, but on average, only seventy-five per cent of patients had an initial report sent to their nominated doctor.

The nursing staff postulated one reason for this low compliance rate was related to the fact that if the child was in fact seen and discharged within that forty- eight hour period, often just one letter was sent to the nominated medical officer[s] indicating that child had been referred, seen by and discharged from POS and it was often recorded as just a discharge letter. This impacted on the data collection component part of the process but did not necessarily compromise the issue of sharing meaningful and timely information with the nominated medical practitioners.

Another factor that may account for some of the times where it seems that nurses did not complete an initial letter, is related to their being no known local doctor to whom a letter could be sent. The usual practice of the nursing staff was to check the nominated doctor details with a parent before sending off the report. In some instances (although few) parents said they did not want correspondence sent to the local doctor; other times they disclosed that they did not really have a local doctor and had just nominated the local medical centre because they thought they needed to nominate a doctor. In truth, it could be argued that, in the absence of a hospital admission, these patients ought never have been seen by POS as they failed to meet one of the main referral criteria, that being there is a medical officer available to oversee their care. Where the child had been admitted and the care plan was determined by the paediatrician, even in the absence of a regular general practitioner, the paediatrician could still be called on to give advise and direction on the plan of care, when it was required.

8.5.4 NUMBER OF PATIENTS FOR WHOM A DISCHARGE LETTER WAS COMPLETED AND SENT TO NOMINATED MEDICAL OFFICER[S] WITHIN 24 HOURS OF DISCHARGE FROM POS

Another important issue related to the management of children by community health services was anecdotally identified by medical staff, particularly general practitioners, and to a lesser degree by paediatricians. This concerned the situation that when the doctor's patients were referred to a community based service for care, they often had no idea whether that service remained engaged with the family or the nature of the outcome from the care implemented. This indicator was designed to address this self-identified need for medical officers.

Where nursing staff were compliant in the process of ensuring that the nominated medical staff received notification related to either ongoing care provided, such as in the case of patients with chronic or complex conditions that required intervention over a long period of time or the discharge of a patient because the requested plan of care had been completed (or sometimes because the family disengaged from services eg moved out of area), medical staff seemed satisfied.

Times still existed where nursing staff failed to keep the nominated medical officer abreast of changes in the status of their patient within the specified timeframe and medical staff sometimes complained about this. However, in the referrer survey (see Appendix Five) where staff were asked to comment on documentation, they were very favourable about the timeliness and meaningfulness of the documentation received, in most cases.

Despite occasional lapses in compliance, POS nursing staff saw this aspect of care as crucial to building and maintaining relationships with referring medical officers and again, the nurses really strived for one hundred per cent compliance with data for this indicator.

As with previous indicators, if staff forgot to record that the letter was sent, it was assumed not to have occurred. A significant factor impacting on the nursing staff's ability to meet the criteria of this indicator (ie within 24 hours) was their workload. For instance, at times when a large number of referrals were received, or the home visits being provided were particularly complex, or times where staff unfamiliar with the service were utilised to cover sick and annual leave, it was noted that staff's ability to complete the letters within the required twenty four hours became compromised. Often the letters were still completed but the timeframe blew out (sometimes up to a week) The fact that the nurses completed the letters, even when it was outside the prescribed timeframes is testimony to their commitment to the ideal of meaningful communication, even when they were unable to address the criteria of timeliness.

Despite the challenges to meet this performance indicator, the nursing staff complied, on average, seventy-eight per cent of the time, with the peak being ninety-four per cent which was achieved in December 1999 (as stated earlier, this is traditionally a quieter month in terms of service delivery as many services reduce their practice over the Christmas holiday period).

A compliance rate of almost eighty per cent is not ideal, but given the competing pressures on the nurses time, it is quite good. An intervention that may positively influence this compliance rate may be the appointment of some clerical support to assist the nurses in the completion of the task. The letter to the doctor was designed as a proforma so that minimal time had to be spent in repetitious documentation but sometimes the actual task of sending the fax was very time-consuming (needing to refax until line clear, or being able to contact someone at the doctor's office to have phone line switched over to fax [as was the case for many of the general practitioners who had only one incoming line]). Appointment of secretarial support was an administrative decision and, not a priority for them at the time.

8.5.5 NUMBER OF PATIENTS REFERRED TO POS WHO WERE SEEN WITHIN TWENTY FOUR HOURS OF THE RECEIPT OF THE REFERRAL

It is considered that timeliness is an important cornerstone of meaningful care. If care cannot be provided at a time when needed, then it's usefulness may cease to exist. This issue supported the development and rationale for this indicator. The average length of stay for paediatric patients at the local hospital was approximately 1.9 days (this is also a gauge of the short period of time that children are generally most unwell).

For POS nursing staff to be able to implement a medical care plan that assisted a child to avoid hospitalisation, or avoid representation at the hospital, POS staff had to be responsive to the request to provide care. For example, a request to provide daily antibiotics could not be deferred for a week or two. This cognisance needed to be balanced with the family's perceptions about their child's condition. For example, where a child was discharged from hospital and the mother was quite anxious about her ability to undertake adequate surveillance on her child at home, a need may exist for a same-day visit in order to prevent re-presentation to the hospital or an unplanned visit to the general practitioner in the immediate post-discharge period. Waiting even until the next day in this case, would most likely mean that the need/value of POS intervention has passed, rendering it useless

Conversely, there may also be times when a visit within twenty-four hours of the receipt of referral was not required. This included patients referred for overnight oximetry, or to have a dressing taken down and changed five days post-procedure. In cases such as this, the emphasis was placed on contacting the family within the first twenty four hours after the receipt of the referral to acknowledge receipt of the referral and make plans with the family to deliver the required care at a time they indicated would best fit with their lifestyle.

The initial indicator was related to a *visit* within twenty-four hours of receiving the referral. After review by the Hospital Quality Committee, and discussion with the staff of the Department of Paediatrics, it was agreed to reword the indicator to reflect management of referrals where a request for a delayed visit was made. Thus, the indicator was changed to read *"Number of patients referred to POS who were **contacted** within twenty four hours of the receipt of the referral"*.

Staff compliance with this philosophical underpinning to care delivery was excellent and rated greater than ninety-six per cent in all but one month in the study period. Again, the pressures of workload may have influenced the nurse's ability to gain one hundred percent compliance with this indicator. Another reason the less than one hundred percent compliance could be attributed to is difficulty in actually making contact with the family when the referral was received. The details that the nursing staff are generally provided with are home contact details. However, in a number of cases what the nurses encountered was parents taking their sick child to the grandparent's house, seeking assistance with their management during the period of illness and/or recovery. This then led to a delay in being able to contact the family.

8.5.6 NUMBER OF PATIENTS EXPERIENCING AN ADVERSE OCCURRENCE (MORBIDITY OR MORTALITY)

During the study period, there was only one patient death, and this was an expected death. The reason for POS involvement was to support the child and their family through the palliative and subsequent terminal phase of the child's condition. The purpose of this indicator is to primarily address morbidity caused by treatment, treatment omission or treatment failure. It was not designed to reflect expected patient deaths.

Following six months of data collection, without any patient morbidity or mortality (excluding the palliative care patient who died), the Hospital Quality Committee recommended that this indicator become a sentinel event (as described in Chapter Three); meaning that monthly data need not be collected and that EVERY reported adverse patient occurrence and/or death would be fully investigated to ascertain any human-related error or systems causes that may have contributed to the event.

8.5.7 NUMBER OF WOUNDS THAT BECAME INFECTED DURING THE PERIOD OF MANAGEMENT BY POS THAT BECAME INFECTED AFTER DAY 3 POST REFERRAL.

The researcher worded this indicator to reflect wound infections identified more than 3 days after referral to POS to compliment a current ACHS indicator that measured infection in the immediate post-operative/post-injury period. The other reason this indicator was worded this way was to minimise contamination of the data pertaining to the POS nurse's care, due to wound infections that were present at the time of referral being included.

During the study period, the data revealed a zero rate of infection in wounds managed by the POS staff. There were a couple of reasons postulated for this:

- *Use of sterile gloves* – This issue is probably more about nurses perceptions than evidence-based practice. Psychologically, the POS nurses felt that they approached the task of wound dressing differently (more conscientiously) when they needed to don sterile gloves.

  Upon checking with their colleagues who provided care for adult patients, it was discovered that they did not use sterile gloves. It was also noted that the adult wound infection rate ran at about ten per cent. As wound dressing requires a non-touch technique, it really should not matter whether the gloves used are sterile or non-sterile (they are principally protecting the nurse) but POS nurses reported that they afforded greater concentration and attention to the task when they approached the task with a “sterile” mindset. The staff decided that the added cost of approximately $1.80 per dressing, was a cost well borne by the service in order to protect the patient and minimise their exposure to health care services.

- *Parents not asked to do dressings* – The POS nurses decided that by minimising the number/quality of people doing the dressings the rate of wound infection could be minimised. It was in rare and unusual circumstances that parents were asked to undertake the task of wound dressing for their child at home. POS staff employed various methods of undertaking the dressings in order to fit within family routines and expectations. As soon as daily dressings were no longer required, the nature of the dressing was changed to those that would last several days at a time without compromising the wound. This probably led to greater parental compliance with the care plan and meant that the nurses were able to do the dressing, undertake timely assessments of the wound and make alterations to the dressing regime before infection became an issue.

- *Frequent medical review* - During the period that POS nurses provided care and performed wound dressings, they regularly encouraged families to seek medical review of the wound healing process. This facilitated early intervention in changing the medical care plan where necessary. Thus again the children and their families benefited because it allowed timely assessment of the wound and alterations to the dressing regime before infection became an issue.

- *Parental encouragement to complete their child's course of antibiotics where prescribed* - Because POS nursing staff were attending the house regularly, particularly in the early days following the wound being sustained, POS nurses monitored completion of the course of antibiotics if an antibiotic had been prescribed in the initial post-operative or post-injury period. Often times, they encouraged parents to coincide drug dosage with the dressing time. This meant that they witnessed ingestion of at least one dose of antibiotics (rather than rely on parental testimony) and monitored the content of the antibiotic packet.

A final reason that the zero wound infection rate may be attributed to is:

- *Nurses adherence to best practice principles…eg challenge medical staff regarding the use of betadine where such a dressing was ordered; use of shower to clean wounds such as pilonidal sinus; moist wound healing* – Where the medical care plan asked for a dressing practice that was inconsistent with the evidence, POS nurses implemented their role as patient advocate and challenged the care requested. That is not to say that they were always able to alter the medical staff's care plan. However, in many cases, after producing the documented evidence, care plans were in fact altered to reflect best practice.

Upon reflection of this indicator and the data it has generated, this is a measure of service success that should be discussed with the Hospital Quality Committee with a view to having it redefined as a sentinel event (as with the morbidity and mortality indicator). This would mean that every episode of wound infection is reviewed within a human-factors framework to determine what the system issues were that contributed to a breakdown in wound-care technique that led to an infection.

8.5.8 NUMBER OF POS PATIENTS WHO WERE RE-REFERRED FOR THE SAME PROBLEM WITHIN 28 DAYS OF DISCHARGE FROM POS.

Re-referral of children to POS care for the same reason within twenty-eight days was believed to possibly indicate a failure of POS to meet one of it's central tenants: to *empower parents to competently and confidently take care of their child at home*.

However, this was found to not necessarily be factual In each of the cases where the child was re-referred, it was almost always related to viral illness for example, gastroenteritis or respiratory illness. It was found to be extremely difficult to determine whether it was residual illness related to the previous episode, or re-infection from another source. Thus, it was difficult for the POS nurses to demonstrate whether the re-referral was related to a failure on their part, as opposed to a natural progression of the child's illness history.

In discussion with the nurses about the cases that had been re-referred, in almost all instances, the nursing staff indicated that the child was not as sick as the original presentation. Re-referral rates were generally less than five per cent except in the month of December 1999 (where re-referrals blew out to nineteen per cent). On review of the admissions for this month, it was noted that there were an unusually large number of patients with gastroenteritis. A postulation supporting the increased rate of re-referrals was attributed to parental anxiety. All the children in question had been admitted to hospital prior to their first referral to POS. Parents actually re-referred their child themselves. It seemed to the POS nurses that the reason for this was to get the POS nurses to review the efficacy of the treatment plan they themselves had implemented at home when the child became sick again (and their actions also seemed to be based on the teachings received during the child's last episode of illness).

The other point of note with regard to these statistics is the relatively small patient numbers involved. These small numbers can skew the perception of the situation: for example, to have a re-referral rate of nineteen per cent, only three of sixteen children had to re-refer.

8.6 INDICATORS IN SUMMARY

In summary, it can be seen that a number of the indicators originally proposed as measures of service success for POS proved useless measures, either because they did not measure that which they were purported to measure (for example, the number of home visits for asthmatics) or happened so infrequently that measuring them monthly or quarterly or even yearly did not necessarily impress their value. For these indicators, re-defining them as sentinel events meant that they would be afforded due consideration each and every time they occurred (such as patient morbidity and/or mortality).

CHAPTER

NINE

CHAPTER NINE – CONCLUSIONS AND RECOMMENDATIONS

9.1 INTRODUCTION

It is only in recent years that the extension of paediatric nursing beyond the walls of the hospital into the community has created an emerging specialty for paediatric nurses in NSW. As with the experience in the United States and United Kingdom, development within this emerging specialty has been relatively slow in Australia. Consistent with the unhurried development of services, discussion of such services in the literature has also been slow to emerge. Further, literature regarding *evaluation* of paediatric outreach services remains scant.

This study sought to determine indicators of family and referrer satisfaction and service success that would signify whether the service, established as the paediatric outreach service, met the expectations of the clients it served. In the immortal words of Dorothy in Frank L. Baum's the Wizard of Oz, "*there's no place like home*" for the provision of paediatric nursing care.

This study has described the establishment of a paediatric outreach service and identified the importance of determining evaluation criteria prior to implementing a service. In addition to satisfaction indicators, the research project developed and evaluated nine success indicators against which a paediatric nursing outreach service can be measured by future service providers.

Determining whether a new service achieves what it aimed to achieve is a complex process. It is easier to undertake evaluation when the aims of the service are clearly stated and all service providers and consumers understand the aims and expected outcomes. These were not available when POS was commenced so evaluative criteria were developed to facilitate the process of accountability.

9.2 KEY STUDY FINDINGS

The findings of the Satisfaction Survey defined by both groups of consumers, that is, the referrers and the parents are summarized here:

9.2.1 ASPECTS OF THE PAEDIATRIC OUTREACH SERVICE THAT CONSUMERS VALUED

The features valued by referring agents include:

- Intake hours were convenient
- Referral processes were easy to use
- Nursing staff were easily contactable

- Effective and timely communication - feedback is provided by nurses about POS patients
- Referrer confidence in the nurses' skills was high
- Referrers believed that the standard of care provided at home by the POS nurses was equivalent to hospital

It was reassuring that the features of POS that were valued by the parents of the children who received care from the POS nurses was very similar to those valued by the referrers. These included:

- Hours of POS operation for home visits were appropriate
- Parent's wait time to first nursing visit was satisfactory
- Number of home visits conducted by the POS nurses was satisfactory
- Parents had a high level of confidence in information provided by the POS nurses and its usefulness
- Parental confidence in the POS nurses' skills was high
- Parents believed that the standard of care provided at home by the POS nurses was equivalent to hospital
- Parents had high levels of confidence in the knowledge of the POS nurses

- Parents had high levels of confidence the nurses' genuineness; that the nurses' valued their parental carer role; and that the care of their child was tailored to the family's lifestyle needs
- Reassurance from the POS nurses was highly valued by parents
- Most families knew the name of the nurse providing their child's care

9.2.2 RECOMMENDATIONS FOR IMPROVEMENT OF THE PAEDIATRIC OUTREACH SERVICE: DEFINED BY CONSUMERS

Respondents from the parental group as well as from the group of referring agents had suggestions for the researcher about ways in which POS might be improved. Suggestions from the parental group include:

- Parents needed to have a clearer understanding of their rights and responsibilities
- Parents had little awareness about how to make a complaint about the service or service providers
- A greater awareness of the service in the broader community was needed
- Some parents complained about a lack of phone follow-up following discharge of their child from POS.

The referring agents identified different concerns. Out-of-area care providers who used POS found the geographical boundaries were a problem, especially when they had complex patients requiring POS-like care.

Another question posed by referring agents was about whether POS provided more of the same or something new.

9.2.3 SERVICE INDICATORS IMPLEMENTED

Following testing of the indicators developed by the researcher during the study period, the researcher (who was, as previously stated, also the clinical nurse consultant within the POS team) asked the Fairfield Health Service Quality Committee to endorse those indicators that it was believed could provide important supporting statistical data for ongoing evaluation of the Paediatric Outreach Service. Following evaluation of the information tabled, the Quality Committee recommended that these service indicators (for which quarterly reporting was required) be adopted by the Health Service:

- Number of patients referred to POS with a diagnosis of asthma for whom a clinical pathway was completed

- Number of patients for whom a discharge letter was completed and sent to the nominated medical officer[s] within **24 hours** of discharge from POS

- Number of patients for whom an initial report was sent to the nominated medical officer[s] within **48hrs** of the child's initial visit.

- Number of patients referred to POS who were contacted within **24 hrs** of the receipt of the referral

- Number of patient's wounds that became infected during the period of management by POS that became infected after Day 3 post referral.

- Number of POS patients who were re-referred for the same problem within 28 days of discharge from POS.

- The morbidity and mortality indicator identified a zero reading for each period during the pilot data collection. Following review of the pilot data, the study Health Sector's Quality Committee recommended that POS nurses did not need to collect data against this indicator for quarterly reporting. However, they required that this indicator be preserved as a sentinel event indicator, meaning that every incident meeting this criteria must be fully investigated by the POS nurses (and other relevant clinicians as required).

9.3 STUDY IMPLICATIONS

There are several implications for nurses, nursing as a profession and patient care that have been high-lighted through the findings of this study. The next pages will describe the potential impacts.

9.3.1 IMPLICATIONS FOR NURSING PRACTICE AND PATIENT CARE

This study has important implications for both the specialty of paediatric nursing and for the management of childhood illness in the future.

With increasing demands on the health care system here in New South Wales such as a reduced nursing workforce, bed-block, decreasing budgets, increased expectations for patient turnover, and an ever-shortening length of stay, pressure remains on health service administrators to develop innovative service delivery models to act as a release valve for a pressurized health system. Services such as the one identified in this study may provide such an answer. A service such as POS also addresses the moral imperative of where best to nurse a child to recovery. Since the Platt report (1959), many authors have espoused the benefits of managing a child's illness as close to home as possible whenever it is safe and practicable to do so.

It behoves health service administrators to give careful consideration to the future development of paediatric outreach nursing services. This would deliver an equivalent standard of nursing care in the child's home setting and meet the demands of the family expecting quality care as well as the medical staff overseeing the care. Development of a paediatric outreach service may also assist organisations to better manage their bed base, particularly during periods of high bed demand.

For clinicians and administrators involved in the planning process, this study has identified a number of indicators of satisfaction and success which may assist hospital and community health services in the development of such services in the future. None of these indicators specifically concern the local area that POS serviced. Rather, they serve as guidelines which focus on various aspects of service provision. They could also be applied across a range of geographical locations, and as such, assist staff who are considering the development a new outreach service.

If underpinned by a family-centered framework, paediatric outreach nursing services have the capacity to empower children and their families in the planning and implementation of a management plan for the child's illness. Such empowerment may lead families to practice better healthcare, develop better health-seeking practices and ultimately lead to healthier children.

9.3.2 IMPLICATIONS FOR NURSING EDUCATION

For the nurses, it is not simply a matter of changing the environment in which they work from hospital to home. The clinical skills required by nurses employed in the community setting are somewhat different to those of the nurse working in an acute inpatient hospital setting. These nurses are potentially the only care provider who reviews a child on any given day. Consequently, the home-visiting paediatric nurses must be competent in observation and assessment skills. They must also be able to give attention to detail in the management plan for the family to follow until the next visit. They must also be able to impart information to the parents about cues to look for that will indicate a need to seek medical review. The need for this extended skill-base is related to the fact that there were no other nurses “on-shift” who might detect any symptoms they missed.

The other important difference for the home-based paediatric nurse is that they must possess very effective communication skills. This is because they need to be able to develop sufficient rapport with the family to “get in the front door”. But more than that, they need to be invited back. In the hospital setting, the child and their parents are in a sense, captive. They have come to the hospital because they believe the child needed hospital attention. In some instances, in the home-setting, parents may not yet have drawn the same conclusion about their child, or they may be highly suspicious of the reason for the nurse’s desire to conduct a home-visit. Should the trend towards home-based paediatric nursing care continue, then there is scope to develop a specialist course to assist paediatric nurses to adapt and extend their hospital-honed skills as they move into a new and challenging environment of family-centered care.

9.4 STRENGTHS OF THE STUDY

There were several strengths identified in this study. They include the fact that it appears that this is one of the first evaluative studies of POS undertaken in Australia and by a nurse.

Several other services have been commenced over subsequent years following the POS evaluation. POS was the first service to enable and facilitate such a process and provide the study findings to other potential service providers.

The POS evaluative study facilitated the initial development and implementation of quality service indicators for use in the paediatric community health setting. It is possible that these may lead current and future service providers to provide evidence that their service has been delivered against a set of criteria (which stakeholders agreed to be important).

A potential educational niche area was identified. The researcher approached The New South Wales College of Nursing and requested they consider the idea of developing a module to address the educational needs of this group of nurses. Following discussions, work has begun on the development of a study module addressing the needs of the paediatric nurse working in the home setting. The researcher has been significantly involved in the development of the structure of this module, with input and insights based both from personal experience in this paediatric nursing specialty, and from understanding the study findings from the two client satisfaction surveys and the service indicators. Consideration needs to be given to the safe and appropriate preparation of paediatric nurses who may choose this career path in order to maximize the outcomes for the child, their family and the nurse themself.

9.5 LIMITATIONS OF THE STUDY

There were a number of limitations in this study. These included the low response rate from the parental survey. It was difficult to track down past patients of the POS. The limited response rate makes it difficult to say conclusively that the opinions of those who did respond are reflective of the larger population. A contributing factor to the low parental response rate may be due to the fact that the study data was collected retrospectively and for some families, it may have been up to twelve months since their child had received care from the POS nurses. Consequently, the time lapse may have impacted upon their willingness to complete a survey or their ability to recall information.

The extremely broad ethnic community of the local government area serviced by POS initially challenged the researcher to seek sources of funding for the translation of the parental survey into community-identified languages. However, funding for the large sum of money required for translation purposes could not be found. Similarly, it was not possible to have the parent satisfaction survey translated for this study. It is considered likely that this fact may have had a direct bearing on the low response rate obtained from the parental surveys.

Study findings may have been enhanced had the researcher undertaken a process of triangulated data collection and included a survey for the nurses employed by POS. This process may have allowed the researcher to gain a deeper understanding of the indicators of satisfaction for the families and the possibly the referrers.

9.6 RECOMMENDATIONS FOR FURTHER RESEARCH

Despite the important contribution of the study findings to the body of nursing and Australian literature, much remains unknown about the cost effectiveness of nursing services such as POS. An opportunity for future researchers would be to explore more empirical aspects of service delivery, for example the costs of providing such a service and investigation into the use of paediatric outreach services as a total substitution for inpatient care.

Further research is required in order to determine what, if any, capacity building is developed within families through the provision of healthcare. In some cases, capacity may be built once families have utilized the respectability of illness to seek assistance from nurses, such as those providing home-visiting, in order to address other family “issues” (as described in Ch 3).

Repeating this study in other areas where a paediatric home-based nursing service is provided could assist researchers to determine whether the elements of service provision, identified by the participants of this study as satisfying, were specifically related to POS and it’s nurses, or were in fact elements of service provision that would satisfy consumers in a range of communities.

A future study could engage members of non-english speaking communities in the feedback process which may elucidate indicators of success from a trans-cultural perspective. Such a study may assist in determining what, if any, elements of service provision require adjustment to meet the needs of individual cultural groups, and collectively, a multicultural community.

Future research may investigate the role and scope of practice of the paediatric outreach nurse; their new educational needs, and their collaborative relationships with other paediatric service providers, including engagement and disengagement with families. This may lead to the development of indicators or criteria for employment of paediatric outreach nurses.

Future research may determine the characteristics and complexities of the nurses providing quality care when working in home-based services. When this study was conducted, there was a small number of nurses and a relatively low referral rate. As both the staff profile has increased, as has the number of referrals, it would be interesting to re-issue the survey to identify whether the study's parental satisfaction findings were related to the service philosophy or the characteristics (qualifications, experience, personal traits) of individual nurses providing the care.

With the increasing emphasis in health on health outcomes, a study that seeks to attribute improved health outcomes to the provision of home-based nursing care would be valuable to those proposing the development of a paediatric nursing outreach service.

Finally, little has been cited in the National and International literature regarding services such as POS and their relationship with general practitioners. Future research could explore general practitioner's perceptions concerning services such as POS and their willingness to engage in professional collaboratives with nurses, families and other care providers.

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APPENDICES

APPENDIX 1

Letter of Request to ACU Ethics Committee

Patricia Boss
Clinical Nurse Consultant
C/- Paediatric Outreach Service
PO Box 5
Fairfield. NSW2165

The Ethics Committee
Australian Catholic University
MacKillop Campus
North Sydney2050.

10th May, 99

To the Chairperson,

Please find attached a copy of my ethics proposal to undertake a research project and hopefully enable me to complete my Masters of Nursing (Research).

I did request ethics clearance for a project that I commenced in 1997. I deferred my studies in 1998 and now wish to continue my studies, looking at a different question. I am anticipating having my project completed by December 1999 in order to meet professional and academic goals.

Thank-you for assessing my proposal and I welcome your feed-back.

Sincerely,

Trish Boss

APPENDIX 2

Letter of Request to SWSAHS Ethics Committee

Patricia Boss
Clinical Nurse Consultant
C/- Paediatric Outreach Service
PO Box 5
Fairfield. NSW2165

The Ethics Committee
C/- Division of Planning
SWSAHS
Locked Bag 17,
Liverpool,NSW,2070.

2nd May, 99

To the Chairperson,

Please find attached a copy of my ethics proposal to undertake a research project and hopefully enable me to complete my Masters of Nursing (Research).

I did request ethics clearance for a project that I commenced in 1997. I deferred my studies in 1998 and now wish to continue my studies, looking at a different question. I am anticipating having my project completed by December 1999 in order to meet professional and academic goals.

Thank-you for assessing my proposal and I welcome your feed-back.

Sincerely,

Trish Boss

APPENDIX 3

Letter of Introduction - Referrers

Paediatric Outreach Service

Dear Colleague,

During the last eight months, the Peadiatric Outreach Service visited a sick child who you referred to the ServiceWe are doing a survey with referring agents who have used the service to see what they thought of the serviceThis will help us to identify any areas we need to improve

I would like to ask you to take a few minutes to answer the following survey. Please use the "Reply Paid" envelope to return the survey to us by *************. If you have any questions, please don't hesitate to call

Thank-you for your help – your opinions are very important to us.

Sincerely,

Trish Boss
Clinical Nurse Consultant.

APPENDIX 4

Referrer Survey

Paediatric Outreach Service

Referrer Survey

The Paediatric Outreach Service of Fairfield would appreciate your assistance in completing these questions in order to continue our efforts to provide quality care to the children of Fairfield. Please take a few minutes to answer these questions. Your answers will be **confidential.** Please return the questionnaire in the reply paid envelope provided.

1. From the following list, please tick the <u>one</u> that best describes your role:

☐ General Practitioner
☐ Visiting Medical Officer
☐ Community Health Worker
☐ Community Liaison Officer
☐ Clinical Nurse Consultant (what specialty?………………………… .)
☐ Registered Nurse (what specialty?………………………… .)
☐ Other ……………………………………… (please describe)

☐ Community Counselling Team
☐ Speech Pathology
☐ Social Worker
☐ Palliative Care Worker

Instruction.
Please tick the box which best answers each question.
If you wish to make a comment in regards to any question below please feel free to do so.

		Yes	No	N/A
2	I found the intake hour of the service convenient to my practice			
	Comment:			
3	I have used this service before.			
	Comment:			
4	I refer patients regularly.			
	Comment:			
5	It was easy to make a referral to the Paediatric Outreach Service			
	Comment:			

		Yes	No	N/A

6	I found it easy to get in touch with staff to discuss my referral.			
Comment:				
7	I receive feedback on my patient's progress by the Paediatric Outreach Nurses.			
Comment:				
8	I feel confident in the skills of the Paediatric Outreach Nurses to meet the needs of my patients.			
Comment:				
9	I will continue to refer patients to the Paediatric Outreach Nurses.			
Comment:				

10. Compared to other services I refer patients to, the Paediatric Outreach Service was:

☐ Excellent
☐ Above Average
☐ Average
☐ Satisfactory
☐ Unsatisfactory

11. Please tell us what you liked about the service?

…………………………………………………………………………………………

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12. Please tell us what you disliked about the service?

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13. Please provide some suggestions on how we could improve our service?

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Thank-you for taking the time to complete this survey.
Please know that your responses are valued.

APPENDIX 5

Letter of Introduction

Paediatric Outreach Service

Letter of Introduction

Dear [Participant's Name],

I would like to ask you participate in my research project by completing the attached Satisfaction Survey.

My name is Trish Boss I am a candidate at The Australian Catholic University (ACU) Mackillop Campus, NSW studying for my Master of Nursing (Research) qualification To complete my studies, I have undertaken a research project.

In May 1998, Fairfield Health Service commenced a new service known as the Paediatric Outreach Service (POS)POS was developed to provide nursing care for sick children at homeAs this is a new service, and because there are very few similar services in Sydney, I would like to undertake an evaluation project to find out what is good about the service, what is not so good, and what we can do to make it better for the children of Fairfield and their families. In order to perform the evaluation, I need your assistance. At least once since May 1998, your child has received home-based nursing care by the POS nurses. I value your opinions about the care provided. The attached survey will be returned anonymously, so please be as honest as you can with your responses.

This study has received ethics approval by the ACU (MacKillop) Divisional Research Project Ethics Committee In the event that you have any complaints about the way you have been treated during the study, or a question that I have been unable to satisfy, please contact The Chair, Research Projects Ethics Committee, C/- Divisional Research Office,179 Albert Road, Strathfield Any complaint will be treated in confidence, fully investigated and you will be informed of the outcome.

If you have any questions concerning the procedures in the study, please direct them to the principal investigator, Trish Boss, on my mobile telephone: 0411862 320 or one of my Supervisors, Lyn Coulon Ph 9739 - 2335 or Elaine Boxer Ph 9739 - 2359.

Thank you for your time.

Yours sincerely,

____
Patricia Boss

APPENDIX 6

Letter of Invitation - Parents

Paediatric Outreach Service

Dear Parent,

During the last eight months, the Peadiatric Outreach Service visited your child who was sickWe are doing a survey with families who have used the service to see what the parents and the children thought of the serviceThis will help us to identify any areas we need to improve.

I would like to ask you to take a few minutes to answer the following survey. Please use the “Reply Paid” envelope to return the survey to us by **********. If you have any questions, please don’t hesitate to call.

Thank-you for your help – your opinions are very important to us.

Sincerely,

Trish Boss
Clinical Nurse Consultant.

APPENDIX 7

Parent Survey

Paediatric Outreach Service

Parent Satisfaction Survey

The Paediatric Outreach Service, Fairfield Health Service, would appreciate your assistance in completing these questions in order to continue our efforts to provide quality care. Please take a few minutes to answer these questions. Your answers will be **confidential.** Please return the questionnaire in the reply paid envelope provided.

1. What country was your child born in? ……………………………………….

2. What languages are spoken in your home?…………………………………..

3 What is your postcode? ***(please fill in the boxes)*** ☐ ☐ ☐ ☐

4. How many times has your child been sick in the last 6 months? ***(please tick one box)***

☐ 1
☐ 2
☐ 3 times or more
☐ unable to remember

5. In the last six months, which of the following health professionals have seen your child? ***(please tick one or more boxes)***

☐ Primary Health Nurse
☐ Paediatrician
☐ Hospital
☐ Occupational Therapist
☐ Unable to remember
☐ Local Doctor
☐ Child Health Nurse
☐ Physiotherapist.
☐ Counsellor
☐ POS Nurse

6. Who referred your child to the Paediatric Outreach Service ?***(please tick one box)***

☐ Local Doctor
☐ Child Health Nurse
☐ Emergency Department of a hospital
☐ Friend
☐ Paediatrician
☐ Hospital
☐ Self/Family

☐ Unable to remember
☐ Other…. -please specify……………………………………………

7. Why was your child referred to the Paediatric Outreach Service? ***(please tick one or more boxes)***

☐ Breathing problem
☐ Gastro
☐ Fever
☐ Counselling
☐ Assistance with medication
☐ Unable to remember
☐ Other. …-please specify……………………………………………
☐ Feeding problems
☐ Equipment needs
☐ Support visits
☐ Wound dressing

8. After you were referred to the Paediatric Outreach Service, how long was it before the first visit? ***(please tick one box)***

☐ within the first 24 hours
☐ between 25-48 hours
☐ after 49 hours
☐ unable to remember

9. Were you satisfied with the time you waited for the first visit?***(please tick one box)***

☐ yes
☐ no

If no why ……………………………………………………………

10. How many times was your child seen? ***(please tick one box)***

☐ once
☐ twice
☐ three times or more
☐ unable to remember

11. In your opinion, was this ***(please tick one box)***

☐ **the right number of visits ?**
☐ **too few visits ?**
☐ **too many visits ?**

12. How would you rate the standard of the service that your family received ?
(please tick one box)

- ☐ **excellent**
- ☐ **above average**
- ☐ **average**
- ☐ **below average**
- ☐ **poor**

13. Do you think the hours that the service operates are adequate?

- ☐ **yes**
- ☐ **no**

14. If no to question 13, what hours do you think would be appropriate and why?

....

....

....

15 Instruction: Please tick the box which best answers each question.
If you wish to make a comment in regard to the questions below feel free to do so.

		Usually	Sometimes	Occassionally	Rarely
A	**Were you provided with information about your child's illness?**				
B	**Was the information useful to you ?**				
C	**Do you feel confident in the Health professionals taking care of your child? Their**				
	1) Skill				
	2) knowledge				
D	**Did you plan your child's care with the nurse?**				
E	**Were your rights and responsibilities explained to you?**				
F	**Did the nurse discuss with you the approximate number of visits needed to achieve a desirable outcome?**				
G	Did you know the name of nurse visiting your house?				
H	Were you told how to make a complaint if you needed to ?				
I	Do you feel that the nurse taking care of your child was genuinely concerned about them?				
J	Do you think that your role as carer for your child was valued?				
K	Did the plan of care for your child fit with your lifestyle?				

Please tell us what you liked about the service you received?

………………………………………………………………………………………………….

…………………………………………………………………………………………………

…………………………………………………………………………………………………

Please tell us what you disliked about the service you received?

………………………………………………………………………………………………….

…………………………………………………………………………………………………

…………………………………………………………………………………………………

Please provide some suggestions on how we could improve our service?

………………………………………………………………………………………………….

…………………………………………………………………………………………………

…………………………………………………………………………………………………

Thank-you for taking the time to complete this questionnaire.
Please know that your views are valued.

Questions adapted from:
Cooper C. , (1998) Patient Satisfaction Survey Fairfield Health Service.
Rowland H. Sand Rowland B. L. , (1994) Nursing Department Forms ManualMaryland. Aspen Publishers IncChapter 12.

Appendix 8

ACPCHN Minimum Standards for Nurses Caring For Children and Young People

Australian Confederation
of Paediatric and
Child Health Nurses
(NSW Branch) Inc

New South Wales

ACPCHN

MINIMUM STANDARD FOR NURSES CARING FOR CHILDREN AND YOUNG PEOPLE*

The goal for paediatric and child health nurses is to work with children and their families to achieve their optimal health and well-being. This will be achieved by engaging all relevant stakeholders in the planning and delivery of care.

The following statements are related to minimum practice standards . The role descriptors are the same for both paediatric and child health nurses, however the emphasis of the role will be influenced by the context in which the nurse practices.

The Nurse:

- assesses children's health, development and well-being, recognising deviations from the norm and acts appropriately on the findings;
- demonstrates knowledge of common child health issues and management, relevant to their area of clinical practice and bases practice on current evidence
- demonstrates an understanding of the impact of hospitalisation on children & families;
- demonstrates an understanding of the impact of community and home environments on children & families;
- critically examines and utilizes relevant evidence to inform and guide culturally inclusive practice
- communicates effectively and works in partnership with children & families;
- utilises contact with families to promote the health of children using relevant health guidelines;
- recognises and acts appropriately to advocate for the health and safety of children;
- encourages age appropriate self care/independence for children and their families;
- liaises with others in the community in meeting children's health needs;

- demonstrates a knowledge of medications and is able to calculate and administer medications and other preparations to children safely and educate parents/caregiver accordingly;

- demonstrates an ability to commence and maintain basic paediatric life support; and

- demonstrates an awareness of relevant Federal, State Legislation and policies and acts accordingly.

REFERENCES

1 ACPCHN Competencies for the Specialist Paediatric and Child Health Nurse (2000)
2 ACHS Guidelines for Maternal and Infant Care Module (1998)
3 United Nations Convention on the Rights of the Child (1989)
4 AWCH Health Care Policy relating to children and families (1974)
5 NSW Health Guidelines for the Hospitalization of Children(1998)
6 Scope of Practice for Child and Family Health Nurses. (2001). CAFNA (NSW) Inc.
7 Code of Ethics for Nurses in Australia Developed under the Auspices of Australian Nursing Council, Royal College of Nursing, Australian Nursing Federation (June 2002)

Reviewed August 2002
For Next Review August 2004

Appendix 9

Media Articles

APPENDIX 10

NSW Health Role Delineation

APPENDIX 11

POS OPERATIONAL PLAN

Paediatric Outreach Service

Fairfield Health Service

Operational Document

(This document is an adaptation and update of the original operational document that was prepared by Dr C.Cooper and P. Boss [CNC] in 1998)

Contents

1. Introduction

There is a worldwide trend towards treating children at home where this is possible, rather than in hospital. With new technologies and different health-care strategies being implemented, the number of children requiring hospitalisation is falling. In addition, there has been a steady decline in the length of time children stay in hospital. The Paediatric Outreach Service, as part of Community Paediatrics, was developed to respond to this world trend.

The development and implementation of the Paediatric Outreach Service has been collaboration between Community Paediatrics, Community and Allied Health, and the Fairfield Division of General Practitioners.

Paediatrics Outreach Service augments the care provided by other paediatric care providers in the Fairfield Health Service, namely Fairfield Hospital and the two Community Health Centres (Prairiewood and Fairfield).

Fairfield Hospital has an Emergency Department that provides immediate emergency services for all paediatrics presentations. A level 4, twenty-four bed paediatric/adolescent ward is located within the hospital for paediatric medical and surgical admissions. Primary Health Nurses from the Community Health Centres provide support for paediatric referrals, early childhood clinics, and school screening. Therapists provide paediatric Allied Health within the Fairfield Hospital, Community Health Centres and the Physical Disabilities unit.

The Paediatrics Outreach Service has been designed as a service that interacts with the current paediatric health providers in the Fairfield Health Service.

2. What is the Paediatric Outreach Service?

It has been well recognised that hospital admissions for children are traumatic, highlighted by authors such as Platt (1959). It is frightening for a child to be placed in a foreign environment, especially when this is compounded by separation from their family. Paediatric programs in which medical and nursing care of children is provided in their own home have been shown to minimize this stress and help children to recover more quickly from their illness reference.

The Fairfield Paediatric Outreach Service reduces the need for children to be admitted to hospital during an acute illness when ever possible. Sometimes an admission cannot be avoided. Where possible, the Paediatric Outreach Service assists the child and their families by shortening the length of the hospital stay necessitated by the illness and/or by assisting the child to complete their recovery at home.

The objective of this service is to allow parents and families to provide care for their child in the security of their own home. Support is provided by a visiting community health nurse, to ensure that the child's ongoing medical and nursing needs are regularly evaluated during the course of the illness.

Paediatric Outreach Service nursing support will be provided conjointly by specialist paediatric nurses from Paediatric Outreach and/or by primary health nurses from the existing Community Health Centres. Involvement of nursing staff from both services allows children with a wide range of ongoing medical and nursing needs to be managed at home.

3. Hours of Operation

Monday to Friday 0830-2000

Saturday/Sunday 0830-1230
Public Holidays

Paediatric Outreach has been developed to offer an extended service outside normal business hours to enable nurses access to children who are able to go to school but required care; to discuss a child's management with working parents; or to speak to both parents. The ability to undertake an evening visit to a child also enables nurses to perform respiratory assessments for bronchiolitic and croup patients when it is colder (as this gives a more valuable indication of the child's true respiratory status).

4. Paediatrics Outreach – Current Staffing

1. Clinical nurse consultant (1.0 FTE)
2. Registered nurses – 2 X Permanent Part-time (1.4 FTE)
   (24 hours/week, 32 hours/week)
3. Casual Pool Paediatrics Nurses

5. The Paediatric Outreach Service is available for the Fairfield Local Government Area

POSTCODE SUMMARY
2171
2170
2176
2177
2166
2163
2165
2164
2161

Abbotsbury

Bonnyrigg
Bonnyrigg Heights
Bossley Park
Cabramatta
Cabramatta West
Canley Heights
Canley Vale
Carramar
Cecil Park
Edensor Park
Fairfield
Fairfield East
Fairfield Heights
Fairfield West
Greenfield Park
Horsley Park
Lansvale
Mount Pritchard
Old Guildford
Prairiewood
Smithfield
St Johns Park
Wakeley

Wetherill Park

6. MEDICAL PRACTITIONER INVOLVEMENT

All children supported by the service require either their general practitioner or paediatrician to oversee the medical management and provide a plan of care. This is important so that the primary health nurse/specialist paediatric nurse can assess the child's ongoing medical needs and arrange for the appropriate management in the home environment. The allocated nurse will maintain regular contact with the medical officer overseeing the child's medical management. Any change in the child's condition that warrants medical review is notified to the responsible medical officer and appropriate management is then arranged. This includes consultation with the general practitioner or paediatrician, or admission/re-admission to hospital in some instances. The success of the program depends on an open line of communication between the nurse managing the case and the overseeing medical practitioner.

7. Referral Criteria to Paediatric Outreach Service

Referral criteria to the Service include the following:

- The child should be aged 0-16 years. Adolescents older than 16 years who are still attending school may be accepted on an individual basis.
- The child should live in the Fairfield Local Government Area. The Paediatric Outreach Service will not be able to accept children living outside this area.
- There must be a primary carer who is willing to work with the nursing staff to provide care in partnership to a sick child at home. The program cannot function successfully without the parents/family care providers providing the majority of the care in the home environment.
- Telephone access is highly desirable. This is to ensure timely sharing of information between carers. Phone contact is also necessary to be able to arrange appointment follow-ups and to notify the family of any change in plans. In the event that the family does not have a phone then a nominated relative or friend who is able to provide a message to the family at short notice is required. If phone contact is with someone outside the family home, or someone other than the child's parent/caregivers, the parents will need to provide consent for

basic patient details / instructions to be given to this third person.

- The child's home environment must be suitable for any required equipment necessary to undertake this program.
- The child's home environment must be safe for the child, the child's carers, and the Paediatrics Outreach Service personnel.

If there are special circumstances/requests for Paediatric Outreach Service then discussion with the Service Director on an individual basis is encouraged.

8. Referral to the Paediatric Outreach Service

The Fairfield Paediatric Outreach Service is available to all medical and allied health paediatric care providers in the Fairfield local government area. Referrals are accepted from:

- General Practitioners
- Paediatricians
- Community and Allied health professionals
- Emergency Departments
- Children's Hospital services
- Non government organisations providing paediatric medical support

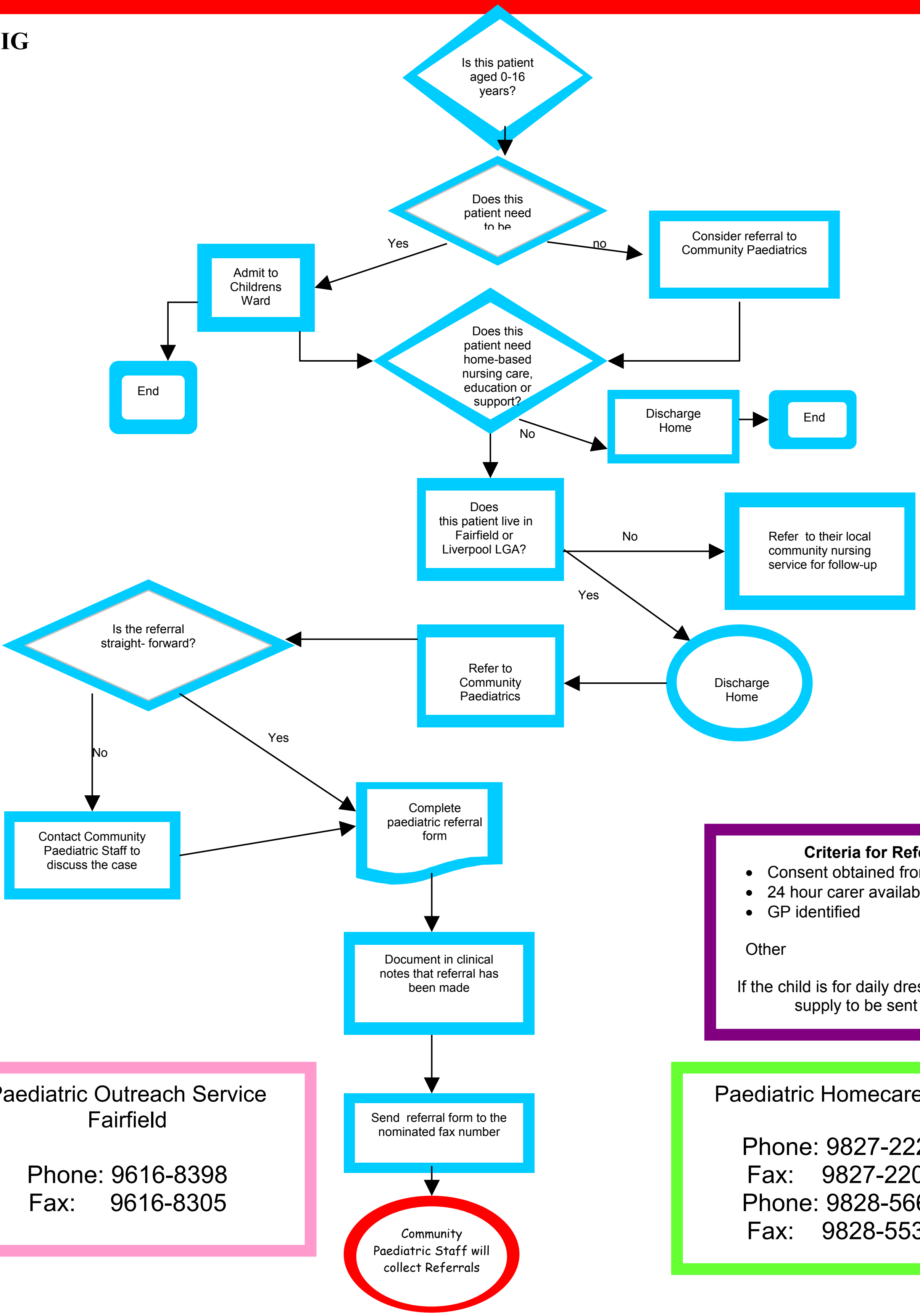
The Fairfield Paediatric Outreach Service covers the entire Fairfield Local Government Area. A centralised referral process has been adopted and all referrals to the Paediatric Outreach Service are co-ordinated by Paediatric Outreach – Fairfield Health Service. Referrals are accepted and processed by Paediatric Outreach staff and then the relevant Community

Health Centre (according to the child’s residential address) is allocated the case when appropriate.

8.1 Paediatric ED – Community Referral Flow-Chart

Making a Referral to the Community Paediatric Service

(FIG



Criteria for Referral

- Consent obtained from parent
- 24 hour carer available
- GP identified

Other

If the child is for daily dressings, 3 days supply to be sent home

Paediatric Outreach Service Fairfield

Phone: 9616-8398
Fax: 9616-8305

Paediatric Homecare Liverpool

Phone: 9827-2222(BH)
Fax: 9827-2200 (BH)
Phone: 9828-5666(AH)
Fax: 9828-5533 (AH)

8.2 Processing of Referrals

Referrals are processed during working hours by staff of the Paediatric Outreach Service. Referrals are faxed to the Paediatric Outreach Office from the referring medical practitioner/health care provider. The referral information should include the documented medical management plan. On receipt of the referral, staff from the Paediatric Outreach Service review it for eligibility for management by POS.

If the referral is accepted, the child and family will be allocated to a nurse according to the child's medical and nursing needs. If the referral cannot be accepted by the Fairfield paediatric Outreach Service, the referring agency is contacted, the reason for the referral not being accepted is explained, and where possible the referrer is given additional information to assist in the management of their paediatric client.

The acceptance or non-acceptance process is co-ordinated by Paediatric Outreach – Fairfield Health Service.

CONTACT DETAILS FOR MAKING A REFERRAL:

Hours:	**Mon – Fri:**	8.30am-7pm	**phone**	**9616 8398**
	Mobile:	8.30am-5pm	**phone**	**0418 276 755**
	Mobile:	11.30am-8pm	**phone**	**0417 201 662**

After 7pm	please phone 9616 8398 and follow voicemail instructions
Sat – Sunday	please phone 9616 8398 and follow voice mail *instructions*

Faxed information can be received at all times on fax no: **9616 8305**

8.3 Referral Forms

The referral form is an adapted HC-9 form (Community Health) which seeks additional, paediatric specific information (see appendix A). The referral form requests information on clinical details, personal details a medical treatment plan and other instructions for the Paediatric Outreach Service. This referral form is included in the child's community medical records.

This generic referral form is made available to all General Practitioners, Paediatricians and Community and Allied health professionals in the Fairfield Local Government Area. In the event that a referrer does not have this form available, a form can be faxed for completion and then faxed back by the referrer once completed with the relevant Outreach Service.

9 What to do if Children need to be seen prior to the next routine working day by the Paediatric Outreach Service

The nature of paediatric illness is such that children can present to the General Practitioner/Emergency Department at all hours of the day. Referrals can only be activated within working hours. This may pose a problem from referrals when they believe a child requires care outside of the business hours of the Paediatric Outreach Service.

IF THE CHILD DOES NOT NEED TO BE SEEN BEFORE THE NEXT WORKING SHIFT.

On weekday evenings/weekends/public holidays, when POS staff are not available,

Phone **9616 8237** – and follow voicemail instructions.

Phone details should be left on the voicemail system and a referral form faxed. The referral will be actioned on the next working shift. If the referral cannot be accepted by Paediatric Outreach Service, the referrer will be contacted as soon as possible to arrange alternative management.

IF THE CHILD NEEDS TO BE SEEN BEFORE THE NEXT ROUTINE WORKING SHIFT

Then child should be referred to their usual General Practitioner or usual Paediatrician or the Fairfield Hospital Emergency Department. This will ensure urgent medical treatment is appropriately provided before the next routine working shift.

10 What can Paediatric Outreach Service Provide?

This list is not meant to be exhaustive. If at any time referral eligibility for the Paediatric Outreach Service is unclear, then discussion with a member of Paediatric Outreach will resolve this difficulty.

Care provided by POS includes:

- Education for first presentation of asthma (not requiring nebulisers)
- Multiple presentations with asthma – education and support
- Asthma presentation requiring ongoing asthma education
- Respiratory assessment and support with asthma management following hospital discharge/Emergency Department Presentation
- Fluid assessment for child with gastroenteritis requiring monitoring of oral rehydration
- Respiratory assessment – for patients with croup, pneumonia and bronchiolitis, (including oxygen saturations) in any age child where parent education and home support is required
- Wound dressings/packings
- Burns dressings (for children not meeting the State guidelines for transfer of patients)
- Assistance with medication administration
- Weight monitoring and support of Premature / Low birth weight infant
- Epilepsy – difficult to control seizures – education/support with rectal medications
- Home enteral feeding program – insertion of NG tubes, support with gastrostomy care

- Home oxygen dependent with acute respiratory illness
- Child with frequent admissions to Paediatric wards (Fairfield, NCH, SCH) for chronic medical conditions
- Child on long term antibiotics
- Assistance with equipment loans and PADP applications
- Chronic illness – provide Parent/family education and long term support to assist the family to care for their child in their home

11 How will a case be allocated to the CNC/RN and/or PHN?

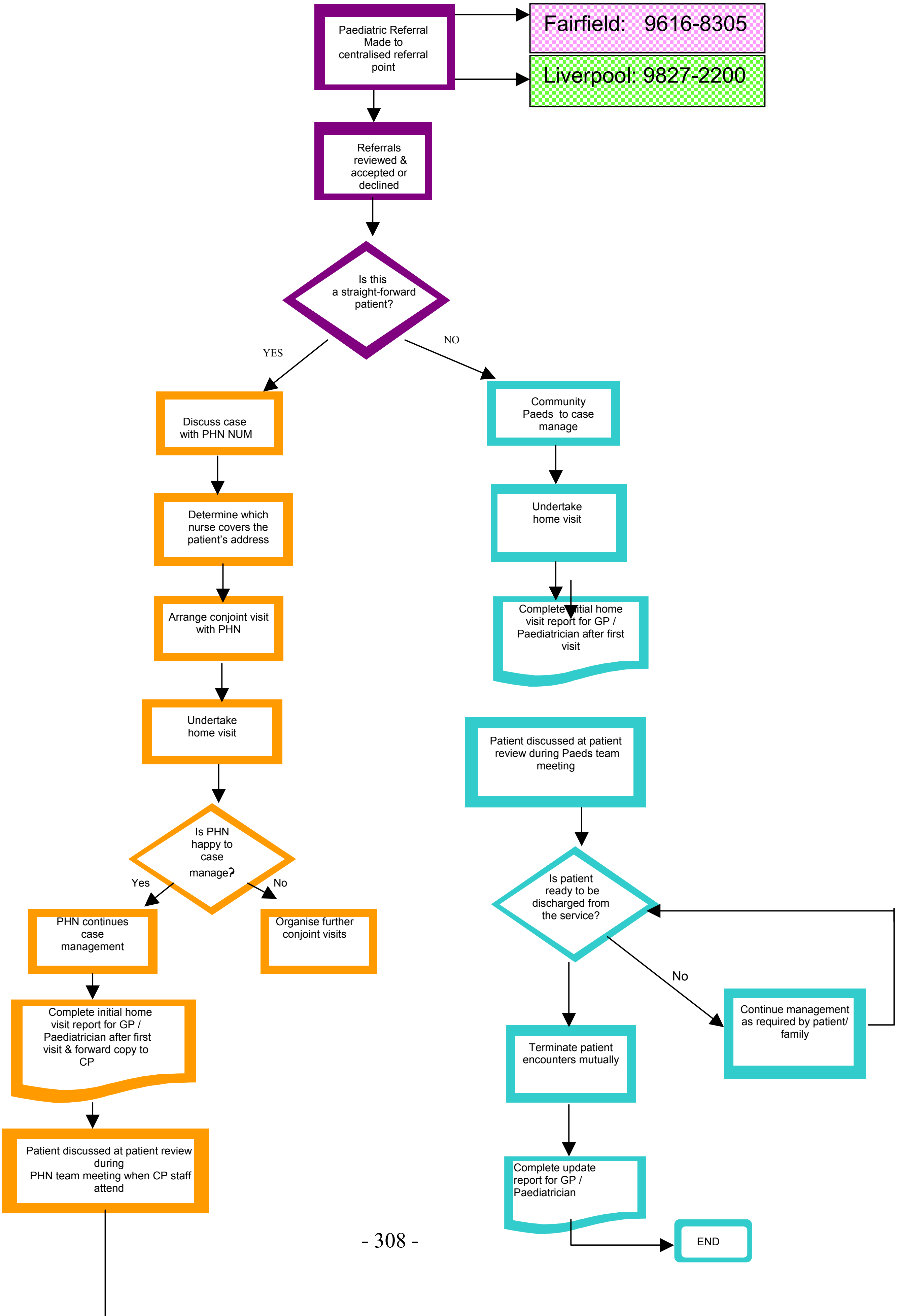
The referral allocation is made after the referral has been accepted by Paediatric Outreach Service. Allocation is made on the basis of the clinical information provided by the referrer and the paediatric nursing requirements for the child and their family (see Fig 1).

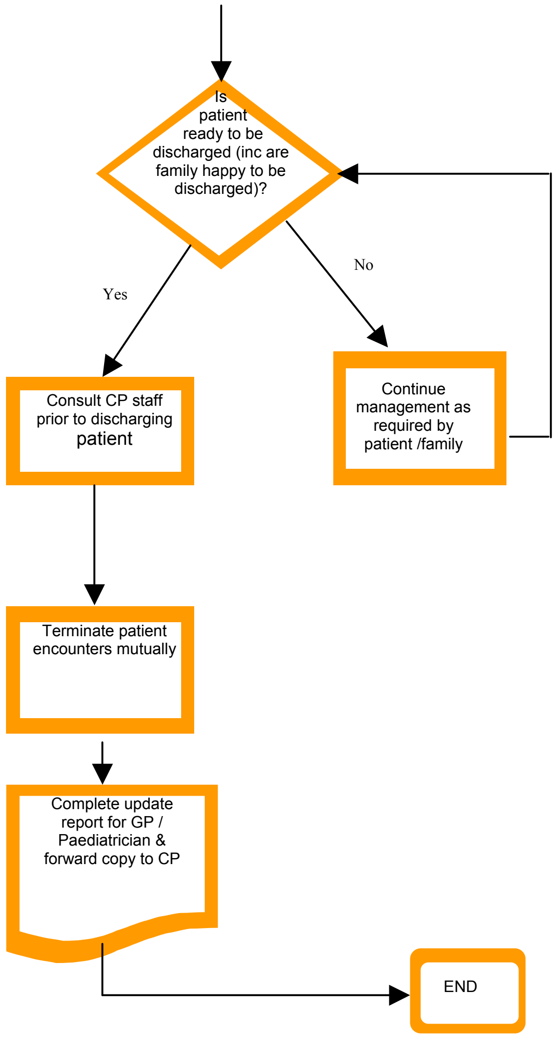
When the patient is referred to a Primary Health Nurse, the first visit is a conjoint visit attended by the allocated Primary Health Nurse and staff of Paediatric Outreach. Case management is decided following this visit. Where the Primary Health Nurse is the case manager, they will continue the ongoing nursing care/visits to the child, the consultation and involvement by the CNC or RN from Paediatric Outreach as required. In some instances, case management is carried by RN's from the paediatric Outreach Service.

A representative from the Paediatric Outreach Service attends each Community Health Center's self-directed workgroup meeting to discuss referrals and management of paediatric clients in the team environment.

(FIG 2)

PAEDIATRIC OUTREACH SERVICE REFERRALS FLOW CHART





POINTS OF EMPHASIS

- Community Paediatric staff should make every effort to attend PHN's first visit.
- If PHN's work-load doesn't allow them to attend home visit with Community Paediatric staff, the PHN concerned should negotiate with their NUM to relieve some of their caseload so PHN can attend visit.
- Where it suits the family, Community Paediatric staff should aim to schedule the first visit to a new patient prior to 5PM to enable PHN to attend conjoint visit.
- When a patient requires nursing care at a time when the PHN is not rostered to work (and the PHN is the case-manager), the patient should be handed back to Community Paediatric staff to manage ie weekends and after hours.

Key to Abbreviations

PHN= Primary Health Nurse

GP= General Practitioner

CP= Community Paediatrics

12 Commitment to Communication

The care provided to each patient is developed on an individual patient basis. The nursing plan of care for each child depends on the family's identified needs, the child's medical status, and the medical plan. The plan will be developed by the case manager, in conjunction with the family. At all times The Paediatric CNC or RN is available for consultation in regard to any child requiring care in the Community.

Following the initial visit to a patient, a home visit report is completed and faxed or posted to the nominated medical care provider.

Further home visit reports are forwarded to the nominated medical care provider as needed on the update form. This ensures that there is regular information provided back to the medical care provider to facilitate seamless health care. Once the patient has been discharged from POS, a final report confirming discharge for the service is forwarded to the nominated medical care provider.

All paediatric patients whose care is shared by POS and the PHN's are issued with a Community Health flow chart which allows all care providers to follow the same plan of care (it includes contact phone numbers and emergency instructions where required).

13 Discharge from the Paediatric Outreach Service

Discharge from the Paediatric Outreach Service occurs when the PHN and/or CNC/RN Community Paediatrics has identified no further need to visit the child at home. The General Practitioner and/or the Paediatrician are informed of the child's discharge, in writing, by the nurse discharging the child from the program. At the time of discharge, medical follow-up needs with the responsible medical officer are discussed with the family.

Following discharge from the Paediatric Outreach Service, if the child's condition changes and the medical care provider requires re-involvement of the program, this needs to be discussed with the CNC or RN from Paediatric Outreach who was previously responsible for the child" care.

In the event that urgent medical review of the child is required, this will need to be arranged with the child's General Practitioner/Paediatrician or Fairfield Emergency Department.

See following pages for REFERRAL TO FAIRFIELD PAEDIATRIC OUTREACH SERVICE and other supporting documentation templates.

Appendix A

COMMUNITY HEALTH CLIENT INTAKE FORM

INSTRUCTIONS:

- **DO NOT** fill in the shaded boxes**.**
- Phone Community Paediatrics, Fairfield Health Service **9616- 8237** with referral details**.**
- **The completed referral form is then to be** faxed to 9616 – 8305
- (Please fax with this referral any medical information that will assist the Paediatric Outreach Service Provider)

Centre Name	Code		Health Record Number Perm		
Surname			Other Names		
Street			Town	Postcode	
Home Phone	Work Phone	Sex	Dob Dd-Mm-Yy	Age	Marital Status
Interpreter Req Y Or N		Country Of Birth	Language Aboriginal/Torres St		Occupation
Employment			Person For Notification		Relation
Address					Phone Number
Local Doctor Surname	Initial		Address		Phone Number
Referred By Name			Agency		Phone Number
Presenting Problem			Intake Date Dd-Mm-Yy		Intake Officer
Data Entry Date Dd-Mm-Yy		Data Entry By	Health Record Number Temp		
Condition 1			Procedure 1		
Condition 2			Procedure 2		
Condition 3			Procedure 3		
Condition 4			Procedure 4		
Signature Of Case Manager	Code		Print Name & Designation		Registration Date Dd-Mm-Yy
Other Health Professionals	Code		Other Health Professionals	Code	
Other Health Professionals	Code		Other Health Professionals	Code	
Case Closed Date Dd-Mm-Yy	Case Closed Reason		Data Entry By		Data Entry Date

Patient History	
Referring Agent's Request/Plan (What do you want POS to do?)	
Safety Issues/Precautions (Is there anything about visiting this family or their house which might put POS staff at risk)	
Is There Anything Else Paediatric Outreach Service Provider Should Know?	
Please List Medications Child Is On And Frequency	***Weight***
Has Consent Been Obtained? Y Or N The Parent Must Provide Consent For Referral To Pos & For Forwarding Of Clinical Information.	
Have You Told Family That Pos Will Visit? Y Or N	
Is The General Practitioner Aware Of Referral To Pos? Y Or N	
Does Child Have A Paediatrician ? ***Y Or N***	***Paediatrician Name & Address***
Referred To	Intake Officer Date

Appendix B

REPORT: Fairfield Paediatric Outreach Service

An initiative of the Fairfield Health Service

Dear …………………………………………..….

The Paediatric Outreach Service has visited your patient at home on ____________________________

1. Child's Details

Name of child :________________________

DOB: _____________MRN:_____________

Address:______________________________

2. Referred to Paediatric Outreach Service by:____

3. Reason for Paediatric Outreach Service Involvement:_________________________________

4. Paediatric Outreach Service assessment: ____

5. Paediatric Outreach Service Management:____

6. Child's current medication/s:

7. The child **HAS/ HAS NOT** been discharged from the Paediatric Outreach Service.

For further information please contact:

Phone number: Date of report:

Appendix C

UPDATE: Fairfield Paediatric Outreach Service

An initiative of the Fairfield Health Service

Dear ………………………………………..….

The Paediatric Outreach Service has continued to visit your patient at home.

The most recent visit was on ____________________ This was visit number ________________

2. Child's details

Name of child :______________________
DOB: ____________MRN:____________
Address:____

2. Ongoing Paediatric Outreach Service Management: ________________

____

____

____

____

____

____

____

____

____

____

____

3. Child's current medication/s (list medications and frequency):_________

____

____

____

4. The child **HAS/ HAS NOT** been discharged from the Paediatric Outreach Service.

For further information please contact:______________________________

Phone number:_____________________ Date of report:______________

Appendix D

Request for Additional Information: Fairfield Paediatric Outreach Service
An initiative of the Fairfield Health Service

Dear ……………………………………..….

3. Child's details

Name of child :______________________

DOB: ____________MRN:____________

Address:____

2. Referred to the Paediatric Outreach Service by:____________________

This request for information is in relation to:____

The Paediatric Outreach Service would appreciate any information/ comments you may have in regard to the management of this child.

Please complete beneath and return to Community Paediatrics by mail or Fax.

Case manager:____

Phone number:___________________________ Date of request:_______

DOCTOR'S COMMENTS

(If you require additional space please attached extra sheet)