

**THE DELIVERY OF FAMILY-CENTRED CARE  
IN HOSPITALS IN ICELAND, SWEDEN AND  
ENGLAND:  
A REPORT FOR  
THE WINSTON CHURCHILL MEMORIAL  
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By

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## TABLE OF CONTENTS

1. AIMS OF THIS CHURCHILL FELLOWSHIP	3
2. INSTITUTIONS INVOLVED	4
3. DEFINITIONS	5
4. ABBREVIATIONS	6
5. EXECUTIVE SUMMARY	7
5.1 The major recommendations from this Churchill Fellowship	8
6. ICELAND	9
6.1 Background	9
6.2 Health parameters	11
6.3 Health services	12
6.3.1 Primary health care	12
6.3.2 Hospital care	13
6.3.3. Health care personnel	14
6.4 Family-centred care	16
6.5 Summary	18
7. SWEDEN	19
7.1 Background	19
7.2 Health parameters	21
7.3 Health services	21
7.3.1 Primary health care	22
7.3.2. Health care personnel	23
7.3.3. Education of health professionals	24
7.4 Play therapy	24
7.5 Family-centred care	25
7.6 Operating theatres	27
7.7 Visit to Örebro	28
7.8 Summary	29
8. ENGLAND	30
8.1 Background	30
8.2 Health parameters	30
8.3 Health services	30

8.3.1. Health care personnel	31
8.3.2. Education of health professionals	32
8.4 Family-centred care	33
8.5 Operating theatres	35
8.6 Summary	36
9. RESEARCH PROJECTS	37
9.1 Parents' needs	37
9.2 Ownership	37
9.3 Publications arising from the Churchill Fellowship	38
10 CONCLUSIONS	39
11 MAJOR RECOMMENDATIONS	40
11.1 Minor recommendations	41
12. PROBLEMS DURING THE FELLOWSHIP	42
12.1 Iceland	42
12.2 England	42
13 LIVING ON A CHURCHILL FELLOWSHIP	44
13.1 Accommodation	44
13.2 Travel	44
13.3 Cultural experiences	45
13.4 Food	45
13.5 Time frame	46
13.6 Funding	46
14 THINGS "CHURCHILL"	47
15 PERSONAL AND CAREER ADVANTAGES	49
15.1 Copies of report sent	51
16 REFERENCES	54

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## **1. AIMS OF THIS CHURCHILL FELLOWSHIP**

1. The first aim of my Churchill Fellowship was to examine the delivery of family-centred care (FCC) in children's hospitals in Iceland, Sweden and Britain, so that it could be better applied in children's hospitals and wards in Australian hospitals, thereby improving the emotional health of children and families admitted to hospital.
2. The second aim was to set up a cross-cultural research project to examine parents' perceptions of their needs while their child was hospitalized and staff's perceptions of the parents' needs. Differences found will indicate where barriers to FCC lie; these can then be examined in more detail.

Three nursing colleagues assisted me:

Dr Gudrun Kristjansdottir  
Senior Lecturer, Faculty of Nursing  
University of Iceland  
Reykjavik  
Iceland

Dr Inger Hallstrom  
Clinical Lecturer, Department of Paediatrics  
University Hospital  
Lund  
Sweden

Ms Judith Hunter MBE  
Assistant Dean, School of Nursing Practice and Midwifery  
University of Northumbria at Newcastle  
Newcastle-upon-Tyne  
England

I visited a second university in Sweden and was assisted by:

Dr Birgitta Andershed  
Senior Lecturer, School of Caring Sciences  
Örebro University  
Örebro  
Sweden

Ms Mats Erikson  
Paediatric Unit  
Örebro Medical Centre  
Örebro  
Sweden

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## **2. INSTITUTIONS INVOLVED**

Iceland  
Faculty of Nursing, University of Iceland  
University Hospital, Reykjavik

Sweden  
Department of Paediatrics, University Hospital, Lund  
School of Caring Sciences, Örebro University, Örebro  
Paediatric Unit, Örebro Medical Centre, Örebro

England  
School of Nursing Practice and Midwifery, University of Northumbria at Newcastle  
Royal Victoria Infirmary, Newcastle-upon-Tyne  
Newcastle General Hospital, Newcastle-upon-Tyne

The Hospital for Sick Children, Great Ormond Street, London assisted by providing accommodation for a meeting at the end of my Fellowship.

### 3. DEFINITIONS

**Cuffed endotracheal tubes:** Endotracheal tubes are used to provide an airway in anaesthetised patients. Cuffed tubes are those with an inflatable cuff which prevents the passage of fluids such as saliva into the trachea. They are not widely used in Australia because it is thought that they cause side effects.

**EMLA cream:** a local anaesthetic cream used to anaesthetise the skin before insertion of an intravenous cannula. Particularly useful in paediatric practice.

**Family-centred care (FCC):** There is no one definition of family-centred care, but essentially it means that when a child is admitted to a health service, the child is always accompanied by a family of some sort, be it the natural parents, adoptive or foster family or, in the extreme case, the state. Accordingly, all care must be planned around the family rather than the individual sick child, as members of the family are always affected when a child requires health care.

**Laryngospasm:** spasm of the larynx caused by the introduction of foreign material such as saliva and other secretions. It can occur during anaesthesia when secretions pass down an endotracheal tube. It can be life-threatening in an anaesthetised patient and is relieved with positive pressure ventilation and oxygen.

**Midazolam:** a drug which alleviates anxiety, often given before a procedure such as an operation.

**Ownership:** . Webster's Dictionary (1994) defines "to own" as "to have or hold as one's own, to possess", and "ownership" as "legal right of possession" (p 1032). For this Fellowship, it refers to ownership of a child once the child has entered a health service.

**Primary nursing:** In "primary nursing", one registered nurse (RN) co-ordinates all care for each patient individually, and is usually the one who gives most of the care.

Few duties are delegated to others while that nurse is on duty, and she/he co-ordinates the care given by others while she/he is not there. Registered nurses have a small number of patients each. The RN provides all care to each patient, and ensures the care is co-ordinated prior to, during and after admission. Primary nursing is comparatively expensive, as the nurse/patient ratio is high (Shields 1999).

**Tracheal stenosis:** a thickening of the walls of the trachea.

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#### 4. ABBREVIATIONS

ENT	ear, nose and throat
FCC	family-centred care
IMR	infant mortality rate
IV	intravenous
MMR	maternal mortality rate
NHS	National Health Service
RN	registered nurse
RSCN	registered sick children's nurse
UNICEF	United Nations International Children's Relief Fund
WHO	World Health Organization

## **5. EXECUTIVE SUMMARY OF CHURCHILL FELLOWSHIP TO INVESTIGATE THE DELIVERY OF FAMILY-CENTRED CARE IN HOSPITALS IN ICELAND, SWEDEN AND ENGLAND:**

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During the three months of my Churchill Fellowship, I travelled to Iceland, Sweden and England to examine the delivery of family-centred care (FCC) in hospitals in which children were nursed. I worked through the University of Iceland, the University Hospital, Lund, Sweden; and the University of Northumbria at Newcastle-upon-Tyne in England. I was assisted by Dr Gurdun Kristjansdottir, Faculty of Nursing, University of Iceland; Dr Inger Hallstrom, Department of Paediatrics, University Hospital, Lund and Dr Birgitta Andershed, School of Caring Sciences, Orebro University in Sweden; and Mrs Judith Hunter MBE, School of Nursing Practice and Midwifery, University of Northumbria at Newcastle, England. I was given information by the nursing, medical and allied health staff and parents of hospitalized children at the health services and universities I visited.

Family-centred care, when all care during admission to a health service is planned around the whole family rather than the individual child, is more successfully implemented in the countries visited than in Australia. There are three reasons for this:

1. Health professionals who work with children in the health care facilities I visited in Iceland, Sweden and England are highly educated about specialised paediatric care. Most importantly, 95% of nurses in England, 80% in Sweden, and 25% in Iceland hold specialist paediatric nursing qualifications, compared to the 4% found in a Queensland study in 1993.
2. Inherent in Nordic cultures is a highly developed respect for individual rights and responsibilities and this includes children. Implicit in FCC is negotiation and so this awareness of rights means that coercion, even in its most subtle form, is never used, rather, time is taken to negotiate issues so that all parties agree. Formal support for these ideas in a health setting is by legislation which uphold the rights of children and families in the health services. Such laws are in place in all three countries.
3. Health services in the two Nordic countries are extremely well-resourced, with high staffing levels. Consequently, time is available to negotiate thoroughly, and support parents and children in making decisions about aspects of care.

### **5.1 The major recommendations from this Churchill Fellowship are:**

1. That laws are developed in Australia to enshrine the rights of children and families within the health services
2. That the Government of Australia commits a large amount of funding to enlarge the base of specialist paediatric nurses to work in areas where children are nursed.
3. That Queensland Health make specialist paediatric nursing education a priority for Queensland nurses
4. That undergraduate nursing courses be extended to four years to allow for broadening of basic speciality education within the course.
5. That a Bachelor of Paediatric Nursing course be implemented at an Australian university
6. That a survey of the number of nurses with paediatric qualifications in Australia and a needs analysis of health services which care for children be undertaken
7. That Australia legislates to ensure qualified paediatric nurses care for children in hospitals and health services.

This report will be disseminated to leaders in child health, paediatric and nursing fields and to legislators and policy makers with an interest in the health of children. Papers for peer-reviewed journals are in preparation and the results will be presented at conferences and lectures in Australia and overseas. A large, international research project to investigate concepts of ownership of children within health services is being planned as a result of the Churchill Fellowship.

## 6. ICELAND

### 6.1 Background

Iceland, an island nation and one of the Nordic countries, lies at the top of the North Atlantic Ocean just below the Arctic Circle. Its nearest neighbours are Greenland to the east and Norway to the west. Geologically, Iceland is very young and its landscape is characterised by volcanic craters, geysers and other geothermal activity, lava fields, sand deltas and icecaps. Only 21% of the land is habitable and arable. The island is prey to earthquakes and volcanic eruptions and both occurred in 2000. The climate is, as its name suggests, cold, with snow in the higher regions much of the year. However, the climate is tempered by the warm Gulf Stream and temperatures range between 25 degrees Centigrade in summer and -20 degrees Centigrade in winter (Embassy of Iceland 2000). From June to August (summer) there is continuous daylight in Iceland, and early spring and late autumn are characterised by long twilights. From mid-November to the end of January there are only three to four hours of daylight.



**Largökull Glacier**

Icelandic history began with the arrival in 874AD of viking settlers from Norway at a place they named "Reykjavik" ("steamy bay" - so called because of the steam rising from thermal springs). Iceland was the site of the world's first parliament in 930AD, and the people of Iceland converted to Christianity in 1000AD (Cornwallis 1999). Leifur Eiríksson travelled from Iceland to discover the American continent that same year (Björgúlfsdóttir 2000). Over the ensuing centuries, control of Iceland was contested by Nordic kings, and in 1397 came under Danish rule. During the Reformation, Lutheran became the official religion, and today, 93% of Icelanders are

Lutheran. In 1944, Iceland gained its independence from Denmark and is now a democratic republic (Cornwallis 1999).



### **Reykjavik**

Icelandic cultural heritage is pervaded by the “sagas” - a collection of epic stories written about the viking people, adventurers and kings who made the island their home, and their exploits in all corners of the globe. There are several sagas written in the early part of the 13th Century which are considered by scholars to be the finest of medieval writings from Western countries (Pálsson & Edwards 1976). There are old tales of trolls and fairy people who are said to have lived in different areas of the country. Icelanders reflect their heritage in their good humour, sense of adventure and innovation, and stoicism.

The population of Iceland in 1999 was 276,000 (UNICEF 2000). About half of the population lives in the capital city of Reykjavík and its suburbs, while the remaining people are settled along the coastline and the lowlands, either in towns and villages or on widely dispersed farms. It is the most sparsely populated country in Europe with an average of about seven inhabitants per square mile (Embassy of Iceland 2000).

Icelandic is the national language and it has changed very little from the original tongue spoken by the Norse settlers; however, English and Danish are widely spoken and understood. Icelanders follow the ancient patronymic naming system of deriving their last name from the first name of their father. As a result, most men's surnames end in "son" and women's names in "dóttir".

Iceland was one of the earliest countries in the world to institute universal literacy, and in the Middle Ages inspectors visited homes to ensure parents were teaching their children to read and write. Schooling is mandatory until year 10. Education in Iceland is free, and children spend 14 years at school – ten years at primary school, four in high school. Consequently, students do not begin tertiary education until they are 20. University education is paid for by student loans which hold 3% interest. The University of Iceland was established in 1911.

Iceland is a democratic republic, with a written constitution and a parliament (*Althingi*) elected every four years. The head of state is a president elected by popular vote, and the parliamentary government holds executive power (Embassy of Iceland 2000). Since World War II the standard of living has risen so that today it is comparable to that of Australia. The main industry is fishing, and fish and fish products constitute more than 70% of Iceland's exports. Sheep and dairy cattle are farmed and industries include geothermal and hydro-electric power, and ferro-silicon and aluminium mining (Embassy of Iceland 2000). Recently, tourism has become a major industry, and in the summer of 1999, the tourists doubled the population figures of Iceland. There is little unemployment, especially during the tourist season and crime is minimal. Iceland has yet to embrace full membership of the European Union.

A strong Protestant work ethic is part of the cultural fabric, and as there are more available jobs than people to fill them, there is a stigma attached to being out of work and on unemployment benefits, although these are readily available. Many people have two or three jobs, child care is easily accessible, though not free, and there are anecdotal reports of children being left alone at home while the parents work. Most high school students have part time jobs which fit very well with the booming tourist season during the summer holiday months. A cause for concern derived from the booming economy and oversupply of jobs is the perceived increasing use of drugs by Icelandic youth (figures are not available) who have relatively large disposable income.

## **6.2 Health parameters**

Iceland experiences some of the world's best health statistics. These are summarised and compared with the other countries in this project in Table 1.

**TABLE 1**  
**Health parameters in the countries visited and including Australia for comparison**

	ICELAND	SWEDEN	ENGLAND	AUSTRALIA
Population (WHO 2000a)	276,000	8,875,000	58,649,000	18,520,000
MMR*(WHO 2000b)	0	5	7	14
IMR# (UNICEF 2000)	5	4	6	5
Average life expectancy: Males	76.1	77.1	74.7	76.8
Females (WHO 2000a)	80.4	81.9	79.7	82.2
Health expenditure (UNICEF 2000)	1,757	1,943	1,193	1,601
Immunization rate UNICEF 2000)	98%	98%	95%	86%

\* /100,000 live births

# 1,000 live births

a expressed in US dollars/capita/1997

IMR: infant mortality rate (UNICEF 2000)

Average life expectancy (World Health Organization 2000a)

MMR: maternal mortality rate (World Health Organization 2000b)

### 6.3 Health services

Icelandic health services are decentralised with a total of 83 health centres, 25 hospitals, as well as nursing homes and nursing wards, rehabilitation centres and institutions for alcoholics and the mentally handicapped. Although government-subsidised, the private sector provides 40% of the hospital beds, places for the elderly, the mentally handicapped and alcoholics, and runs rehabilitation centres.

#### 6.3.1 Primary health care

As defined by the Icelandic Health Service Act, primary health care refers to preventive health care measures as well as every type of health service performed for the benefit of the healthy and sick who do not need hospitalization. Health centres function in association with a hospital, often in the same building. They are modern and well-equipped and are responsible for primary medical and nursing care, home nursing, health examinations including mass screening for cervical, breast and prostate cancer; maternal and child health services, school health services, vaccinations, and health education in co-operation with the Ministry of Education. Physiotherapy is sometimes offered at the health centres, but more often delivered by physiotherapists in private practice.

Citizens have the right to seek medical assistance at the health centre or clinic most easily accessible to them. Voluntary organizations such as Red Cross, service

clubs and women's organizations work with some health centres to raise funds for specific supplies and equipment.

### 6.3.2 Hospital care

Hospitals are divided into the following categories:

Regional (tertiary) hospitals, which provide specialised treatment and care

District general hospitals, which provide specialised treatment and care in the main centres

General hospitals: do not have specialised wards though the staff may include specialists

Nursing homes for patients who, after diagnosis, can be treated and cared for outside the general or regional hospitals

Rehabilitation centres for patients who, after diagnosis, need specialised rehabilitation for varying periods of time

Hospital lodgings, which are for patients needing long-term observation or treatment but who can care for themselves

Nursing and occupational homes: for the mentally handicapped or ill, the disabled and alcoholics who are admitted for treatment and occupational activities

Hostels which cater for hospital out-patients who are unable to live at home at the time of treatment.

The average length of stay in Icelandic hospitals in 1997 was 7 days for medical beds, 5 for surgical and 52 for psychiatric (Nordic Medico-Statistical Committee 2000). All patients receive free health care, both in the hospitals and health centres. There are some private hospitals and practitioners, and individuals may choose to use (and pay for) their services.

### 6.3.3. Health care personnel

**TABLE 2**

**Numbers of health professionals in the countries visited including Australia for comparison, expressed as /100,000 population/year (WHO 2000b)**

	ICELAND	SWEDEN	ENGLAND	AUSTRALIA
Doctors	326	311	164	240
Nurses	865	821	497	830
Midwives	86	72	43	40
Dentists	105	152	40	40
Pharmacists	83	67	58	N/A

Numbers of health care personnel in Iceland, Sweden and Australia are shown in Table 2. Iceland boasts one of the best-staffed health systems in the world, though the world-wide nursing shortage is being felt as it is difficult to recruit new nursing staff. Registered nurses (RN) comprise the largest part of all health care personnel. Midwives must be RNs before they can undertake midwifery education. Almost all health care workers are educated at university level except practical nurses (equivalent to enrolled nurses in Australia) and physicians' secretaries who are educated in a number of higher secondary comprehensive schools in a 3 year programme. There are few technicians employed in health care except as medical laboratory and X-ray technicians.

### 6.3.4 Education of health professionals

Medical students attend university for six years followed by at least one year as a resident medical officer in a hospital. Most of them go abroad for specialist education although increasingly the initial speciality training is being provided in Iceland's growing health care industry. At present about half of Iceland's physicians work abroad. The over-specialization of the profession has created a shortage in physicians in the rural areas of the country.

Registered physical and occupational therapists complete a four year Bachelor of Science degree, and pharmacy is taught at the University of Iceland. Technical colleges provide three year education for laboratory and radiology technicians. There is a shortage of allied health staff, and situations usually handled by professionals such as social workers and psychologists are now often handled by nursing staff.

Nurses played a large role in reducing the effects of the tuberculosis and measles epidemics at the beginning of the 20<sup>th</sup> Century. These diseases were significant causes of mortality and morbidity in Iceland before the discovery of drugs and immunisation. Nurses were also instrumental in development of the primary health care system. Nursing practice and registration of professional nurses are regulated. Accreditation of specialities in nursing has existed since 1976 but is at present being reviewed due to changes in the profession. Nurses are not subordinate to physicians or other professions in matters relating to nursing care.

Since 1986 a Bachelor of Science degree has been the basic requirement for entry into professional nursing practice and registration. Two university programmes offer a Bachelor of Science degree preparation in Nursing – the University of Iceland since 1973, and the University of Akureyri (in northern Iceland) since 1987. For entry into those programmes, a junior college examination pass (equivalent to high school plus one year) is required. Nursing programmes are four years ending with a dissertation. At the University of Iceland only the top 60 students at the end of the first semester are allowed to continue with the course. Registered nurses with a diploma in nursing from a previous three-year programme can be admitted for study into a two-year conversion programme. About 60% of all registered nurses now hold the Bachelor of Science degree, 10% have a Masters degree in nursing and 1% have attained their doctorate. Most graduate education is found abroad, though a Master's degree programme is available in selected nursing areas at the University of Iceland. Many nurses have enrolled in distance learning programmes, for example, the University of Akureyri conducts distance education courses for nurses through the Royal College of Nursing (Britain). A full time Master's degree at the University of Iceland is half course work, half thesis. A system of continuing education points is under consideration for nurses.

Nursing services are generally well staffed (at present there is an 8% shortage) both in hospitals and health care centres. Responsibility for management rests with the nursing directors who work with assistant nursing directors in larger institutions. Head nurses manage first level management and are mostly clinicians as well as administrators. There are three levels of nurse in Iceland (though only registered nurses are employed in the children's wards). Registered nurses must hold a Bachelor of Nursing, practical nurses (equivalent to Australia's enrolled nurses) receive nursing

education in the last two years of high school and auxiliary nurses have no nursing education. There is no set career path for nurses, except through administration or education, for which nurses move into academia. Promotion is usually by experience. Each ward has one head nurse and one deputy, all other nurses are on the same level.

Nursing research has been a priority at the Faculty of Nursing, University of Iceland since tertiary education began. As each undergraduate student must complete a dissertation, the emphasis is on introducing students to research as part of their normal nursing education (Kristjánsdóttir 1991, 1998).

As in all countries, the world-wide nursing shortage is being felt in Iceland. Compounding this is the high level of employment opportunities in the country in all fields and nurses are often employed in areas other than nursing for their administrative and personal relationship skills. Often these jobs are paid at a much higher rate than nursing.

#### 6.4 Family-centred care

**TABLE 3**  
Percentage of nurses working with children with paediatric specialist qualifications

	% of nurses who work with children
ICELAND	25
SWEDEN	80
ENGLAND	95
AUSTRALIA	4

Table 3 shows the proportion of nurses who hold specialist paediatric qualifications expressed as a percentage of nurses who work with children in the hospitals in the three countries visited, and, for comparison, figures from a study of Queensland hospitals completed in 1993 (Shields 1993). In Iceland, paediatric nursing and related subjects comprise 18 credit points in a 120 credit point undergraduate degree, and 25% of nurses working in the children's wards have postgraduate paediatric nursing qualifications, either at Master's degree level or by attainment of a specialist paediatric nursing certificate. Specialist nurses register as such. While there is no mandatory requirement for nurses who work in children's wards to hold specialist paediatric qualifications, these requirements are sought.

In October 2000, a merger took place between the University Hospital and the City Hospital in Reykjavik. This will result in a decrease in bed numbers, but in 2001

a new, free-standing children's hospital will be opened which will hold 100 beds and provide a wide range of specialities. For more arcane services which cannot be provided in Reykjavik, agreements are in place with Swedish and American hospitals. If a child requires treatment at a foreign hospital the cost is born by the state. Children in Iceland stay in hospital much longer than they do in Australia, for example, average length of stay for a three-month-old boy with hypospadias repair is 7-9 days (usually a day stay in Australia), for a child having reimplantation of ureter length of stay is 7-10 days (three to five days in Australia).

Nurses in the children's wards at the University Hospital were convinced that FCC was appropriately implemented and parents substantiated this. Parents are freely and widely involved in the care of their child, including decision-making about the child's care. Facilities for parents are basic, for example, accommodation is provided in apartment blocks near the hospital and fold-down beds are provided in the wards for one parent to stay. The parents' waiting room in the day ward is cramped, but in the new children's hospital facilities will be improved.



**Family in the Children's Ward, University Hospital, Reykjavik**

Nurses felt that in most instances parents were genuinely welcomed in the wards. Even the most difficult parents were accepted and negotiation used to ease problems and facilitate the child's stay in hospital. Nurses had a very real sense of the need for parents to be involved, and of the way their paediatric education had prepared them to deliver effective FCC. Culture and the Icelandic emphasis on family was seen as very important, though it was felt that this was under some threat with the booming economy, which meant many parents had two or three jobs and relied on child care (heavily subsidised by government) for extended child minding.

One of the contributing factors to the successful implementation of FCC was the use of primary nursing, and the fact that there were enough staff to implement it effectively. Nurses were concerned that because of the limiting of nursing staff levels brought about by the world-wide nursing shortage, the delivery of primary care and FCC would be affected.

## **6.5 Summary**

Iceland is a small country whose economy is booming. Social services such as health are well resourced and a sound and generous social security system is in place. The culture and people are characterised by a strong work ethic, stoicism, strength and humour. This is reflected in the health services where respect for human rights is important.

Family-centred care is delivered effectively because:

1. individual rights and a strong sense of family are important within the culture,
2. the well-resourced health service allows health professionals the time and flexibility to negotiate with parents and children about their level of involvement and their needs while a child is hospitalized,
3. there is a high level of specialist paediatric education of nurses.

## **7. SWEDEN**

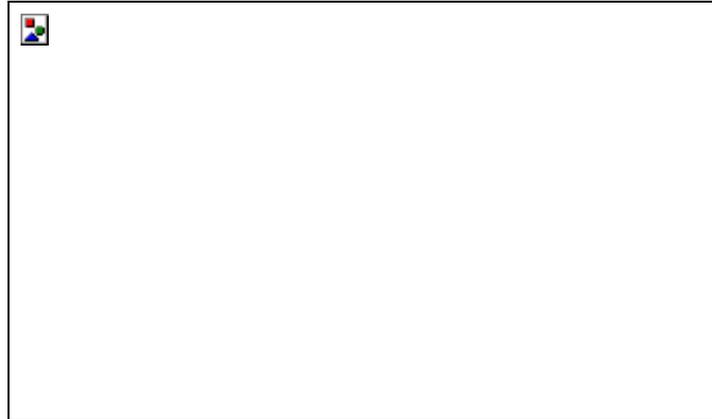
### **7.1 Background**

Sweden, a Nordic country, has Norway on one border, Finland on the other. Stone and bronze age civilizations were followed by the vikings with a culture characterized by expansion eastwards and the implementation of trade and plunder routes as far away as Constantinople. Christianity was brought to Sweden by St Ansgar in the 9<sup>th</sup> Century and co-existed with the ancient Norse religions until about the 12<sup>th</sup> Century. The various kingdoms which made up Sweden were first unified during the 11<sup>th</sup> and 12<sup>th</sup> Centuries, although each region retained its own assembly or parliament and laws. A unified, feudal society was instituted by King Magnus Ladulås in 1280 (Sweden.com 2000).

Sweden became a major trading partner in the Hanseatic League of traders from Germany. Sweden remained a largely agrarian society, but lively commercial activity through trade meant increased prosperity and development. In 1389, Sweden, Denmark and Norway were united under the Danish crown forming the Kalmar Union. This was a turbulent period in the history of the Nordic countries, marked by wars and rebellion. In 1523, the newly-elected King Gustav Vasa led a rebellion to free Sweden from Danish rule. Sweden became powerful under Gustav Vasa and embraced the Protestant Reformation (Sweden.com 2000). Following repeated wars with Denmark and with European Catholic countries, Sweden was defeated in 1721 and lost most of its provinces in Finland and Russia. Following the Napoleonic wars, the French Marshall, Bernadotte, was elected to the Swedish throne and the present day royal family is descended from him (Bendure 1999).

Sweden has not been involved in any wars since the beginning of the 19<sup>th</sup> Century and has maintained a foreign policy of non-alignment in peacetime and neutrality during war. It played an active role in the setting up of both the League of Nations and the United Nations and has been a full member of the European Union since 1994 (Bendure 1999). Since abolition of absolute monarchy in the 18<sup>th</sup> Century, Sweden has had a parliamentary government. Economic crisis following the Napoleonic wars affected Sweden and it remained one of the poorest, least developed countries of Europe well into the 20<sup>th</sup> Century. One-fifth of the population emigrated to America before World War I (Sweden.com 2000), and industry was not developed

until the 1930s. However, since the end of World War II, Sweden has developed into one of the leading industrial nations of Europe, with a concomitant rise in the standard of living and implementation of a socialist welfare state, supported by high taxation rates (Sweden.com 2000). Income tax rates are similar to Australia's, except for a 25% value added tax (Swedish National Tax Board 2000).



**House in the woods, Sweden**

Sweden has one of the best social security systems in the world. Health care is heavily subsidised, and patients pay only nominal fees if charged at all. Medicines and medical aids are subsidised, and there are generous allowances for those who have to care for ill or disabled family members at home, for example, each parent is allowed 60 days per year on full pay to care for a sick child. Maternity leave gives mothers up to one year leave on full or part pay, and fathers three months (Social Insurance Office 2000). All education - primary, secondary, technical and tertiary - is free, books are subsidised and generous student loans available so tertiary education is readily accessible to all.

Swedish society and culture is pervaded by an egalitarian ethic (despite the paradox of having a royal family and aristocracy). Equality, recognition of and respect for individuals' rights are accompanied by a very real acknowledgment of corresponding responsibilities. Swedes are "community conscious", and contribute to their society. As an example, although there is no compulsion to vote, 95% of people do so. Children are taught rights and responsibilities at school and home. Sweden was the first country to introduce legislation to make smacking of children a crime. Men are expected to do an equal share with women in a household and with child-rearing, and an important part of a partnership is "working together". Child care is free or at

nominal charge up to the age of 6 years when children start school, and is available for both working and studying parents.

There appears to be a negative side to the social service system in Sweden. Women who choose to stay at home and care for their children themselves (after the first 12 months on maternity leave) are financially disadvantaged, as allowances paid to parents who work are higher than benefits paid to parents who stay at home. Anecdotal reports indicate that because of the social imperative to work, contact between parent and child can be affected. Nurses who care for children in hospital tell of some parents who do not know what their children like to eat. University lecturers complain of students who never come to lectures and suggest that if they had to pay they may value education more highly and would attend lectures. Senior nurses in hospitals describe colleagues who spend time at free education sessions rather than in the wards caring for patients.

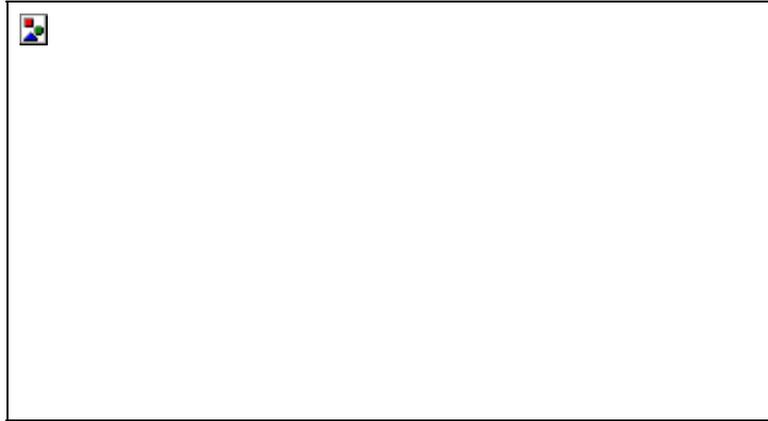
## **7.2 Health parameters**

Sweden experiences some of the world's best health statistics. These are summarised and compared with the other countries in this project in Table 1 on page 12.

## **7.3 Health services**

There are 87 region/county hospitals in Sweden with its population of 8,875,000, five long-term hospitals, and five psychiatric institutions. Adult patients pay a daily fee for hospital admission, children receive free care (Schutyser & Edwards 2000). Health services in Sweden are characterised by generous funding which allows the implementation of services only dreamt of in less well-off nations. Table 1 shows that Sweden spends more per capita on health than any of the other countries in the project (UNICEF 2000). The structure of the health services is similar to that in Iceland, and explained in Section 6.3.2, page 13.

The rights of children are enshrined in law, as is the right for children to have their parents accompany them to hospital (Söderbäck 1999). A large amount of liaison goes on between different regions in Sweden to ensure needs of children and families who are transferred from their own regions for specialist care are met.



### ***Vårdcentrale, Örebro***

#### **7.3.1 Primary health care**

Community health services in Sweden are very effective. There is one community health centre – *Vårdcentrale*, in every district, with one doctor for every 2,000 people and one child health nurse for every 500 children under the age of 6 years. Adults pay to use these services, but children under 18 years do not. Access to services begins with a telephone call taken by a receptionist who may make an appointment for a patient to see a doctor or nurse, as required, or may transfer the caller to one of the nurses who gives advice over the phone and acts as first triage point. If a person presents to the clinic, they are seen by a nurse who decides where to refer them for treatment. Consequently, the patients are seen appropriately. Screening services (breast, pap smear, testicular examination and others) are conducted in the *Vårdcentrale*, as are antenatal, baby health, sexual health, and immunisation clinics. School nurses (Swedish law states that there must be at least one school nurse in every school) work closely with the *Vårdcentrale*. The “womb to tomb” health care concept works well. Mothers come to the *Vårdcentrale* for antenatal care, and at the final antenatal visit/class meet the baby health clinic nurse who will be caring for the new infant. Co-ordinated care continues throughout the life span. If an older person becomes unable to care for themselves, they are settled in a state-run nursing home which often is attached to the *Vårdcentrale*. Nurses and doctors both do house calls as required, and the baby health nurse does routine home visits. Nurses and doctors are mandated to report child abuse. Referral to specialists is via medical and nursing staff, except in paediatrics where parents are entitled to present independently either to a private specialist or to a hospital. Except for emergencies, admission to hospital is through the *Vårdcentrale*.

Within the *Vårdcentrale* is a fully equipped and staffed laboratory for pathology tests, in many there are radiological facilities, though for more complicated procedures such as CAT and MRI scans patients attend a hospital. Physiotherapy, speech therapy, social workers and dietitians and a range of other allied health services are available. A visitor's impression of the community health system is that it is efficient, cost effective and provides extremely good co-ordinated care to the people of Sweden. The culture aids the full use of the system as people are used to accessing these community and screening services rather than having a heavy reliance on hospital and tertiary care.

### 7.3.2 Health care personnel

Numbers of health care personnel in the countries involved are shown in Table 2 on page 14. Nurses in Sweden complain that their staffing levels are being affected by the world-wide nursing shortage, and this may be so. It would seem, though, that if that were the case prior staffing levels must have been high when compared with Australian hospitals. Doctors also complained that they were short-staffed.

Registration of health professionals in Sweden is mandatory, though it is a one-off payment after graduation, quite different to Australia where a yearly fee and demonstration of competence and on-going education is required. There seems to be no on-going mandate to ensure continuance of practice or educational competence, however, rights and responsibilities are so deeply ingrained in the Swedish culture, and education so highly valued, that health professionals accept on-going education and the need to keep up to date as an important part of everyday practice.

The nursing structure in Swedish health services is characterised by an absence of middle management positions. Nurses in charge of wards answer directly to the hospital executive, and nurses in the community to their local employing body, usually the county council. There is usually no director of nursing position. Nursing is held in the same regard and holds the same status as medicine and the other health-related disciplines. This is obvious during observation of work relationships within areas such as the operating theatres.

An awareness of the need to "look after oneself" is a characteristic of the culture of work in Sweden, and this is true within the health professions. Consequently, staff take all their breaks and are encouraged to do so by management,

and facilities are provided for staff well-being, for example, most hospitals have a free staff gymnasium. Food at staff canteens is cheap and good.

### 7.3.3. Education of health professionals

Medical education is similar to that in Iceland (see Section 6.3.4 page 14), with students spending up to seven years at university followed by an internship and then specialisation if they choose. Allied health professionals are educated at university, as are nurses. Nursing degrees are three years with specialist education usually by postgraduate diploma. In Sweden, 80% of nurses working with children have specialist paediatric education (see Table 3, page 16). Within nursing positions in the hospitals, there are generous allowances for time off for study and financial support is given to allow nurses to undertake extra education.



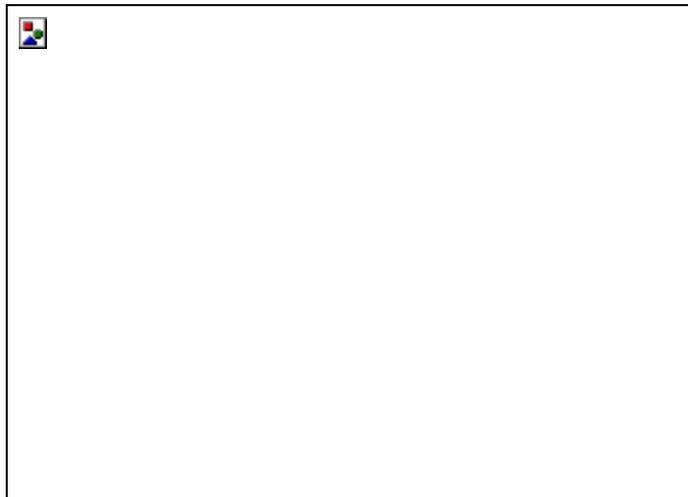
**Entrance to the Children's Hospital, Lund**

## **7.4 Play therapy**

Play therapy is an important part of hospital care in Sweden. In the 150 bed *Barn-och-Ungdomsjukhuset* (Children's and Adolescents' Hospital), part of the University Hospital in Lund, six pre-school teachers with postgraduate specialist play therapy qualifications are employed full time. Also, an actor with special qualifications in play therapy and cross-cultural awareness is employed part time to tell stories to the children and to assist children from different cultures. The play therapy centre situated within the hospital has both indoor and outdoor play areas and facilities include: an area for babies, a play hospital for children to act out what is happening to them, woodworking, water play, dress-up, dolls' houses, art (of many kinds), formal games, music, cooking and a room for teenagers. A highlight of the

play area is the fairy tale room, where children can listen to stories told by the actor who uses a fleet of puppets and wonderful effects in this specially created room, complete with fairies and trolls, wicked witches and wolves, kings and queens, handsome princes, beautiful princesses and so on. The abiding principle of the play area is that it be a haven for children, that no procedures or any distressing event will take place there and that children must never be frightened while in the play centre. Play therapists are included in case conferences about children and their reports of the child's behaviour while in the play therapy centre are valued.

**Play therapy centre, University Hospital, Lund**



**7.5 Family-centred care**

Family-centred care is successfully implemented in the hospitals I visited in Sweden. Because of the generous allowances paid for parents to look after a sick child, there is an expectation that parents will stay with a hospitalized child. It is recognised that occasionally this may not be possible, so negotiation will take place to find the best way to enable parents to stay. Social workers may be called in, relations such as grandparents contacted, or neighbours and friends enlisted to help. Much of this is done by the nursing staff. There is no stigma attached to using the welfare system, as people expect it as their right as they perceive they pay large amounts of tax. No stigma is attached to using welfare services such as psychology and social work.

“Child-centredness” is considered an important part of relationships within families, there is a respect for children as individuals and a respect for parents. Care is described as “interactive” rather than just giving, or passive acceptance, of care, the child is in the middle of this and there is equality within the relationship, including

relationships between parents, children and health professionals, and between health professionals themselves.

Negotiation with children is a very important part of the culture. If a child does not want to do something, every effort will be made to talk him/her into compliance. I saw this in practice in the operating theatres, where a six-year-old boy who had been in hospital many times before came for yet another operation. He had stated that he did not want to have a gas induction, rather, he agreed to be anaesthetised using drugs via an intravenous (IV) cannula. The doctors and nurses could not access a vein for the cannula, as the boy had had so many drips in the past. It became obvious that gas induction would have to be used. Rather than force the boy to accept the gas mask, the nurses and doctors spent a great deal of time talking with him, negotiating and convincing him to have the gas induction. The remaining children on the operating list stayed in the wards and the surgeons and other members of the operating teams were delayed until this child was ready to be anaesthetised. The surgeons or other professionals were not upset by this, rather it was seen as good practice, and the families whose surgery was postponed acknowledged the situation as perfectly acceptable, because they knew that if the same thing happened during their turn the same consideration would be shown. Another interesting aspect of this case involved the father who accompanied the boy to the operating theatre. They were an immigrant Romanian family who had been living in Sweden for six years. As the boy remained determined that he would not have gas, the father became quite agitated and began to speak roughly to him. The nurses and doctors included the father in the negotiations, explaining why they were happy to wait till the boy was ready and in this way calmed the father down, thereby minimising the child's upset.

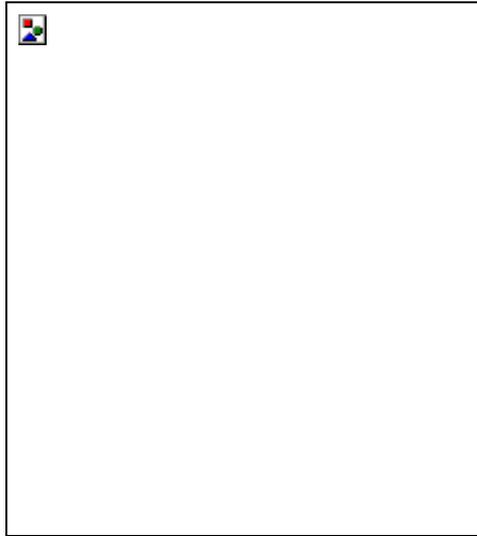
Education is highly valued in Swedish society and this carries over into health care, where education, both formal as in university courses, and within the health services with in-service and continuing education is freely and widely available to all health professionals. Two experienced nurses working in the children's wards believe that successful implementation of FCC depends on education of paediatric nurses. They see the negotiation which is an important part of FCC as an integral part of Swedish culture. Negotiation is an important tool in solving problems. If a large, extended family arrives at a hospital to stay with a child they are made welcome but because of space constraints, only one parent is allowed to stay at night. This is

particularly important for the many migrant families who live in Sweden, and for these families interpreter services are always readily available. Nurses who had worked in paediatrics for a long time felt that successful implementation of FCC has occurred only in the past 10 years with extra specialist education for nurses.

## **7.6 Operating theatres**

I spent one day in the operating theatres in the hospital in Lund. They had two theatres where general and urological paediatric surgery was done. Other specialities operated in other theatres throughout the hospital, for example, cardiac surgery was done in the cardiac theatres in the adult hospital, ear, nose and throat (ENT) surgery in the adult theatres. As a new children's hospital is under construction, ENT surgery will, in the future, be done there. There was one induction room for the two theatres, parents of all children except infants under four months of age are encouraged to accompany the child and to stay until the child is fully unconscious. The parents and child are given a detailed explanation (according to the child's developmental stage) of what will happen. Most procedures were similar to those used in Australian paediatric operating theatres, with a few exceptions. Cuffed endotracheal tubes are used routinely and a large research project in the hospital of over 3,000 anaesthetised children showed that they reduce the incidence of laryngospasm and cause no side effects such as tracheal stenosis (the rationale behind not using them in Australia). Also, unconscious children are not routinely nursed on their side. They are turned if they are about to vomit, and it is believed their airway is better maintained if they are left to wake up on their backs.

EMLA local anaesthetic cream is always used if children are to have IV cannulation, all children are given midazolam as premedication; local anaesthetic infiltration of the operation site and paracetamol suppositories are often used. Children stay (with their parents) for 2 hours in the recovery room. There is one nurse to two children. Observations are taken at 15 minute intervals. No patient-controlled analgesia service exists as there are not enough anaesthetists employed by the hospital to give adequate coverage. This is seen by the nurses and doctors as a real deficit.



**Induction room, Operating Theatres, Children's Hospital, Lund**

### **7.7 Visit to Örebro**

Although my visit to Sweden was primarily based in Lund, I was able to visit Örebro, a town to the west of Stockholm, to spend a week in the School of Caring Sciences at Örebro University. I visited the children's wards at Örebro Hospital, asked them about the implementation of FCC and made contacts. There is a strong research ethic in the children's wards there, largely due to one person, Mats Erikson, a nurse who has worked at the hospital for a long time and who is now completing doctoral studies about pain relief in neonates. I gave some lectures at Örebro University and have been invited back next year as Visiting Professor.



**Örebro, with hospital in background**

## **7.8 Summary**

During my visit to Lund and Örebro I found that FCC is successfully implemented in Sweden. Three conditions exist which ensure its success. Firstly, cultural constructs provide philosophical background for the acceptance of a model in which individual rights of child and family are so important, and this is enshrined in law. Secondly, 80% of nurses have specialist paediatric nursing qualifications, thus ensuring a sound knowledge base for the implementation of FCC. Thirdly, the Swedish health care system is extremely well-resourced, with a large complement of staff. There are enough people who can utilise time effectively to implement the negotiation necessary for successful functioning of FCC.

## **8. ENGLAND**

### **8.1 Background**

Providing a history of England seems unnecessary in a report to the Winston Churchill Memorial Trust, however, a brief history of health care and nursing in Britain will be given.

Before the 19<sup>th</sup> Century, the delivery of formalised health care was dependent on the class from which the patient came. The rich avoided hospitals, were nursed in their own homes, often by family members or household servants and doctors plied their limited skills on patients while visiting them in their homes. The poor used folk healers. Charitable organizations conducted hospitals for the poor, but because of poor understanding of disease transmission and hygiene these places were often little less than places where people went to die.

Throughout the 19<sup>th</sup> Century, advances in medical science saw new knowledge which revolutionised health care. Ignaz Semmelweiss in Austria suggested methods of transmission of puerperal fever by the passing of cadaverous material from autopsies to live women (though his ideas were not widely accepted) (Donohue 1985), John Snow in London demonstrated improvements in the incidence of cholera once sources of contaminated water were removed (Ellis 1994), Frenchman Louis Pasteur discovered that microbes caused disease (Compton 1932). One of the greatest revolutionaries of the time, Florence Nightingale, changed nursing from a disreputable job taken by the lowest classes to a profession for ladies, and changed hospitals forever, turning them from places of death to institutions where people could be cured (Nightingale 1859).

### **8.2 Health parameters**

England's health statistics are shown and compared with the other countries in this project in Table 1 on page 12. British people are not as healthy as their Nordic cousins, or as Australians, and their government spends the least amount on health of all the countries visited.

### **8.3 Health services**

At the end of World War II, Britain implemented the National Health Service (NHS), a complete system of health care which was designed to ensure that people

from all levels of society had equal access to health services (Johnson 1962). The NHS is something of a “sacred cow” which successive governments have tried to change, most notably the Thatcher government of the 1980s which drastically reduced its funding. Consequently, the NHS is now struggling to maintain standards and this, coupled with the world-wide nursing shortage, has caused a reduction in staffing levels, a lowering of standards of patient care and much controversy. There have been various scandals within the NHS recently, for example the deaths of several people from Creutzfeldt-Jakob Disease from eating meat contaminated with bovine spongiform encephalitis or “mad cow disease” (Elliott 2000), outrage about removal of organs from dead children’s bodies without the knowledge or consent of the parents (Harvey 2000), and chaos in hospitals during the annual winter crisis when hospital beds are filled with patients suffering from diseases such as influenza while at the same time staff numbers are reduced because of illness and the world-wide nursing shortage (Murray 2000).

Admission to hospital is by referral from a doctor, by direct admission through accident and emergency or outpatients departments, or for routine surgery. As in Australia, this can entail placement on a waiting list.

### 8.3.1 Health care personnel

The NHS is plagued by the same staff shortage problems as most other countries. Nursing staff are being recruited from countries such as the Philippines, and the shortage of doctors has led to alarming “solutions”. The Sunday Times of 22 October ran a story of a new scheme proposed by the Royal College of Surgeons and the Royal College of Nursing to train nurses to undertake complex surgical procedures such as assistance with coronary artery bypass grafting. Questions to ask about this are:

1. Should nurses be participating in something that is not nursing?
2. Who is going to be legally liable if something goes wrong?
3. If this is a cost-cutting measure, are nurses going to be paid the same as surgeons for this work?

There is a proscribed career path for nurses with promotion dependent on experience and education. Table 4 shows the levels at which nurses are employed in

Britain and the corresponding levels of the Queensland award nursing career path. The Director of Nursing is accountable to the hospital executive.

**TABLE 4**  
**Nursing levels in Britain, related to the Queensland nursing career structure**

Queensland levels		Britain	
1	Registered Nurse	D	Staff Nurse
		D	Junior Staff Nurse
2	Clinical Nurse	E	Senior Staff Nurse
3	Clinical Nurse Consultant	F	Sister Ward Manager
	Clinical Nurse Specialist	F	Clinical Nurse Specialist
4	Assistant Director of Nursing	F	Nurse Manager
5	Director of Nursing	G	Director of Nursing

There are three other types of nurses employed in British hospitals. The first is the auxiliary nurse, equivalent to the enrolled nurse in Australia, who has been educated in either a hospital or trade education facility, and who works as a nurse but who has little formal responsibility. The nurses' aid has no formal education or training but performs some basic nursing duties. Both are accountable to RNs. The third nurse, called "nursery nurse" has special training in the care of children, usually at technical college level. They may continue their education to become play specialists. Nursery nurses are an invaluable part of the ward team. They are employed full time in most wards where children are nursed, specifically to play with children, give basic care to infants and in general, provide child-centred nursing care.

### 8.3.2 Education of health professionals

Doctors in Britain are educated under a system similar to Australia, Iceland and Sweden and includes six or seven years at university, followed by at least one year's internship. Specialization is by completion of training programmes with series of examinations and practical periods. Professions such as physiotherapy, social work, speech therapy and others moved into universities at times similar to the same professions in Australia

Nursing education in Britain was moved to the tertiary sector in the 1980s with the implementation of "Project 2000" in which students with O level (Grade 11) education enter university to study a programme from which they graduate with a diploma. During the course, the students choose a specialty branch of nursing and

then spend the rest of their education within that speciality. One of the specialities is children's nursing and once graduated, these nurses register as sick children's nurses (RSCN). A characteristic of the course is the 18 months spent in the hospitals after an initial 18 months in university. This seems good at first glance as it gives students much clinical exposure, in reality, it is detrimental to the students' education as they are part of the work force in the hospital and not supernumerary or in a true learning environment. They work with little supervision, carry a heavy load of responsibility and are very task oriented. About 10% of students enter with A levels (matriculation) and complete a Bachelor of Nursing degree, often with an honours year. These nurses are well-educated and become leaders in the profession (Royal College of Nursing 1996).

Table 3, page 16 shows that in Britain, 95% of nurses working with children in health services have paediatric nursing qualifications, usually having completed the children's nursing branch (Shields 1999). A few have Master's degrees in paediatric nursing. This is in direct contrast to Australia where a study in 1993 showed that in Queensland, only 4% of nurses who worked in hospitals with children had specialist paediatric qualification (Shields 1993). The high proportion of paediatric specialist nurses in England leads to a highly developed awareness of the needs of children and their families when a child requires health care. In 1991, a major tragedy occurred within the NHS which led to legislative changes to ensure a high level of employment of paediatric nurses. Beverly Allitt, an enrolled nurse working at a NHS hospital killed four children and caused grievous bodily harm to nine others. The subsequent inquiry produced a report which recommended that in all hospitals where children were nursed, at least two RSCNs should be on duty 24 hours a day (Clothier 1994).

#### **8.4 Family-centred care**

Results of my doctoral studies have indicated that FCC is much better practiced in Britain than in Australia (Shields 1999). Because the large proportion of English nurses working with children have speciality paediatric nursing education, I spent time with academic nurses who taught children's nursing. Paediatric nursing in Britain is taught throughout the three years of the course. In the first year, all students, not just those in the children's nursing branch (the first 18 months students have not chosen their speciality) are taught the historical background to paediatrics, with an

overview of the work of people like John Bowlby (Bowlby 1971) and James Robertson (Robertson 1952). Anne Casey (1995), a New Zealand nurse working in Britain, devised a care model called “partnership in care” which is widely taught in Britain. First year students are introduced to her work and to models such as FCC, their importance in paediatric and the role of the children’s nurse.

Once students have moved into the children's nursing branch, they are taught to challenge such models. A wide range of other models is examined and students encouraged to critically evaluate each one. In their assignments, they have to discuss the merits and useability of different models of paediatric care. Critical incident analysis is often used for comparison and evaluation. Family-centred care is examined from a community nursing perspective as well as acute care, and models of care for the non-acute settings, for example, with children with special needs are examined. Families are involved and are sometimes brought in to discuss models of care with students, and students are encouraged to observe and interact with families during their work in the wards. Other subjects covered include children’s rights, family dynamics, parental responsibilities, and child-centred care.

The nurse academics felt the weakest point in the implementation of FCC in Britain is the negotiation needed, as the NHS is so short staffed and nurses and other health professionals so busy that there is no time for effective communication and negotiation. It also needs a commitment from staff and good leadership to ensure it is done properly. As an example, a lot of money has been spent on a new oncology unit in one of the hospitals visited and an energetic and committed nurse is in charge. The nurses working there are highly educated, all are RSCNs and most hold either postgraduate honours degrees in paediatric and/or paediatric oncology nursing. The unit has a full complement of motivated staff. Its multidisciplinary staff are committed to a genuine partnership approach. Power is shared equally between the nurses and doctors and each respects the other’s expertise and judgements. All these factors contribute to the successful implementation of FCC. In other wards at the same hospital, the same conditions do not prevail, and so FCC is not so well implemented.

The NHS was set up to provide equal access to health care for all, and as such should be an ideal vehicle for the delivery of FCC. However, a sad story emerged about inequalities that have developed. Children with cystic fibrosis (CF) have a very

poor prognosis, lead a restricted life style with strict adherence to severe treatment regimes necessary for every-day functioning, and often require hospital admission. Children with cancer may have up to a 50% chance of survival and while the treatments are often gruelling, are similar in intensity to the treatments for CF. As a result of media coverage, the public know more about cancer than CF, and donate a lot of money to organizations which support children with cancer. At a British hospital, a large, well equipped and comfortable teenage cancer unit was set up with donated money. However, the teenage CF patients are still nursed in the general wards. One evening, the CF teenagers settled themselves in the new cancer unit, stating that it was an adolescent unit, they were adolescents and their prognosis was a lot worse than the adolescents suffering from cancer. They felt they were discriminated against because they could not use the unit. When they were taken back to their own ward they vandalised the ward. While this is not a recommended way of dealing with discrimination issues, it highlights inequalities in care which are detrimental not only to the well-being of all the children involved, but to the families, staff, the hospital and the NHS. It is a salutary lesson for the Australian health care system.

### **8.5 Operating theatres**

I visited the one of the operating theatre suites at the Royal Victoria Infirmary, Newcastle-upon-Tyne, where plastic and burn surgery is conducted. Parents are encouraged to come into the induction room and stay till the child is unconscious, and are allowed in the post-operative recovery room once the staff are sure the child's condition is stable. The hospital employs anaesthetic nurses as well as anaesthetists, but do not have anaesthetic technicians. However, they employ assistants in nursing who have attained a national vocation qualification, which gives very basic education for the field in which they want to work. They assist the anaesthetic nurse and anaesthetist after on the job training and are allowed to do the instrument count with the scrub nurse. However, most nurses who work in the operating theatres must have completed either the anaesthetic or perioperative nurse courses accredited by the English National Board. Procedures were similar to those in paediatric operating theatres in Australia, but Creutzfeldt-Jakob Disease has meant extra care has to be taken with cleaning of instruments and equipment.

## **8.6 Summary**

The British NHS was set up to make health care available and equal to all. Severe funding cuts during the Thatcher era and current staff shortages have put the system in jeopardy, with scandals common and the public disenchanted about the ability of the NHS to meet their needs. However, one of the best points about the NHS is the high level of specialist paediatric education of nurses. In Britain FCC is better delivered than in Australia, and from my observations on this Churchill Fellowship I will state that this can be directly attributed to the high level of specialist paediatric education held by British nurses.

## **9. RESEARCH PROJECTS**

### **9.1 Parents' needs**

One of the aims of the Churchill Fellowship involved a research project to investigate barriers to FCC in hospitals. A research study which examined parents' perceptions of their needs while a child is hospitalised and staff's perceptions of parents' needs was implemented, using a validated questionnaire devised by Dr Kristjansdottir. She has been using the questionnaire in her work at the University of Iceland to examine what parents feel they need during a hospital admission and if their needs are being met. I used the same questionnaire for parents and adapted it slightly for use with staff. If discrepancies are found between parents' perceptions of their needs and staff's perceptions of parents' needs, then barriers to FCC will be revealed. These will be examined in more detail.

The questionnaire was translated into Swedish, and trialed there and has been trialed in Australia. Data are being collected from the University Hospital in Reykjavik, at the University Hospital in Lund, Sweden; and in England at the Royal Victoria Infirmary and Newcastle General Hospital in Newcastle-upon-Tyne. Data collection is underway in Australia. On completion of the research project next year, publications will acknowledge the Winston Churchill Memorial Trust.

### **9.2 Ownership**

Another international project was planned by my three colleagues and I. We are curious as to how concepts of who "owns" a child once admitted to a health service influence the delivery of care by staff, of parents' and children's expectations of care, and how these impact on FCC. We have agreed that this important idea should be investigated as widely as possible and have a paper underway for publication in a peer-reviewed journal. We will seek funding to enable a colloquium of experts in fields relating to children to be held, and to set up research projects to investigate the subject. All those involved in the colloquium will be expected to conduct their own research into the topic. A book is planned after the colloquium, and a publisher has indicated an interest.

Such a project will take many years and planning has been implemented for the first three. The Winston Churchill Memorial Trust will be kept informed as the project develops.

### **9.3 Publications arising from the Churchill Fellowship**

Several publications will result from this Fellowship and all will acknowledge the Winston Churchill Memorial Trust.

Shields, L., Kristjansdottir, G. (2000) Nursing and health care in Iceland. Collegian – in press.

Shields, L., Kristjansdottir G., Hallstrom, I., Hunter, J. (2000) Who owns the child? - guarding the interests of the child in the health care system. Abstract submitted to the International Council of Nurses' International Conference, Copenhagen, June 2001.

Shields, L., Hallstrom, I. (2000) Nursing and health care in Sweden: in preparation.

Shields, L., Hunter, J. (2000). Paediatric nursing in Australia and the United Kingdom: in preparation.

Shields, L., Kristjansdottir, G. (2000) Nursing and health care in Australia: submitted to the Icelandic Nurses' Association journal.

Shields, L., Kristjansdottir G., Hallstrom, I., Hunter, J. (2000) Who owns the child in the health service?: in preparation.

## 10. CONCLUSIONS

### 1. **Family-centred care is delivered successfully in Sweden because:**

- The health system is very well resourced which means staff have time to spend negotiating with parents and children about their level of involvement in care;
- 80% of nurses have specialist paediatric nursing qualifications;
- implicit in the culture is knowledge about and respect for individual rights and responsibilities and this includes the rights of children;
- Legislation exists which enshrines the rights of children and families within the health services.

### 2. **Family-centred care is delivered successfully in Iceland because:**

- Knowledge of and respect for individual and children's rights is embedded in the culture;
- 25% of nurses hold specialist paediatric nursing qualifications, and a large component of the undergraduate nursing degree is paediatric nursing;
- Family is an important cultural construct so there is a strong imperative to involve the whole family in the care of the child, though there are perceptions that this under threat because of the strong work ethic and the need for people to hold multiple jobs;
- The health service is well-resourced.

### 3. **Family-centred care is better practiced in England than Australia because:**

- 95% of nurses have specialist paediatric nursing qualifications;
- Britain's NHS is suffering from budget constraints put in place during the Thatcher era and from staff shortages caused by the world-wide nursing shortage. If the NHS was better resourced, with the high level of paediatric nursing education then FCC would be much better implemented as staff would have more time to spend with the children and parents.

## **11. MAJOR RECOMMENDATIONS**

1. That laws are developed in Australia to enshrine the rights of children and families within the health services;
2. That the Government of Australia commit a large amount of funding to enlarge the base of specialist paediatric nurses to work in areas where children are nursed;
3. That Queensland Health make specialist paediatric nursing education a priority;
4. That undergraduate nursing courses be extended to four years to allow for broadening of basic speciality education within the course;
5. That a Bachelor of Paediatric Nursing course be implemented at an Australian university;
6. That a survey of the number of nurses with paediatric qualifications in Australia and a needs analysis of health services which care for children be undertaken;
7. That funding be made available to set up play therapy centres in Australian hospitals, for courses for play therapists who can then be employed to work with children in hospitals, and for “nursery nurses” similar to those in Britain to work with children in hospital wards;
8. That Australia legislate to ensure qualified paediatric nurses care for children in hospitals and health services.

### **11.1 Minor recommendations**

- That a national survey of FCC in Australian hospitals which care for children be undertaken;
- That the Association for the Welfare of Child Health be empowered to once again become active in all states of Australia;
- That a Churchill Fellowship be awarded for a visit to the Nordic countries to examine the centralised community and public health services;
- That the Australian health care system never support practices which see one group of patients disadvantaged in comparison to another;
- That Australian universities examine the system used in Scandinavian universities of publishing doctoral theses in book form, thereby making them readily available to many people.

## **12. PROBLEMS ENCOUNTERED DURING THE FELLOWSHIP**

### **12.1 Iceland**

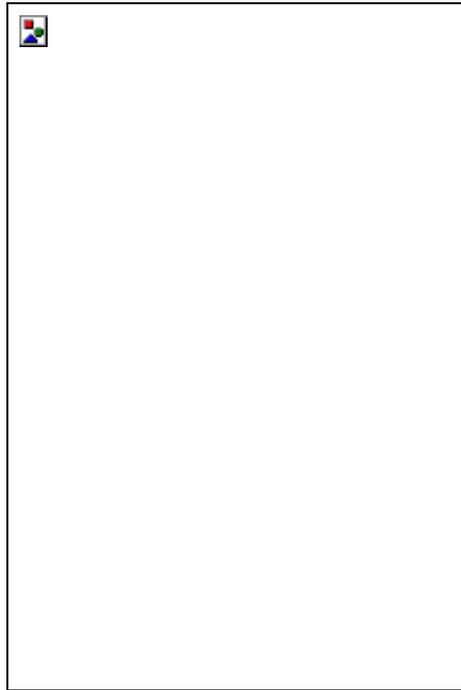
A merger is occurring between the University Hospital and the Reykjavik City Hospital, and a new, stand-alone children's hospital is being built. A period of unrest has resulted from these changes which had implications for my study. During my visit, I was not able to access the wards as freely as I had wished, as many staff were unsettled and it was not deemed politic for me to visit the wards at that time. As a result, I was able to visit the wards for the final week of my visit only. While I was able to speak with nurses, I had no access to other health professionals. However, I was able to speak with some parents and found an Australian woman, married to an Icelander, whose little boy was a long-term inpatient with a rare disease. She was able to give me quite a lot of information from the parents' perspective.

### **12.2 England**

On 10 April 2000, I sent an application for ethical approval to the Newcastle-upon-Tyne National Health Service Trust via Ms Judith Hunter. In June I was asked to send another copy of the application to the Research and Development. That was posted on 27 June. Ms Hunter was told that the ethics application was being facilitated but when I arrived in Newcastle in October I was told that it had never been seen by the ethics committee. This meant I could not collect any data for the research project. However, Ms Hunter and I duly sent the application to the committee and she will pay a research assistant to collect the data once approval has been granted, so the project can continue as planned.

I had an experience in England as part of the Churchill Fellowship which, while not related to health care, was nonetheless enlightening and educative. In October, there was a rail accident caused by faulty track in which four people were killed. Subsequently, the company responsible for rail lines in Britain decided to examine every mile of track and lay new lines where necessary. This caused many lines to be closed and ensuing chaos in the transport system, including the Underground (tube). On 28 October, severe storms lashed southern England, causing flooding and further closure of transport systems. I had arranged a meeting at the Hospital for Sick Children, Great Ormond Street, London with my colleagues with whom I had been working during my Fellowship – Dr Gudrun Kristjansdottir, Dr

Inger Hallstrom, and Ms Judith Hunter. The meeting, planned for four hours, lasted only one. I was staying with friends at Wimbledon and it took me three hours to travel from Wimbledon to the hospital near Russell Square because of congestion on the tube, Dr Hallstrom was an hour late for the same reason; Dr Kristjansdottir had to leave hours early to catch a bus to the airport as the tube was not running there, and Ms Hunter could not get from Newcastle to London at all. We have had to change our *modus operandi* for our on-going research project, and I have learned a lot about traffic chaos in London.



## **13. LIVING ON A CHURCHILL FELLOWSHIP**

### **13.1 Accommodation**

In Iceland, I was fortunate to stay in a flat in Reykjavik, where rents are notoriously high, and “house sit” for a family. Although I paid rent it was nothing like the normal rents charged in the city. When the family returned during my final week in Iceland, I was looked after by the extended family of the people in whose home I was staying.

My husband joined me in Sweden and in Lund we stayed in the Patient Hotel attached to the University Hospital for a nominal rent. In Örebro, we stayed with friends. We had two days in Copenhagen before I went to England and my husband returned to Australia, and we found a very cheap bed and breakfast home in an outer suburb.

In Newcastle-upon-Tyne I stayed in the staff quarters of the Freeman Hospital, where the rent was comparatively cheap for accommodation in England. At other times and in London, I stayed with friends. Anywhere I stayed with people, I took them out for dinner.

### **13.2 Travel**

In Iceland I walked everywhere, except for two bus tours to see the countryside. As Reykjavik is so small, walking was a good option. When I left Iceland, my husband collected me from the airport in Copenhagen. He had flown in to Hamburg and hired a car – it is much less expensive in Germany than Sweden, and we drove over the new bridge between Denmark and Sweden. A note for future travellers to Scandinavia: the bridge is convenient, but the toll was about A\$50.00. Having a car in Sweden enabled us to explore at least the southern parts of Sweden and to travel to Örebro. Time constraints prevented us from travelling further.

I hired a car in England and with the transport chaos I encountered there was glad I had done so. The flexibility of driving myself became important for getting to work each day.

### 13.3 Cultural experiences

I took advantage of any event that enabled me to learn more about the culture of the countries. I was taken to a midnight fireworks display in Reykjavik by Dr Kristjansdottir and her family; enjoyed the world premier of a ballet entitled “Baldur”, based on one of the Nordic sagas and danced by the Finnish Ballet, with music by an Icelandic composer played by the Iceland Symphony Orchestra. One of the tours I enjoyed took us to *Thingvillir*, the site of the world’s first parliament, and I attended both a cultural festival and a jazz festival. The museum in Reykjavik had two major exhibitions: one about the vikings, another about Christianity in Iceland.

In Sweden we attended a performance of “Giselle” by the Royal Danish Ballet and a more *avant garde* work by the Cullberg Ballet from Stockholm. We attended a concert by the Lund Symphony Orchestra in the *Domkirke* in Lund, a wonderful Romanesque medieval cathedral begun in the year 1000. Exploring Lund, a very old university town was fascinating. It is a bit like Oxford, but Lund has few tourists and is every bit as beautiful as Oxford. There are several museums in Lund, a cultural museum with old Swedish houses, farms and buildings, a history museum with displays about viking culture, and a museum attached to the cathedral, with wonderful medieval exhibits. Learning about viking culture and the sagas was an important part of the Scandinavian experience as so much of the viking culture seems to be a part of the modern Nordic countries. The countryside abounds with viking burial mounds and rune stones, and stories of trolls and fairies are told. There is a medical museum in Lund which displays medical and nursing care from about the 1700s including one of the first heart-lung machines and an extensive display of psychiatric nursing.

From Newcastle-upon-Tyne I explored Northumbria and North Yorkshire, visited Castle Howard, the Roman ruins at Wallsend and Hexham Abbey. The art gallery in Newcastle had the Lindisfarne Gospels on display. In London at the Imperial War Museum I visited the Holocaust Museum, a harrowing but important exhibition that brought to life the reasons behind the rightness of Churchill’s effort to win World War II.

### 13.4 Food

Food in Iceland was very expensive, except for salmon of all kinds, including smoked salmon. One of the culinary highlights of the trip was some smoked salmon

and trout given to me by a friend. He had caught it that week and smoked it himself. One cross-cultural experience I was pleased to miss was the local delicacy in Iceland. Shark is buried in sand for six weeks then taken out and dried. It is eaten with a mouthful of a strong cherry brandy. Although not courageous enough to try this, I did try puffin, which tastes like strong duck.

Swedish cuisine was much less adventurous, and I put on weight trying all the delicious cakes. Sweden has a wide variety of pickled fish – all delicious.

Food in England was wholesome and despite the scare about eating beef, I found it impossible to decline when given a beef dish at a friend's home. I did try partridge and found it tasty though strong.

### **13.5 Time frame**

Three months was long enough for my plans, and I was pleased that I had chosen only three countries to visit because when things went wrong, I still had time to complete my investigations.

### **13.6 Funding**

As I embarked on my travels, I was concerned that, with the weakness of the Australian currency, my funds may not have gone far. The allowances paid by the Churchill Fellowship were sufficient for my needs.

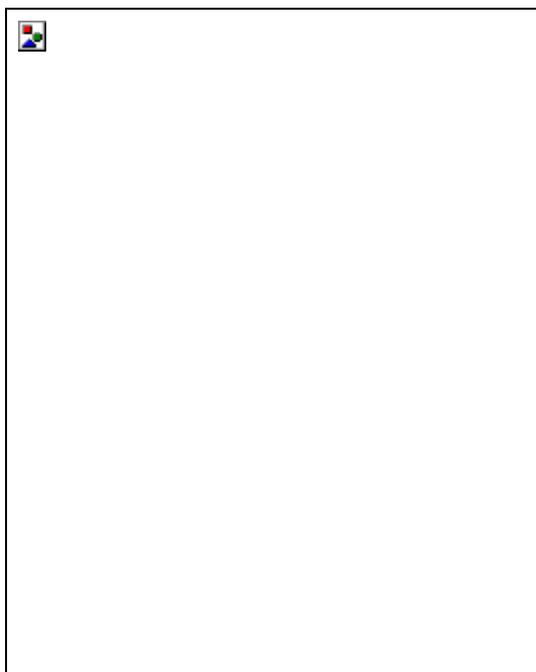
#### **14. THINGS “CHURCHILL”**

I took the opportunity to visit as many sites related to Sir Winston Churchill as possible during my time in England and I contacted Dr Ken Day, the Tyne and Wear Churchill Fellows’ Association representative although was unable to meet him. Our paths crossed for one day only as he returned from a trip to Canada to photograph polar bears the day before I left Newcastle.

Blenheim Palace was one of the few tourist attractions still open even though summer was well and truly over. As the place where Churchill was born and the home of the Churchill family, it has an extensive display of Winston Churchill Memorabilia. I left my card with the staff.

In London, I visited the Imperial War museum and again left a calling card. There was a display about the role of the Spitfire in the Battle of Britain and Sir Winston Churchill was featured. I visited the Cabinet War Rooms, but because of the dreadful storms in England were closed due to flooding.

I was attracted to the Churchill Hospital in Oxford because of its name and found it was an off-site campus of the main hospital, the Radcliffe Infirmary. The Churchill Hospital was set up in 1942 as an emergency wartime hospital for American servicemen. It is now a centre for cancer services.



**Statue of Sir Winston Churchill, Churchill Park, Copenhagen**

In Copenhagen, I accidentally came across the Churchill Park, situated near the Friedriksburg Castle and the Little Mermaid statue. Denmark was occupied by the Nazis in World War II and a museum about the Danish resistance to the Occupation has been built beside the Churchill Park. Unfortunately, it was closed on the day I visited, but I managed to take some photographs of the statue of Sir Winston Churchill.

As a Churchill Fellow, it was a privilege to be able to pay tribute to a man who contributed so greatly to the welfare of the world.

## **15. PERSONAL AND CAREER ADVANTAGES**

The Churchill Fellowship enabled me to travel and learn not just about the care of children in hospital in countries outside Australia, but enabled me to meet and establish contact with many people and renew my acquaintance with others. They include:

Sir John Pattison, Director of Research and Development, Department of Health, United Kingdom;

Dr Sarah Stewart-Brown, Health Services Research Unit, University of Oxford;

Professor Alan Craft, Director, Sir James Spence Institute for Child Health, University of Newcastle, England;

Ms Sarah Neill, Senior Lecturer, School of Nursing, University College, Northampton, England;

Ms Sally Nethercott, Director of Nursing, The Hospital for Sick Children, Great Ormond Street, London;

Professor Royston Stephens, Dean, Faculty of Health, University of Northumbria at Newcastle, England;

Dr Irene Jakobsen, Director, Department of Paediatrics, University of Lund;

Professor Harriett Jakobsen, President, Save the Children Fund, Sweden;

Dr Margretta Ehnfors, Deputy Dean, School of Caring Sciences, Örebro University, Sweden;

Dr Erla Kolbrun Svarvasdottir, Head, Faculty of Nursing, University of Iceland.

My personal development was enhanced by my Churchill Fellowship, as I found I was able to travel in European countries on my own, was able to forge links with other health professionals in countries very different to Australia and learned a small amount of two other languages. The independence and self-esteem I have gained through my travels will enhance both my career and relationships with my family, friends and colleagues.

I thank the Winston Churchill Memorial Trust for the opportunity to grow and will take pleasure in passing the knowledge I have learned on to others, both in Australia and overseas.

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and others.

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