Informing parents of their child's disability: a survey of health care professionals' preparedness for informing practice

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INFORMING PARENTS OF THEIR CHILD'S DISABILITY:
A SURVEY OF HEALTH CARE PROFESSIONALS' PREPAREDNESS FOR INFORMING PRACTICE

A thesis submitted in fulfilment of the requirements for the award of the degree

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by

FUMIKO TACHIBANA, R.N.,

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CHAPTER 1 INTRODUCTION

1.1 Introduction................................................................. 1
1.2 Background to the Study.................................................. 2
1.3 Statement of Problem...................................................... 3
1.4 Justification of the Study.................................................. 4
1.5 Aim.............................................................................. 6
1.6 Objectives.................................................................. 6
1.7 Research Questions....................................................... 7
1.8 Structure of the Thesis..................................................... 7
1.9 Operational Definition.................................................... 8

CHAPTER 2 THEORETICAL FRAMEWORK OF THE STUDY

2.1 Introduction.................................................................... 16
2.2 Development of Grief Models.......................................... 16
2.2.1 Stages Model.............................................................. 16
2.2.2 Chronic Sorrow........................................................... 19
2.2.3 Cyclical Grief Model.................................................... 23
2.2.4 Discussion ................................................................. 26
2.3 Inconsistent Findings of the Impact of a Child with a Disability on the Family ................................................. 27
2.4 Development of the Family Stress and Coping Models .......... 38
  2.4.1 Crisis Theory .......................................................... 40
  2.4.2 ABCX Model ......................................................... 42
  2.4.3 Double ABCX Model .............................................. 45
  2.4.4 Family Adjustment and Adaptation Response (FAAR) Model .......................................................... 47
2.5 Conclusion ................................................................. 52

CHAPTER 3 LITERATURE REVIEW

  3.1 Introduction .................................................................. 57
  3.2 Parent-Professional Relationship ................................. 58
  3.3 Parents’ Dissatisfaction with Informing Practice ............. 59
    3.3.1 Dissatisfaction with Manner and Communication Skills of Professionals ......................................................... 61
    3.3.2 Professionals’ Perception Adversely Affecting Their Practice ........................................................................ 71
    3.3.3 Dissatisfaction with Information .................................. 96
    3.3.4 Dissatisfaction with Circumstances of Informing .......... 113
  3.4 Factors Affecting Professionals’ Preparedness for Informing Practice .................................................................. 124
  3.5 Conclusion .................................................................. 133

CHAPTER 4 METHODOLOGY

  4.1 Introduction .................................................................. 139
  4.2 Research Design ......................................................... 139
  4.3 Subjects in the Study .................................................. 139
  4.4 Data Collection .......................................................... 141
<table>
<thead>
<tr>
<th>Chapter 4.5</th>
<th>Data Analysis</th>
<th>142</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chapter 4.6</td>
<td>Validity and Reliability of the Procedure</td>
<td>145</td>
</tr>
<tr>
<td>Chapter 4.7</td>
<td>Ethical Considerations</td>
<td>146</td>
</tr>
</tbody>
</table>

**CHAPTER 5 QUANTITATIVE RESULTS**

<table>
<thead>
<tr>
<th>Section</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.1</td>
<td>Introduction</td>
<td>147</td>
</tr>
<tr>
<td>5.2</td>
<td>Response Rate</td>
<td>147</td>
</tr>
<tr>
<td>5.3</td>
<td>Demographic Characteristics of the Subjects</td>
<td>147</td>
</tr>
<tr>
<td>5.4</td>
<td>Attitudes toward Having a Child with a Disability</td>
<td>151</td>
</tr>
<tr>
<td>5.5</td>
<td>Knowledge to Give Sufficient Information to Parents</td>
<td>156</td>
</tr>
<tr>
<td>5.6</td>
<td>Skills Necessary in Informing Parents of Their Child’s Disability</td>
<td>161</td>
</tr>
</tbody>
</table>

**CHAPTER 6 DISCUSSION**

<table>
<thead>
<tr>
<th>Section</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>6.1</td>
<td>Introduction</td>
<td>167</td>
</tr>
<tr>
<td>6.2</td>
<td>Attitudes toward Having a Child with a Disability</td>
<td>168</td>
</tr>
<tr>
<td>6.3</td>
<td>Knowledge to Give Sufficient Information to Parents</td>
<td>173</td>
</tr>
<tr>
<td>6.4</td>
<td>Skills Necessary in Informing Parents of Their Child’s Disability</td>
<td>179</td>
</tr>
<tr>
<td>6.5</td>
<td>Relationships Between Variables</td>
<td>194</td>
</tr>
</tbody>
</table>

**CHAPTER 7 QUALITATIVE RESULTS AND DISCUSSION**

<table>
<thead>
<tr>
<th>Section</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>7.1</td>
<td>Introduction</td>
<td>198</td>
</tr>
<tr>
<td>7.2</td>
<td>Results and Discussion</td>
<td>200</td>
</tr>
</tbody>
</table>
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Fumiko Tachibana
Informing parents of their child’s disability is an important task of health care professionals because it can affect the future parent-professional relationship and parents’ adaptation to their child’s disability. The current study investigated health care professionals’ preparedness for informing practice among different professional groups through a questionnaire survey. The literature suggested factors that possibly affect professionals’ practice. These were professionals’ attitudes toward having a child with a disability, knowledge to give sufficient information to parents, and skills necessary in informing parents of their child’s disability. There were no research instruments available to investigate professionals’ preparedness for informing practice in these areas, except for an attitude questionnaire. A questionnaire was consequently developed with knowledge from the literature. Based on the subjects’ responses to the questionnaire, comparisons were made to determine whether differences in preparedness for informing practice in these areas exists among different professional groups, including doctors, nurses, and social workers.

The groups did not significantly differ in their attitudes toward having a child with a disability, however, distinct differences between the doctors and the social workers were found in knowledge to give parents sufficient information and in skills necessary in informing practice. The doctors tended to be familiar with medical aspects of the disability, and were significantly more confident in informing practice. In contrast, the social workers tended to be familiar with community resources, and were significantly more confident in their education/training related to informing practice. Although the nurses failed to show any distinct expertise in group comparisons, the data did suggest
the advantage of their involvement in informing practice. The results acknowledge the doctors' primary responsibility in informing practice, yet support an assertion that there are likely advantages of the involvement of other professionals in this professional practice.

The final section of the questionnaire was an open-ended question asking the subjects their opinions about the guidelines for informing in order to investigate their awareness of aspects of informing, and to determine the relevance of the guidelines in actual practice. The guidelines were integrated from those that had been suggested in the literature. The subjects varied in their level of awareness of aspects of informing practice. Some appeared to be unfamiliar with this issue, yet the others seemed well aware of this, sharing their opinions or policy based on their clinical experience. A substantial minority of the nurses and the social workers seemed to believe that informing practice is doctors' territory and they are not responsible for this.

The findings were discussed in terms of implications for future practice and professional education/training in this area. Several recommendations were made, including the routine involvement of social workers in informing practice, the evaluation of informing practice by nurses, the establishment of standard procedures and continuing educational programs to prepare staff for informing practice in hospitals, and additional professional education/training in this area.
LIST OF FIGURES

Figure 2.1  Stages Model Pattern and Chronic Sorrow Pattern of Parents’ Adaptation (Damrosch & Perry, 1989)

Figure 2.2  Cyclical Grief Model (Anderegg et al. 1992)

Figure 2.3  Linear Grief Model (Worthington, R.C., 1994)

Figure 2.4  Cyclical Grief Model (Worthington, R.C., 1994)

Figure 2.5  Phases of Crises (Graves & Lancaster, 1992 (173) U.S.)
Adapted from Caplan’s Crisis Theory (1961)

Figure 2.6  ABCX Model: Hill (1949)

Figure 2.7  Double ABCX Model (McCubbin & Patterson, 1993)

Figure 2.8  Family Adjustment and Adaptation Response (FAAR) Model
(Patterson, 1988)

Figure 5.1  Comparisons of Mean Scores for Each Statement among Professional Groups in Attitude Section

Figure 5.2  Comparisons of Percentage of Subjects in Each Professional Group Indicating Sufficient Knowledge of Each Item in Knowledge Section

Figure 5.3  Comparisons of Mean scores for Each Item among Professional Groups in Skill Section
LIST OF TABLES

Table 3.1 
Studies of Parents’ Dissatisfaction with Informing Practice

Table 5.1 
Demographic Characteristics of Subjects

Table 5.2 
Mean Scores for Each Statement for Professional Groups in Attitude Section

Table 5.3 
Percentage of Subjects in Each Professional Group Indicating Sufficient Knowledge of Each Item in Knowledge Section

Table 5.4 
Mean Scores for Each Item for Professional Groups in Skill Section

Table 6.1 
Comparative Ranking of Percentage of Subjects in Each Professional Group Indicating Sufficient Knowledge of Each Item in Knowledge Section

Table 6.2 
Comparative Ranking of Mean Scores for Each Item in Skill Section for Each Professional Group

Table 7.1 
Studies of Guidelines for Informing Practice and Guidelines Identified in Each Study

Table 7.2 
Frequency with Which Each Guideline Was Mentioned

Table 7.3 
Frequency with Which Each Aspect of Informing Practice Was Mentioned
CHAPTER 1  INTRODUCTION

1.1 Introduction

The birth of a child brings joy but also challenges to every parent. Parents of children with a disability have to deal with additional challenges pertaining to the child’s disability (Hanson et al., 1989). The presence of the child can have a profound impact on the family unit that may threaten their financial situation, social life, psychological well-being, and marital and family relationships. Parents, usually mothers, need to make extra involvement with their child regarding his/her special needs (Barnett & Boyce, 1995), which requires them to, unavoidably, develop life long relationships with a variety of professionals.

The relationship with professionals can be a major source of family support, yet parents often regard this relationship as a source of additional stress (e.g., Stainton & Besser, 1998). For most families of children with a disability, the relationship with professionals is initiated at the time of the interview informing parents of their child’s disability. This interview is of great importance both for parents and professionals because it may affect the future parent-professional relationship (Clarkson et al., 1996) and parents’ adaptation to having a child with a disability (Wooley et al., 1989).
1.2 Background to the Study

There is an increasing awareness of the importance of a family-centred approach in health care services due to changes occurring in home and long-term care (Craft & Willadsen, 1992). This approach is especially necessary for families of children with a disability, because the family unit has a significant role in establishing and optimising the health and development of the child. In the latter half of the twentieth century all aspects of care for these children have dramatically changed due to advances in medical technology and the move from institutional care to the child remaining in the family home. The results of these changes are not only a greater survival rate with a more normalised life for these children but also extraordinary demands falling on parents in supporting the child within the family home. These demands may arise from normal duties of child rearing, additional childcare duties with treatment programs and a need to adapt emotionally to having a child with a disability (Pain, 1999). Briskin & Liptak (1995, p.263) argue that parents of children with a disability need to:

- "accept/acknowledge the child's condition;"

- manage the condition on a daily basis;

- meet the child's developmental needs;

- meet the needs of other family members;

- cope with ongoing stress and periodic crises;
• assist family members to deal with their feelings;
• educate others about their child's condition;
• establish support systems;
• deal with health care and other professionals;
• cope with hospital experiences; and
• maintain solvency.”

Professionals who work with children with a disability and their families can be an important resource for these families. They can directly enhance the child's health and development through health care or other interventions, and can also do this indirectly by supporting parents' adaptation to the child's disability.

1.3 Statement of Problem

Despite the importance of professional support, parents often cite the relationship with professionals as a source of additional stress (e.g., Stainton & Besser, 1998). This is more likely when they have had negative experience with professionals in the past. For the majority of families of children with a disability, their first experience with professionals occurs at the time of the interview informing of their child's disability. If parents have negative experience with professionals at this time, they may fail to
trust professionals as a whole and become reluctant to utilise them as a resource (Lian & Aloia, 1994).

Among different professional disciplines, health care professionals are often the first to come into contact with these families and are thus likely to be responsible for the informing interview (Sloper & Turner, 1993). This event may be one of several unpleasant tasks for professionals, yet will be an experience never to be forgotten for parents (Sablewicz & Kershaw, 1994). Studies view it as a crisis producing grief (e.g., Worthington, 1994), and as a time when problems often develop in the parent-professional relationship (Nursey et al., 1988), contributing to parents’ dissatisfaction with the service they receive at this time (e.g., Hasnat & Graves, 2000b). Parents tend to be dissatisfied when professionals involved in the informing interview fail to meet expectations that they be emotionally available, communicate well, provide sufficient amount and quality of information, and arrange satisfactory circumstances in which the interview takes place.

1.4 Justification of the Study

Professionals who are involved in the informing interview take an important position in establishing a good parent-professional relationship and building rapport with parents to
facilitate their adaptation to the child’s disability by providing sufficient information to parents in appropriate manner and circumstances. In this respect, professionals must be skilled at inspiring trust, have sufficient knowledge to give useful information to parents, and must be aware of parents’ preferences for informing practice.

Investigating professionals’ preparedness for informing practice is therefore warranted to improve the provision of services for these families. Factors likely to affect professionals’ practice, that have been identified in the literature, include their attitudes toward having a child with a disability, knowledge to give sufficient information to parents, and skills necessary in informing parents of their child’s disability.

The majority of data on professionals’ preparedness for informing practice are obtained indirectly through parents’ reports on services that they received, and only a few studies have examined this issue by asking professionals directly. Moreover, most of the latter studies have investigated only a particular variable of professionals’ preparedness. The remaining studies investigated more than one variable of professionals’ preparedness but only among doctors.
There is no study, the researcher is aware of, that has investigated professionals’ preparedness for informing practice in the areas identified among different health care professionals. Although doctors generally assume the primary and often sole responsibility in informing practice, the advantage of involvement of other health care professionals should not be discounted because these other professionals may have unique expertise relating to their own professions. The current study thus investigated professionals’ preparedness for informing practice in the areas identified by different health care professions by asking professionals directly.

1.5 Aim

The aim of the study is to determine health care professionals’ preparedness for informing parents of their child’s disability among different professional groups.

1.6 Objectives

- To investigate health care professionals’ preparedness for informing practice in the areas affecting their practice.
- To explore health care professionals’ opinions regarding the guidelines and informing practice as a whole
1.7 Research Questions

The study investigates the following research questions:

- What is the nature of health care professionals' attitudes toward having a child with a disability?
- What is the perceived knowledge of health care professionals about information to give sufficient information to parents?
- What is the perceived skills or experience of health care professionals in informing parents of their child's disability?
- What is the opinion of health care professionals on the guidelines for informing practice?
- Are there any relationships between attitude, knowledge, skills and demographic variables of health care professionals?

1.8 Structure of the Thesis

This thesis is presented in eight chapters. Chapter 1 provides background to the study, identifies problems relating to the study, and justifies the study. Chapter 2 establishes a theoretical framework of the study and Chapter 3 reviews literature pertinent to the research. Chapter 4 outlines the research design and methodological procedures used. Chapter 5 reports the quantitative findings of the study and these are discussed in
Chapter 6. Chapter 7 presents the qualitative findings of the study while discussing about these simultaneously. Finally, limitations of the study, conclusions and recommendations are included in Chapter 8.

1.9 Operational Definitions

For the purpose of this study the following operational definitions are used. It is important to distinguish definitions of terms concerned with disability because there is some confusion about meanings of these terms. Different terms are used to define certain aspects of disability in different contexts.

The terms 'impairment', 'disability', and 'handicap' are often used interchangeably, though the World Health Organisation (WHO cited in Physical Disability Council of NSW Inc., 2001, p.1) distinguishes these terms and provides the following definitions:

"Impairment - an anatomic or functional abnormality or loss which may or may not result in a disability. This is understood as the medical condition."

Disability - the loss or reduction of functional ability which results from an impairment. This is understood as the functional consequence of a medical
Handicap - the disadvantage caused by the disability i.e. a person may have a transport handicap or an employment handicap. This is understood as the social consequence.

The handicap is therefore an artificial barrier which can usually be avoided with insight and proper planning for both the physical environment and the provision of services. People are only handicapped when the community and its representatives fail to consider the needs of people with disabilities- it has nothing to do with the disability itself.”


Health care is a field that is closely related to individuals with a disability. Health care professionals’ views of disability put the focus on pathology, and classification is according to aetiology. In the context of health care services, the term ‘disability’ may be classified into ‘intellectual disability’, ‘physical disability’ and ‘sensory disability’.

For the purpose of administration of service delivery to a part of the population of individuals with a disability, the term ‘developmental disability’ is widely used in
Disability

'Disability' is the term that is used in the current study, and is defined as broadly as possible to include various chronic conditions and impairments affecting developmental outcomes of children. The use of this term was decided for two reasons. First, a larger literature could be reviewed when a broad definition of disability is used. Second, it seemed to be appropriate to use such a definition in order to attract flexible responses to questions from participants based on their personal and professional experiences in disability.

The term 'disability' can be classified broadly into 'intellectual disability', 'physical disability' and 'sensory disability'. It may be useful to present definitions of these terms because studies cited in this thesis often focus on one or more of these disabilities.

Intellectual Disability

According to NSW Council for Intellectual Disability (2001), there are three core features that someone must comply to receive a diagnosis of an intellectual disability. These are:
• "An IQ score of less than 70-75.

• Difficulties with 'adaptive skills' – such as following and understanding directions and understanding abstract concepts.

• The existence of the first two characteristics prior to the age of 18.

In practical terms, having an intellectual disability may mean:

• The need for support (either short term or life-long) with some daily living tasks, such as financial management, meal planning, accessing public transport or self care.

• Some difficulties with learning new information and understanding complex instructions."

NSW Council for Intellectual Disability (2001)

There are four categories of intellectual disability – mild, moderate, severe, and profound – these indicate the degree of disability an individual has with learning. These days, however, the main reason for knowing someone's level of intellectual disability is recognised as to identify suitable ways of providing support for this person. The level is thus increasingly defined according to support needs of the person (NSW Council for Intellectual Disability, 2001).
Physical Disability

"Physical disability pertains to total or partial loss of a person's bodily functions (i.e. walking, gross motor skills, bladder control etc) and total or partial loss of a part of the body (i.e. a person with an amputation).

Examples of physical disability include: amputation; arthritis; cerebral palsy; multiple-sclerosis; muscular dystrophy; paraplegia; post-polio syndrome; quadriplegia; and spina bifida."

Physical Disability Council of NSW Inc. (1999, p.1)

Sensory Disability

The term ‘sensory disability’ can be defined as the loss or reduction of functions which results from a sensory impairment. Blindness and deafness are examples of sensory impairment.

According to Kozier et al. (1995), sensory functions are related to the reception or perception of external or internal stimuli to the body. Functions associated with external stimuli include the sense of sight, hearing, smell, touch, and taste, and other functions associated with internal stimuli are kinaesthetic or visceral. The former refers to
awareness of the position and movement of body parts (i.e., which leg is forward), and the latter refers to awareness of the state of any large organ within the person (i.e., fullness).

During the past decade, the broader term 'developmental disability' has been increasingly used in NSW, Australia, for the purpose of service delivery to a part of the population of individuals with a disability where the disability commenced prior to the person reaching 18 years of age that divides their developmental period.

Developmental Disability

"The term 'developmental disability' means a severe chronic disability which:

• is attributable to an intellectual or physical impairment or combination of intellectual and physical impairments,

• is manifested before the person attains age 18,

• is likely to continue indefinitely,

• results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living and economic self-sufficiency,"
• reflects the person’s need for a combination and sequence of special inter-
disciplinary or generic care, treatment or other services which are of life-long or
extended duration and are individually planned and co-ordinated.

For practical purposes this includes persons with intellectual handicap, severe
epilepsy, cerebral palsy, brain damage acquired in childhood and those with other
neurological disorders needing similar provision.”

NSW Department of Health (1985)

**Health Care Professional**

A person who is qualified and working in one of health care professions. In this thesis,
health care professionals specifically means those who are working in areas of
paediatrics or obstetrics where they are likely to be involved in the interview informing
parents of their child’s disability, such as paediatricians, obstetricians, midwives,
registered nurses, and social workers. The term ‘professional’ is often used
synonymously with this term throughout the thesis.

**Informing Interview**

An interview conducted by professionals for the purpose of informing parents of the
diagnosis of their child's disability.

**Informing Practice**

Informing practice refers to professionals' practice that aims to communicate to parents the diagnostic and related information pertinent to the child's disability at the time around the informing interview. This may begin with the interview informing the parents of their child's disability and complete with follow-up interviews.

**Parent**

A primary caretaking adult in a family of a child with a disability. In most cases, this is a natural parent, although in other cases this includes grandparents, relatives, step-parents, adoptive parents, and foster parents.
2.1 Introduction

This chapter provides the theoretical framework of the study. Theory is an inherent component of professional practice and research. It informs and guides how people think and how they behave in a particular circumstance, and thus allows professionals to predict what might happen in that circumstance or provides a way for them to interpret and explain reality (Ellis & Crookes, 1998).

Since the latter half of the twentieth century researchers have proposed several theoretical models to explain parents' adaptation to having a child with a disability. It is suggested that these models have influenced how professionals view families of children with a disability, and as a result, the provision of services for these families.

2.2 Development of Grief Models

Regardless of the nature of their child's disability, many parents report similar experience of intense feelings at the time around the diagnosis of their child's disability. It is essential professionals to acknowledge possible parents' emotional reactions to this event in order to support them effectively. In the following section, several grief models including the Stages Model, Chronic Sorrow, and the Cyclical Grief Model, are reviewed within the historical context.

2.2.1 Stages Model

Traditionally, parents' adaptation to having a child with a disability has most commonly been described within the stages model. This model sees the process of parents'
adaptation through a sequence of stages that is time-bound and concludes with an acceptance stage. In this view, adaptation implies an acceptance of the child’s disability.

Many researchers agree that there is a similarity between the sequence of stages of grieving and parents’ emotional reactions to having a child with a disability. There are several models of grieving, perhaps the most famous of which is Kübler-Ross’s five stages (1969): Denial; Anger; Bargaining; Depression; and Acceptance. Based on this model, past authors developed several grieving models that explain an individual’s emotional reactions to a tragedy or a loss (Klein, 1993; Sablewicz & Kershaw, 1994; Kozier et al., 1995). Integrating the grieving models proposed by these authors, parents’ emotional reactions to having a child with a disability are articulated as follows:

- **DENIAL:** ‘No, not me.’ Denial serves as an emotional buffer between parents and the current situation that they are not yet ready to deal with. They refuse to believe their child has a disability, and may show artificial cheerfulness to prolong denial.

- **ANGER:** ‘Why me?’ Parents feel anger at the fact that this has happened to them. They may direct anger toward themselves, the baby, health care professionals, or other people.

- **BARGAINING:** ‘Yes, me, but...’ Parents accept the fact that it has happened or is inevitable but want to do something to reverse it. They may seek to bargain to avoid loss, and may demonstrate so-called “shopping behaviour” in that they search for alternative diagnoses from other sources.
• DEPRESSION: ‘Yes, me.’ Parents grieve over what has happened and what cannot be. They may express a feeling of guilt for any wrongs (real or imagined).

• ACCEPTANCE: ‘It's all right.’ According to Kübler-Ross, this is not resignation but, rather, a coming to terms with the situation. Parents may wish to obtain information regarding programs and services needed for their child.

An early study conducted by Solnit & Stark (1961) in Connecticut, U.S., examined parents’ grieving process caused by the diagnosis of their child’s disability. A three-stage of grieving was proposed: Numbness; Disappointment; and Re-experience. The researchers stated that parents first must mourn the loss of their expected child in order to accept their child with a disability. While the researchers acknowledged the similarity between the sequence of stages in acceptance of a stillborn baby and adaptation to having a child with a disability, they stressed the difference between both instances in that parents of children with a disability must begin caring for their living child during a period of emotional upheaval. The study, however, failed to identify the number of subjects involved, thus possibly limiting the applicability of the findings.

To determine the process of parents’ emotional reactions to the birth of a child with a disability, Drotar et al. (1975) interviewed 20 mothers and 5 fathers of 20 children with a disability, in Ohio, U.S. The children’s disabilities included Down syndrome, intellectual disability, congenital heart disease, microcephaly, cleft palate, and other varieties of congenital malformations. The subjects were recruited from parents of children who had been admitted to a paediatric hospital during a two-month period. Non-structured interviews took place 7 days to 60 months after the child’s birth. The
researchers concluded that the stages model was relevant as they found a common sequence of reactions: Shock; Denial; Sadness, Anger or Anxiety; Adaptation; and Reorganisation. However, as Blacher (1984) pointed out, there may be an inherent problem in this kind of studies. That is, one parent may label an expression as guilt, while the other may label the same expression as shock or denial.

The stages model helps professionals become aware of possible parents’ emotional reactions to the diagnosis of their child’s disability. Yet, as Wiker et al. (1981) argued, it may mislead professionals to believe parents’ adaptation to having a child with a disability will be ultimately completed, and underestimate the impact of a child’s disability on parents’ later lives.

2.2.2 Chronic Sorrow

The concept of ‘chronic sorrow’ was presented by Olshansky (1962). From his personal as well as professional experiences with parents of children with a disability, he suggested that these parents experience a life-long suffering in rearing the child. According to Olshansky, chronic sorrow is “a natural, rather than neurotic, reaction to a tragic fact” (p.192), and its intensity varies “from time to time for the same person, from situation to situation, and from one family to another” (p.190).

Later researchers also questioned the idea held by the stages model that parents of children with a disability go through an ordered sequence of discrete ‘stages of adaptation,’ or that they achieve a ‘final stage’ of acceptance. Searl (1978), from his own experience of rearing a child with a disability, criticised the stages model since it failed to explain individual differences in parents’ adaptation, and discounted parents’
life-long experience of having a child with a disability. He described a long-term suffering in which shock, guilt, and bitterness never disappear from parents’ emotional life, confirming chronic sorrow.

The findings of Wilder et al.’s study (1981) carried out in Madison, U.S., also favoured Olshansky’s proposition. Initially 100 social workers were randomly selected from a roster of names from the social service department, and 100 parents were selected from a client list at a diagnostic evaluation service for children with an intellectual disability. Of those sent the questionnaire, 32 parents and 32 social workers completed and returned the questionnaire by mail. The questionnaire included a selection of linear graphs depicting the pattern of parents’ adaptation. The parents’ responses indicated that they experienced periodic crises during the child’s development rather than time-bound grief and eventual acceptance, and that they experienced various periods of stress and sadness over time. The findings of this study should, however, be taken with caution because of the use of a non-random sampling method for parent subjects and the relatively low response rate.

Blacher (1984) reviewed 24 studies that supported the stages model of parents’ adaptation to having a child with a disability, and pointed out some methodological weaknesses involved in the studies, including the small size of sample, inclusion of only mothers in the study, possible response bias to self-reported questionnaires, and lack of consideration to other variables. Although Blacher found some consistency of stages of parents’ adaptation in the literature, she questioned whether such stages were a clinically and scientifically derived fact, or a product of researchers’ attempts to perpetuate ideas from the literature.
Damrosch & Perry (1989) in Baltimore, U.S., conducted a survey of 25 families of children with Down syndrome, and compared responses of mothers and fathers. Questionnaires were sent and returned separately by 18 fathers and 22 mothers, including 17 couples. The subjects were recruited from a local parent support group. The researchers used a modified version of the graphs developed by Wikler et al. (1981, for details of this study, see p.20), one of which depicted the stages model pattern (time-bound, steady, gradual pattern), and the other depicted the chronic sorrow pattern (periodic crises pattern).

**Stages Model Pattern**

**Feeling**

Great

Awful

**Diagnosis**

**Time**

**Now**

**Chronic Sorrow Pattern**

**Feeling**

Great

Awful

**Diagnosis**

**Time**

**Now**

*Figure 2.1 Stages Model Pattern and Chronic Sorrow Pattern of Parents' Adaptation (Damrosch & Perry, 1989)*
The parents were asked to choose one of these graphs to describe their adaptation to having a child with a disability. The results indicated a difference in adaptation pattern between mothers and fathers in that 68% of mothers (n=15) reported their adaptation as a chronic sorrow pattern, while 83% of fathers (n=15) described their adaptation as a stages model pattern. The results of this study should, however, be used cautiously due to the use of a non-random sampling method and the relatively small sample size, possibly limiting the applicability of the findings.

The findings of Cameron et al.'s study (1992) conducted in Ontario, Canada, supported the chronic sorrow pattern of parents' adaptation. Mothers of children with a disability were recruited by convenience sampling through four local school boards. The children's disabilities included Down syndrome, cerebral palsy, chromosomal abnormalities, and other disabilities with unknown causes. Semi-structured interviews were carried out with 63 mothers at home. The mothers reported that their emotions such as sadness, guilt, anger and frustration did not occur in a sequence of stages and repeatedly emerged throughout their lives.

In relation to generalised views toward parents' adaptation to having a child with a disability held by the stages model, Briskin & Liptak (1995), in a descriptive study, stressed individual differences of parents' adaptation in that parents experience various emotional states in unique ways and in unique orders with no definite time limit. They supported chronic sorrow and suggested that the term 'acknowledgment' was more accurate to describe the process of parents' coming to terms with their child's disability rather than 'acceptance'.
A longitudinal study carried out by Bruce et al. (1996) in Victoria, Australia, examined the process of parents' adaptation to having a child with a disability in 49 mother-father pairs. The parents were recruited through widespread publicity in the community, and interviewed annually, over a 3-year period. The disabilities of children were either congenital or sustained within the first two years of their lives. The researchers used two measures that had been previously established with acceptable reliability. In these measures, two variables were conceptualised to indicate that a parent was still in grieving. These variables were the presence of intrusive thoughts and avoidance behaviours related to the child's disability, and the distress when recalling the time of the child's diagnosis. The results showed the presence of parents' grief over time, and significant gender differences in which mothers showed higher levels of intrusive thoughts and avoidance behaviours and were more distressed at the time of the diagnosis than fathers. The researchers concluded that grief was an ongoing feature of having a child with a disability and was more intense for mothers than fathers.

The concept of 'chronic sorrow' informs us continuous support needs of parents of children with a disability throughout their lives, however, it may result in a professionals' pessimistic view toward parents' experience of having a child with a disability.

2.2.3 Cyclical Grief Model

Other researchers propose the cyclical grief model of parents' adaptation to having a child with a disability. This model combines the stages model and the chronic sorrow concept, and seems to be more flexible and articulate than the previous models in explaining parents' complex and individual emotional reactions to having a child with a
disability. Anderegg et al. (1992) in Georgia, U.S., developed a visual representation of the grieving model based on the primary researcher’s observation in working with two support groups for parents of children with a disability, consisting of totally 130 parents. The researchers considered that these parents moved through a grief cycle with a single entry and no exit through three phases (Figure 2.2).

![Cyclical Grief Model Diagram](image)

**Figure 2.2 Cyclical Grief Model**

The circle has a single entry point and no exit with three distinct phases Confronting, Adjusting, and Adapting: (Anderegg et al. 1992)

In this model, the responses of Shock, Denial, Blame, and Guilt form the first phase (Confronting); the responses of Anger, Depression, and Bargaining form the second phase (Adjusting); and Life-style Changes, Realistic Planning, and Altered Expectations form the third phase (Adapting). The researchers supposed that these parents regress in their movements and are usually at different points in the grieving process, and thus should be supported in accordance with their individual needs.
Similarly, Worthington (1994) suggested the cyclical grief model as more appropriate to explain parents’ adaptation to having a child with a disability than the linear grief model (i.e. the stages model). In his view, the linear grief model (Figure 2.3) assumes that: the future is generally knowable; an individual will “get used to” the cause of grief; adaptation is time-bound accompanied by a series of stages; and the source of grief will ultimately no longer be physically present.

![Figure 2.3 Linear Grief Model (Worthington, 1994)](image)

The model shows progression from
A: “Normal” emotional state to
B: Grief event to
C: Emotional “low” point to
D: Reminder events to
E: Grief completion or resolution

On the other hand, the cyclical grief model (Figure 2.4) suggests that: parents go through a series of continual adjustments to recurring, sometimes predictable, stressful life events relating to the child’s disability.
The cyclical grief model enables professionals to understand changes and recurrences of parents’ emotions over time, and predicts that certain events are likely to provoke parents’ grief. It also informs parents that grieving is a coping mechanism with positive implications and that recurrence of grief is natural.

2.2.4 Discussion

The grief models provide possible explanation of parents’ emotional experience of having a child with a disability, and may have an impact on professionals’ views toward these parents and the provision of services for them.

The stages model deepens professionals’ understanding of parents’ emotional reactions to the diagnosis of their child’s disability. Bloch (1996) states that professionals may experience less anxiety themselves and be better prepared in the informing interview by understanding a broad range of parents’ emotional reactions. This model, yet, fails to
consider individual differences of parents’ adaptation in its intensity, order and pace, and seems to mislead professionals to believe parents’ adaptation will be ultimately completed or discount parents’ life-long experience of having a child with a disability. This may result in professionals’ failure to meet continuous support needs of these parents. Further, the model may cause parents’ feeling of inadequacy as they may think of recurrences of grief as a breakdown in their adaptation.

The chronic sorrow concept draws professionals’ attention to continuous support needs of parents throughout their lives. It may, however, give a false impression that parents’ adaptation is a static state of suffering, and fails to recognise strengths or resilience of an individual family. This concept may, as a result, contribute to a professionals’ pessimistic view toward parents’ experience of having a child with a disability.

The cyclical grief model seems to be more flexible and articulate in explaining parents’ complex and individual emotional reactions to having a child with a disability. This model explains changes and recurrences of parents’ emotions over time, and predicts that certain events are likely to provoke parents’ grief. It also reassures parents that grieving is a coping mechanism with positive implications and that recurrence of grief is natural.

2.3 Inconsistent Findings of the Impact of a Child with a Disability on the Family

The grief models discussed above attracted professionals’ attention to the impact of a child with a disability on the family unit. These models view parents of children with a disability have special needs and difficulties, and inevitably experience extraordinary stress pertaining to the child. Studies generally found that the child had adverse effects
on his/her family's financial situation (Barnett & Boyce, 1995) and social life (Harris & McHale, 1989). However, studies that examined the impact of the child on his/her parents' psychological well-being or marital and family relationships often reported inconsistent findings, with some failing to find any adverse effects of the child.

The inconsistent findings in the literature regarding the impact of children with a disability on their families are reviewed in the following section.

PSYCHOLOGICAL WELL-BEING

Parents of children with a disability are, as discussed previously, thought to experience grief at the diagnosis of their child's disability. This event potentially has negative effects on their psychological well-being. Nevertheless, the literature on the impact of the child on his/her parents' psychological well-being is inconclusive.

Kazak & Marvin (1984) in Virginia, U.S., reported that mothers of children with spina bifida showed a higher level of stress compared with mothers of children without a disability. Fifty-six mothers of children with spina bifida who attended a paediatric orthopaedic unit were asked to volunteer. Fifty-three mothers in the control group were recruited through local paediatricians, general paediatric clinics and a newspaper advertisement. The results showed that mothers of children with spina bifida experienced a higher level of stress, spending significantly more time for childcare at bedtime and less time on themselves and with their spouses than did mothers in the control group. The findings of this study may, however, need to be seen cautiously because of a significant group difference in family income, with a significantly lower
income in families of children with spina bifida. This may have resulted in a higher level of stress in these families.

Breslau & Davis (1986) conducted a large comparison study in Detroit, U.S., and found no difference in the morbidity of clinical depression between mothers of children with a physical disability and mothers of children without a disability. A total of 310 mothers of children with a disability were selected from four paediatric clinics, and 357 mothers in the control group were randomly selected from all families residing in the area. Mothers in both groups were interviewed and completed a questionnaire at home.

The results showed no group difference in the number of mothers with clinical depression. However, the onset of clinical depression in mothers of children with a disability was significantly earlier than in mothers in the control group. In addition, mothers of children with a disability often attributed the onset of their first severe depressive episode to the child’s birth. Furthermore, despite no difference in the morbidity of clinical depression, mothers of children with a disability reported depressive symptoms twice as frequently as did mothers in the control group, resulting in a statistically significant difference. This finding remained when mothers’ education, family income, and racial composition were matched.

Here, it may be useful to distinguish clinical depression from depressive symptoms. Clinical depression is regarded as a mental illness that is usually incapacitating, while depressive symptoms indicate that a person feels unhappiness and has a lack of energy but continues to function in social roles. This state is called ‘demoralisation’ and is
characteristic of people under enormous stresses (Dohrenwend et al., 1979 cited in Singer & Irvin, 1989).

In contrast, Romans-Clarkson et al. (1986) in Dunedin, New Zealand, found a higher psychiatric morbidity in mothers of children with a disability than mothers of children without a disability. Of parents whose children attended three preschool facilities for children with a disability, 54 mothers and 43 fathers returned a questionnaire. The children had an intellectual or physical disability, or a combination of both. Parents of children without a disability who attended mainstream preschools were also distributed the questionnaire when they collected their children. A total of 184 mothers and 132 fathers returned the questionnaire by mail.

The results indicated that mothers of children with a disability reported significantly more psychiatric symptoms than did mothers in the control group, even after matching for social class and employment status. Unlike mothers, there was no group difference in frequencies of psychiatric symptoms in fathers.

Dyson conducted a series of comparison studies (1991, 1993 & 1997) on parents’ stress in families of children with a disability in Victoria, Canada. The original study (Dyson, 1991) compared 55 families of children with a disability and 55 families of children without a disability, and found a significantly higher level of stress in families of children with a disability. Families of children with a disability were contacted through early childhood special education programs and disability service agencies. The children’s disabilities included intellectual, physical and sensory disabilities. Families of children without a disability were recruited through regular preschools, daycare centres,
and primary schools in the same areas. The groups were matched for the age of child, socioeconomic status (SES) and family structure, with a majority of families being a two-parent household with middle SES. The only group difference was maternal education in that mothers of children with a disability had significantly less formal education than did mothers in the control group. Parents who agreed to participate were sent questionnaires investigating family stress and family functioning.

The results indicated that parents of children with a disability scored significantly higher on family stress than did parents in the control group, suggesting a higher level of stress in families of children with a disability. Their stress was especially related to childcare problems, parents' pessimistic views, and negative perception of the child's limitations. Little group difference, however, was found in the score of family functioning. In general, families with middle SES are regarded as being free from economic and social disadvantages. Nevertheless, the results of the study showed that middle-SES families of children with a disability did have a higher level of stress than their counterparts, indicating support needs for these families regardless of their SES.

In a 1993 study, Dyson followed-up 38 families of children with a disability and 34 families of children without a disability from the original study. At follow-up, a significant group difference in maternal education remained, and mothers in the control group were significantly more employed. The questionnaires were the same as those used in the original study, and were completed by the same parents who took part in the original study. The results indicated that there was no significant change over time in parents' stress and family functioning in families of children with a disability. At both periods these families had a significantly higher level of stress than did families in the...
control group, while their family functioning was similar in quality to that of families in the control group.

In the third study, Dyson (1997) further followed-up 30 families of children with a disability and 32 families of children without a disability from the original study. Statistical tests were performed to determine whether the sample was representative of the original one, with a result confirming this. The questionnaires used in the original study plus a questionnaire of family's social support were sent and completed by both parents in each family. The findings of this study again strengthened the previous finding that families of children with a disability had a significantly higher level of stress than did families in the control group.

The findings of Dyson's studies may, however, need to be taken cautiously as a majority of families in these studies were from two-parent households with middle SES and all had received early intervention programs.

MARITAL AND FAMILY RELATIONSHIPS

There is some evidence in the literature that differences exist between the maternal and paternal roles. In general, fathers assume a breadwinner role, whereas mothers usually play a primary caregiver role. While the sex difference in parenting roles is common, Kazak & Marvin (1984) found that this was somewhat more remarkable in families of children with a disability. In some cases, as described in an anecdotal study by Kratochvil & Devereux, (1988), the father may not be available to support the mother due to his own distress, and may withdraw from the situation, turning to work or outside activities, leaving the mother responsible for the child. In addition, as shown in the
study by Damrosch & Perry (1989, for details of this study, see p.21), mothers and fathers may differ in style and pace of their adaptation process. It is supposed that these sex differences of parents in degree of their involvement with the child and in their adaptation process can place additional stress on marriages.

In an early study conducted in Seattle, U.S., Friedrich & Friedrich (1981) found a significantly lower level of marital satisfaction in 34 families of children with a disability compared with 34 families of children without a disability. The children had an intellectual or physical disability, or a combination of both. The families were randomly selected and did not differ in the age of the child, SES and maternal age.

The findings of other studies seem to conflict with this. Longo & Bond (1984) reviewed the literature and found that the incidence of divorce and separation in families of children with a disability was not significantly higher than national norms, and that the quality of marriage in the families appeared to remain stable regardless of the child’s disability.

Even positive effects of a child with a disability on marital relationship were reported by Kazak & Marvin (1984, for details of this study, see p.28). This study found that a child with a disability strengthened his/her parents’ marital relationship.

Similarly, in the study conducted by Taanila et al. (1996) in Oulu, Finland, a majority of parents of children with a disability or diabetes mellitus reported no adverse effects of the child on their marital relationship. The children were 14 to 17 years of age, and had an intellectual or physical disability, or diabetes mellitus. A total of 89 families,
consisting of 88 mothers and 74 fathers, were recruited from registries of a university hospital and organisations for children with a chronic illness or a disability. These organisations were thought to cover a study population of all children with one of these three conditions in the area. The parents were sent and returned a questionnaire for the family demographic, and then interviewed. The results indicated that for 70% of the parents (n=62) the quality of their marital relationship had either remained unchanged or changed positively. The reminder (n=22, 25%) reported adverse effects in some areas of marital relationship, while only 7% (n=6) felt that they had drawn apart from each other. The study, however, failed to identify validity and reliability of the interview procedures, possibly limiting the applicability of the findings.

Dyson (1997, for details of this study, see p.32) found no difference in stress between mothers and fathers of children with a disability, and no difference in family functioning between parents of children with a disability and parents of children without a disability.

An Australian study conducted by Kearney (1996) in Sydney, reported positive impacts of a child with a disability on his/her family. The researcher questioned prevalent negative views of professionals regarding parents’ experience of having a child with a disability, which conflicted with her own professional experience as a community nurse working with families of children with a disability. Six parents of children with a developmental disability, who had had a previous contact with the researcher through her nursing practice, took part in the study and were interviewed privately. Although the parents acknowledged sorrow as the integral part of their experience, they did report positive aspects of parenting the child. They felt: the existence of the child, not dying,
as a source of joy; 'little things' becoming special and serving as a source of joy; and their experience in parenting the child resulting in new perspectives and strengths.

Similar findings were reported by Stainton & Besser (1998) in Montreal, Canada. Seventeen families of children with an intellectual disability were recruited from membership lists of local parents' associations. Two group interviews and two individual family interviews were conducted to investigate whether there were any positive contributions made by the child despite difficulties and negative impacts. Nine major themes identified by the families were: source of joy and happiness; increased sense of purpose and priorities; expanded personal and social networks and community involvement; increased spirituality; source of family unity and closeness; increased tolerance and understanding; personal growth and strength; and positive impacts on others and the community.

Studies examining effects of a child with a disability on siblings have also led to contradictory findings. It is common to view siblings bearing feelings of resentment toward parents for insufficient attention and toward the child with a disability for being the focus of attention, as well as anger, embarrassment, and guilt for having these negative feelings.

Breslau & Praducki (1987) conducted a large comparison study in Detroit, U.S., and found adverse effects of children with a disability on their siblings. A total of 192 siblings of children with a disability and 284 age-matched children who had siblings without a disability were involved in the study. Subjects and sampling procedures were the same as described previously (Breslau & Davis, 1986, for details of this study, see
Longitudinal data were obtained from mothers of children in both groups at the primary researcher’s earlier study (Breslau, Weitzman & Messenger, 1981) as well as at the follow-up study by the use of questionnaires. In addition, data on children’s psychological well-being, the rate of clinical depression and the level of depressive symptoms, were collected in the interview with children in both groups at follow-up.

Mothers’ report revealed that the siblings of children with a disability maintained the initial excess of tendencies in the aggressive domain: conflict with parents; fighting; and delinquency, and showed increases in the domains of depression and isolation, which were the areas where the siblings in the control group indicated no change. Moreover, while despite no group difference in the rate of clinical depression, the siblings of children with a disability reported significantly more depressive symptoms than did the siblings in the control group. The applicability of the findings may, however, be limited due to the use of mothers’ report as a measure of children’s behavioural and emotional tendencies.

On the other hand, Bischoff & Tingstrom (1991) in Nebraska, U.S., reported no apparent negative effects of children with a disability on psychological and behavioural characteristics of their siblings. Sixteen siblings of children with a disability were compared with 16 siblings of children without a disability. The children with a disability were receiving special education services through the public school system. Their disabilities included intellectual, physical and sensory disabilities. Mothers of children in both groups were asked to participate in the study through the public school system by letter. Those who agreed to participate were sent a child’s behaviour checklist and a sibling relationship questionnaire to complete and return by mail. Following this,
one of the researchers met with each child individually, and administered questionnaires on sibling relationship, and self-esteem. No significant group differences were found on measures of sibling relationship, behaviour, or self-esteem. The findings of this study should, however, be taken with caution as a majority of the siblings were from middle to high SES families and may have been exposed to less stress related to the family’s financial and instrumental resources.

Positive contributions of children with a disability on their siblings are often reported in sibling narratives and anecdotal literature (Klein, 1972; Sullivan, 1979), but such findings are rarely reported in empirical studies. Of the few investigators who reported positive effects in empirical literature, Ferrari (1984) in Delaware, U.S., found that siblings of children with a disabling condition demonstrated a higher level of social competency than did siblings of children without a disabling condition. The study examined adjustment among three groups of siblings, who had a brother with autism or diabetes, or without a disabling condition, by the use of multiple measures. A total of 48 siblings and their 96 parents were involved in the study. Three groups did not significantly differ in SES or family size.

The results indicated that the siblings of children with autism or diabetes scored significantly higher on social competency than did the siblings of children without a disabling condition. Moreover, during interviews mothers often mentioned positive effects of children with a disabling condition on their siblings, including the development of the siblings as compassionate, understanding individuals. However, the applicability of the latter finding may be limited due to the reliance on mothers’ report rather than siblings’ report.
In summary, the literature on the impact of a child with a disability on his/her family is inconclusive. These studies tend to see families of children with a disability alike, and rarely consider strengths of the individual family. The studies, moreover, focus on a specific family member, and rarely view the family as a system when examining the impact of a child with a disability.

2.4 Development of the Family Stress and Coping Models

As shown in the previous section, the literature reports inconsistent findings in that some families experience no apparent adverse effects of having a child with a disability, while others do experience adverse effects resulting from this. What makes this difference? It is generally supposed that stability of the family prior to the crisis is a predictor of an outcome. A child with a disability tends to intensify strengths and weaknesses of the family (Briskin & Liptak, 1995).

Researchers sought factors that affect the family’s adaptation to having a child with a disability, and found that certain factors predict their adaptation (Scorgie et al. 1998).

The level of the family’s stress appeared to have relation to the severity of the child’s disability (Donovan, 1988) as well as natures of the disability such as: uncertainty of diagnosis and prognosis (Miller et al., 1992); pervasiveness of the disability (Donovan, 1988); intellectual level (Barakat & Linney, 1992); communication problems (Frey, et al., 1989); lack of progress (Hancock et al., 1990); and caretaking demands (Dyson, 1991 & 1993). Socioeconomic status (SES) of the family also seemed to bear relation to the family’s adaptation to having a child with a disability. Families with higher SES showed a greater level of marital satisfaction (Willoughby & Glidden, 1995) and had
more varied support networks (Barakat & Linney, 1992), while families with lower SES indicated fewer coping strategies (Flynt & Wood, 1989).

Although these factors may affect the level of the family’s stress, they have little practical usefulness for intervention because they are generally unchangeable (Scorgie et al. 1998). As a result, researchers came to examine factors that can be changed to enhance the family’s adaptation to having a child with a disability. Thus, the focus of study has shifted from the impact of a child with a disability on the family to the coping of the family.

The family stress and coping models were developed to explain how a family copes with various stressful life events (Friedman, 1992). These models emphasise the importance of the relationship between a family and a stressful event, and regard the family’s resources and coping strategies as important factors of an outcome of the event. The models offer possible explanations of individual differences of the family’s adaptation to having a child with a disability. Within the family stress and coping models, health care professionals can see themselves as a resource for the family and help the family maximise their resources and coping strategies to deal with the event. Crisis Theory, the ABCX Model, the Double ABCX Model, and the Family Adjustment and Adaptation Response (FAAR) Model, are examples of the family stress and coping models. In the following section, these models are discussed in relation to the family’s adaptation to having a child with a disability.
2.4.1 Crisis Theory: Caplan (1961)

Caplan (1961, p.18) defined ‘crisis’ as a state that exists:

“...when a person faces an obstacle to important life goals that is, for a time, insurmountable through the utilization of customary methods of problem solving. A period of disorganization ensues, a period of upset, during which many different abortive attempts at solution are made.”

A crisis can result in one of three outcomes: improved level of functioning; pre-crisis level of functioning; and decreased level of functioning. The progression of a crisis is described through four phases (Figure 2.5).

![Diagram of Crisis Phases]

Figure 2.5 Phases of Crises (Graves & Lancaster, 1992, p.623)
Adapted from Caplan’s Crisis Theory (1961)

In the first phase, a problem is encountered, and tension increases. This causes a person to recall coping strategies that have been successful in the past. When the past coping...
strategies are unsuccessful in solving the problem, the second phase follows, with a further rise in tension. The person in the second phase may experience psychological and physiological symptoms and impaired ability to function. In the third phase, another rise in tension stimulates the person to mobilise internal and external resources, and to try new coping strategies. If the strategies used in this phase are successful, the problem will be resolved and the person will either regain the pre-crisis level of functioning or move to an improved level of functioning. If the strategies are not successful, the fourth phase follows. In this final stage, if the problem continues and cannot be solved or avoided, tension further increases leading to a decreased level of functioning with a risk for major disorganisation.

Having a child with a disability may result in a crisis if the family lacks sufficient resources and effective coping strategies. The family in a crisis often feels helpless and feels they have lost control over their lives. They are both particularly vulnerable and particularly responsive to help. Crisis theory suggests that most crises are temporary and last between four to six weeks, indicating that the resolution is reached within a relatively short period of time. It also assumes that if an earlier experience of a crisis is severe or traumatic, the reaction to later crises will be distorted or exaggerated. These indicate that the family of a child with a disability must be provided with appropriate intervention immediately after the child’s diagnosis.

Based on Crisis Theory, researchers developed some intervention frameworks. Aguilera (1990) established a framework of crisis intervention, which aims to assist the family to resolve the immediate crisis and restore at least the pre-crisis level of functioning, with the ideal goal of gaining an improved level of functioning. The basic framework for this
intervention is a problem-solving approach within which the family is encouraged to develop support networks and new coping strategies. Coping strategies that have been beneficial are reinforced and assistance is provided to make realistic plans for the future.

Ormerod & Huebner (1988) also presented an intervention framework for school psychologists working with parents who have been told of their child’s disability. The goals of the intervention include: developing a supportive relationship with parents; minimising negative outcomes; and providing links with non-school services.

2.4.2 ABCX Model: Hill (1949)

Hill (1949 cited in Mederer & Hill, 1983) established the earliest conceptual foundation of the process of the family’s adaptation to a ‘stressor event’. The ABCX model identifies intervening variables that account for individual differences of the family’s adaptation (Mederer & Hill, 1983, p.45):

“A (the stressor event)--- interacting with B (the family’s crisis-meeting resources)--- interacting with C (the definition the family makes of the event)--- produces X (the crisis).”

The A factor (the stressor event) is a problem situation that causes change in the family system. This change has an impact on various areas of family life such as its boundaries, goals, patterns of interaction, roles, or values (McCubbin & Patterson, 1983). A stressor event, for example, is a diagnosis of a child’s disability.
The B factor (the family's resources) is the family's ability to accommodate and adapt to the stressor event. Sloper & Turner (1991, p.18-19) identified three types of resources:

- "Physical and material resources (e.g. health, finance, employment, housing),
- Social and family resources (e.g. informal social networks, support systems, formal support from services, family environment, marital relationship), and
- Psychological resources (e.g. personality, control orientation, problem-solving skills and strategies)."

It is recommended to include ‘family functioning’ under the ‘social and family resources’ in the above classification. Family functioning is an essential concept of the family system theory, and may offer possible explanations of individual differences of the family’s adaptation to a stressor event. The family system theory views a family as a...
complex open system in that each member influences and is influenced by the other members, at the same time the member or a family itself interacts with its surrounding environments to achieve growth and change (Friedman, 1992). Within this theory, the family’s ability to accommodate and adapt to a stressor event is related to the degree of ‘cohesion’ and ‘adaptability’ of the family, which are two central components of family functioning. Cohesion refers to the emotional bonding that family members have toward each other, the degree of which is characterised in a continuum ranging from enmeshed to disengaged. Adaptability refers to the family’s ability to change in response to a stressor event, the degree of which is characterised in a continuum ranging from rigid to chaotic (Olson, 1988). According to Olson (1988), families existing in the middle of the continuum of these dimensions are found to be well functioning.

The C factor (the family’s perception of the event) reflects the family’s value system and their previous experience in dealing with stressor events. According to Lazarus (1993), the perception of a stressor event is more important than the event itself. This perception includes potential harms, threats, and challenges as well as the family’s perceived ability to cope with it. Not all families experience a crisis through a stressor event, and their definition of the event may in part determine whether the event becomes a crisis. If the family defines the event as threatening and harmful, the possibility of their experiencing a crisis increases.

The X factor (the crisis) reflects the family’s inability to restore balance in the family system. The three factors: (A) the stressor event; (B) the family’s resources; and (C) the family’s definition of the event, all affect the family’s ability to solve a problem situation caused by the event. McCubbin & Patterson (1983) stated that an event might
never be a crisis if the family can use existing resources and defines the event as manageable.

2.4.3 Double ABCX Model: McCubbin and Patterson (1983)

McCubbin and Patterson (1983, p.90) suggested the Double ABCX Model that adopted Hill’s ABCX Model as its foundation and included four additional factors to explain the efforts that a family makes over time to manage stressor events:

“(aA) the pile-up of additional stressors; (bB) family efforts to activate or acquire new resources; (cC) modifications by the family of their perception of the total crisis situation; and (xX) the role of family coping strategies in bringing about immediate adjustments and eventual adaptation.”

Figure 2.7 Double ABCX Model (McCubbin & Patterson, 1993 p.91)

The left half of the figure depicts the pre-crisis situation, and the right half depicts the post-crisis situation (for details, see text)
McCubbin & Patterson assumed that most families deal with one or more stressor events simultaneously. The left half of Figure 2.7 depicts the pre-crisis situation, a, b, c, x, corresponding to Hill’s model of A, B, C, X factors. The right half of the figure, on the other hand, depicts the post-crisis situation, aA, bB, cC, xX are the additional post-crisis factors which account for;

- "additional life stressors and strains which may make family adaptation more difficult to achieve;"
- the critical psychological, intrafamilial, and social factors families use in managing crisis situation;
- the processes families engage in to achieve satisfactory resolution; and
- the outcomes of these family efforts.”

(McCubbin and Patterson, 1983, p.90-92)

The aA factor (the pile-up of stressors) occurs especially in the aftermath of a major change in the family system. Additional stressors may emerge from individual family members, the family system, the extended family or the surrounding community. For example, after the diagnosis of their child’s disability, parents may suffer from the pile-up of stressors that emerge from care demands of the child, medical and therapeutic needs of the child, grief reactions to the loss of an ideal child, uncertainty regarding the child’s condition, interaction with professionals and strain from recent life events.

The bB factor (existing and new resources) is the family’s attempt to meet demands resulting from the crisis calling on existing resources, and expanding new resources. For example, the parents may call friends and grandparents for emotional and practical
support. At the same time, they may come into contact with other parents in a support group to obtain information and share emotional experience.

The C factor (the family’s perception of the total crisis situation) reflects the family’s value system and their previous experience, and is influenced by the family’s belief about what caused the original crisis, the presence of additional stressors, and old and new resources the family is using to cope with the current situation. The family’s perception of the situation is also influenced by their interactions with others, such as grandparents and close friends. If those people define the family’s situation positively, the family also tend to define it positively (Darling, 1991a).

The X factor (the outcome of the stressor events) reflects the interaction between all previous factors. Failure to resolve the crisis or to facilitate change and growth in the family system results in maladaptation. This X factor is reminiscent of Caplan’s theory of the three outcomes of crisis. In their model, McCubbin & Patterson (1983) also identify three outcomes of the crisis that are bonadaptation [sic], adaptation and maladaptation.

The Double ABCX Model suggests that two intervening variables, the family’s resources and the family’s perception of the stressor event, are major mediators in the family’s adaptation to the event. Studies have examined causal relationships among variables to evaluate credibility of the model (e.g., Orr et al., 1991).
Patterson (1988) incorporated the Double ABCX Model into a process model, called the Family Adjustment and Adaptation Response (FAAR) Model. This model also consists of three domains: sources of stress, mediators of stress, and outcomes of stress. The sources of stress are called demands. The mediators of stress are called capabilities. Both demands and capabilities can emerge from individual family members, the family unit, or from the community. The underlying assumption of this model is that a family makes efforts to maintain balanced functioning in the family system by using its capabilities to meet its demands. Within this model, stress is defined as a family’s response to an imbalance between demands and capabilities. The meanings that the family attaches to a situation are a critical factor in achieving balanced functioning. The outcomes of the family’s efforts to achieve balanced functioning is called family adjustment or family adaptation, both ranging on a continuum from good to poor.

Demands (sources of stress) produce or call for changes in the family system. There are three types of demands: stressors; strains; and daily hassles. Stressors result from both normative life events (e.g. marriage, birth of a child) and non-normative life events (e.g. disaster, acute illness, death of a family member). A birth of a child with a disability is, for example, a normative as well as non-normative life event casting extraordinary stress on the family. Strains are ongoing tensions emerging from prior stressors or enacting life’s roles. An example of strain is a parent’s feeling overloaded in caring for a child with special needs. Daily hassles are minor upsets to daily routines such as losing car keys, which can place additional stress on the family. Most families deal with one or more demands at one time in the form of a combination of stressors, strains, and
daily hassles that create a pile-up of demands. These factors also interact with each other. Stressors can increase family strains, for example, when a child is diagnosed with a disability, marital conflict may deteriorate as a mother and a father manage this new demand in different ways.

**ADJUSTMENT PHASE**

![Diagram showing the ADJUSTMENT PHASE of the Family Adjustment and Adaptation Response (FAAR) Model.](image)

**ADAPTATION PHASE**

![Diagram showing the ADAPTATION PHASE of the Family Adjustment and Adaptation Response (FAAR) Model.](image)

*Figure 2.8 Family Adjustment and Adaptation Response (FAAR) Model (Patterson, 1988 p.209)*

*CHAPTER 2 THEORETICAL FRAMEWORK OF THE STUDY*
Capabilities (mediators of stress) are used to meet demands in the family. Patterson (1988) emphasised two types of capabilities that are resources and coping behaviours. Resources are what the family has, including both tangible (e.g. money, health care services) and intangible (e.g. self-esteem, health, education). Many resources are not innate in an individual or a family but acquired over time, usually in response to demands, and need to be maintained or fostered to prevent depletion both in quantity and quality. The pattern of family functioning can be resources as well as demands depending on the nature and quality. Social support is a range of material and emotional supports from others, and acts as a buffer against stress. Coping is the behavioural component of capabilities; it is what the family does to meet its demands. Families who have a variety of coping behaviours are more likely to maintain a balance in family functioning than families with only one repertoire of coping behaviour. Patterson (1995) identified five patterns of coping behaviours, these are: reducing family demands; increasing family resources; maintaining and allocating resources; managing personal and internal tension; and changing the perception of the situation.

Meanings (a critical factor in achieving a balance) that the family attaches to a situation, consisting of three levels, these are the family's perception of the situation, their identity as a family, and their view of the world. The family develops positive meanings of the situation (demands and capabilities) as a way of coping. Demands are often generated from subjective definition (e.g., role strain associated with unrealistic expectations). Similarly, many capabilities are the result of subjective appraisal (e.g., self-esteem). The family’s identity emerges from their values, and is developed and maintained through their routines and rituals. When major stressors occur in the family system, their routines and rituals may be disrupted and their values may be modified. The family’s
world view is based on their interpretation of reality and life purpose, including cultural and religious beliefs. It may influence the way the family chooses to deal with changes, whether they believe in their own ability to solve problems, and their receptiveness to new information. The family is particularly vulnerable when both their world view and identity are seriously threatened. When the family fails to establish a new identity, they are at risk of malfunctioning.

Family Adjustment and Family Adaptation (outcomes of stress) are the two phases composing this model, through which the family makes efforts to achieve balanced functioning. The adjustment phase is relatively stable through which the family deals with relatively minor demands. A crisis occurs when the demands surpass the existing capabilities and this imbalance persists. Through the adaptation phase, the family attempts to maintain balance in the family system in dealing with more intense or complex demands by using their existing and acquired capabilities.

In summary, the family stress and coping models provide possible explanations of inconsistent findings in the literature regarding the impact of a child with a disability on the family in that some reported the presence of the child strengthened them, whereas others reported it completely shattered them. These models seem to support Briskin & Liptak’s (1995, p.264) assumption that “strong families become even stronger in the face of such a crisis, and more fragile ones may disintegrate or may be riddled with conflict”.

The family stress and coping models give us a better understanding of the family’s coping with various stressful life events, and inform factors that can be changed to
facilitate the family's adaptation to these events. Within these models, health care professionals can see themselves as a resource for the family and help them enhance their resources and coping strategies to deal with demands resulting from stressful life events.

2.5 Conclusion

It is essential for health care professionals to understand possible parents' adaptation to having a child with a disability in order to support parents effectively at the time around the diagnosis of their child's disability.

The grief models provide possible explanation of parents' emotional experience of having a child with a disability, and may affect professionals' view toward these parents and the service provision for them.

The stages model deepens professionals' understanding of parents' emotional reactions to the diagnosis of their child's disability. Thus, it may help professionals better prepare in dealing with parents at the interview informing of their child's disability. It, however, fails to explain individual differences of parents' adaptation, and seems to mislead professionals to believe parents' adaptation will be ultimately completed, and discounts parents' life-long experience of having a child with a disability.

The chronic sorrow concept draws professionals' attention to continuous support needs of parents of children with a disability. It, however, assumes that parents' adaptation is a static state of suffering, and fails to recognise strengths of an individual family. It may, as a result, contribute to a professionals' pessimistic view toward parents' experience of
having a child with a disability, which can affect the family’s perception of the situation and consequently their adaptation.

The cyclical grief model seems to be more flexible and articulate in explaining parents’ complex and individual emotional reactions to having a child with a disability. This model explains changes and recurrences of parents’ emotions over time, and predicts that certain events are likely to provoke parents’ grief. It also reassures parents that grieving is a coping mechanism with positive implications and that recurrence of grief is natural.

The literature of the impact of a child with a disability on the family is inconclusive. Past researchers tended to see these families alike, focusing on a particular family member, and failed to see individual strengths of the family. They sought factors that affect the family’s adaptation to having a child with a disability, and found that certain factors, such as severity and nature of the disability or the family’s socioeconomic status, seemed to predict the outcome of the family’s adaptation. These factors may affect the level of the family’s stress, yet have little practical usefulness for intervention as they are generally unchangeable.

The family stress and coping models see a family as a system that deals with stressful life events over time. These models emphasise the importance of the relationship between a family and a stressful life event, regard the family’s resources and coping strategies as important factors of an outcome of the event, and provide possible explanations of individual differences of the family’s adaptation to having a child with a disability.
Crisis Theory (Caplan, 1961) assumes that a crisis will result in one of the three outcomes, and most crises are temporary, lasting between four to six weeks. These assumptions explain individual differences in outcomes of stressful life events across families, and inform the need of immediate intervention to the family after the diagnosis of their child’s disability. This theory, however, fails to identify factors contributing to the family’s adaptation, thus somewhat limits its practical usefulness in developing specific intervention strategies within its framework.

The ABCX Model (Hill, 1949 cited in Mederer & Hill, 1983) suggests the importance of the relationship between the family and the event, and seems to account for individual differences of the family’s adaptation to stressful life events. It identifies critical factors, the family’s resources and perception, which predict the outcome of the family’s adaptation. Because these factors are changeable, the model provides professionals with opportunities for intervention to facilitate the family’s adaptation. However, its focus on the family’s adaptation to a single life event discounts the impact of other life events that are making up the family’s current stress.

The Double ABCX Model (McCubbin & Patterson, 1983) allows a better understanding of complex interactions among factors in the family’s adaptation to successive stressful life events. It enables us to realise the impact of unresolved stressful events in the past on the family’s current stress. The model, however, fails to explain the family’s continuous efforts to meet demands that result from not only major life events but also relatively minor life conditions.
The FAAR Model (Patterson, 1988) conceptualises an insidious dynamic between demands and capabilities in the family system, which is intervened by meanings that a critical factor in achieving a balance. The model allows us to become aware that, besides major stressors, strains and daily hassles also can create additional demands in the family system that make up the family’s current stress. It informs that, by enhancing resources and coping behaviours or by changing perception, we can manage demands in our lives that we often regard as helpless or out of control.

There is no doubt that these models try to interpret the same reality: the family’s emotional experience of, and their adaptation to having a child with a disability, yet probably through different perspectives. From the researcher’s own experience as a registered nurse working with families of children with a disability, each of the models seems to be, to a greater or lesser degree, veracious in interpreting this reality, and their notions appear to complement each other. In this regard, the notions of these models must be integrated so as to develop a more accurate interpretation of the family’s emotional experience of, and their adaptation to having a child with a disability. Such integrated notions of the models may be as follows:

A diagnosis of a child’s disability causes intense emotional reactions in parents. They experience similar emotions, yet in unique ways and in unique sequences. Even well after the diagnosis, they may never completely accept their child’s disability, and go through a series of continual adjustments to recurring, sometimes predictable, stressful life events relating to the child’s disability. In each adjustment process, they may regress in their movements and each parent is usually at a different point in the process.
A family is a system that manages demands over time to maintain a balance in its functioning. The demands result from major stressful life events as well as minor life conditions, and the family deals with this using their resources and coping strategies. The family’s perception of the current situation is an important factor in achieving a balance. The diagnosis of the child’s disability may result in a crisis if the family has a large number of demands, their resources and coping strategies are insufficient or ineffective, or their perceptions of the situation are maladaptive. When the family experiences enormous stress, they are often vulnerable and unable to maintain and use resources. In the face of the magnitude of stress, self-esteem of members may be diminished, their physical and mental health may decline, integrity and morale may be decreased, communication patterns may be impaired, and social isolation may be manifest. Thus, the family may not have enough resources or may not be aware of existing resources at the very time they most need them.

This thesis uses the integrated notions of the models, which give us a better understanding of the family’s emotional experience of, and their adaptation to having a child with a disability. The integrated notions are practically useful for health care professionals to establish an intervention framework, as this identify factors that can be changed to facilitate the family’s adaptation. Within such an intervention framework, health care professionals can see themselves as a part of the family’s resource, and support them to enhance their resources and coping strategies, and change their perception of the situation to deal with demands in their lives more effectively.
3.1 Introduction

Professionals can be a major resource for families of children with a disability to achieve positive adaptation to their child’s disability. Nevertheless, these families consider the relationship with professionals as both a support and a source of additional stress (Stainton & Besser, 1998).

For many families, this relationship is first initiated at the time of the diagnosis of the child’s disability. This parents’ experience is thought to affect their future relationship with professionals and their adaptation to the child’s disability.

This chapter discusses the parent-professional relationship, sources of parents’ dissatisfaction with informing, and factors influencing professionals’ preparedness for their practice in informing. Unfortunately, these are neglected fields of professional practice, and this is reflected in the available literature: many studies used in the current study are not recent, with some even carried out decades ago. The majority were, moreover, conducted in the U.S., U.K., or Canada, with only a few taking place in Australia. Using studies that are not recent or were conducted in overseas may be
limiting to accurately grasp the current situation of informing practice in Australia, nevertheless, these do provide useful background and general information.

3.2 Parent-Professional Relationship

Parents of children with a disability need to unavoidably develop life long relationships with a variety of professionals because the nature of the child's disability often yields medical, therapeutic and educational needs. Professionals can be a major resource for parents, yet parents often see the relationship with professionals as a source of additional stress.

In Stainton & Besser's study (1998, for details of this study, see p.35) conducted in Canada, parents of children with an intellectual disability reported a high degree of negative interaction with professionals. All families expressed negative feelings toward professionals that were generally related to a professionals' pessimistic view to the family's situation, and their failure to recognise positive aspects of the family's experience of having a child with a disability.

Communication between parents and professionals is a reciprocal process. Parents are clearly responsible too, but it is professionals who are paid to develop a trusting,
constructive relationship with clients and their families (Madden, 1995). Several factors often interfere with communication between parents and professionals, including differences in their life experience, degree of involvement with a child with a disability, age, social class, ethnicity, and gender. Professionals, especially doctors, tend to be held in high esteem because of their high levels of education and socioeconomic status. Parents may be intimidated and hesitate to voice their concerns directly to professionals because of such perceived social distance, but also because of the traditional power-subordination relationship (Quine & Pahl, 1986). These taken all together may contribute to a strained parent-professional relationship as well as professionals’ unawareness of parents’ needs, further resulting in parents’ dissatisfaction with services.

3.3 Parents’ Dissatisfaction with Informing Practice

For the majority of parents of children with a disability, their first experience with professionals occurs at the time of the interview informing of their child’s disability. This may be one of several unpleasant tasks for professionals, while it may be the single most important event that happens to the family (Sablewicz & Kershaw, 1994). Professionals involved in the informing interview are in an important position because this event may affect the future parent-professional relationship (Clarkson et al., 1996) and parents’ adaptation to having a child with a disability (Wooley et al., 1989). If this
parents’ initial experience with professionals is negative, parents may fail to trust professionals as a whole and become reluctant to utilise them as a resource (Lian & Aloia, 1994).

Among different professional disciplines, health care professionals are often the first to come into contact with these families because the majority of disabilities are apparent soon after birth or during early childhood and require medical and therapeutic intervention. For example, according to Sharp et al. (1992), approximately 39% of families (n=74/189) in their study were informed of their child’s disability at birth, and a further 37% (n=70) learned of this during the first year of the child’s life. This indicates that health care professionals tend to be the informer of the child’s diagnosis.

Several studies reported a high level of parents’ dissatisfaction with informing, though interestingly, this appeared to be in a much lower level in a recent Australian study (Table 3.1). Although the finding of this study may suggest better informing practice in Australia than overseas or an improvement of the service, it should be used cautiously because of several limitations involved, such as a small sample size and a possible interviewer bias (Hasnat & Graves, 2000b, for details of this study, see p.88).
Table 3.1 Studies of Parents’ Dissatisfaction with Informing Practice

<table>
<thead>
<tr>
<th>Study</th>
<th>Parents Dissatisfied</th>
<th>Diagnosis of Children</th>
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</thead>
<tbody>
<tr>
<td>Cunningham et al, 1984 U.K.</td>
<td>59</td>
<td>Down syndrome</td>
</tr>
<tr>
<td>Quine &amp; Pahl, 1987 U.K.</td>
<td>190</td>
<td>Severe intellectual disability</td>
</tr>
<tr>
<td>McKay &amp; Hensey, 1990 Eire</td>
<td>84</td>
<td>Cerebral palsy</td>
</tr>
<tr>
<td>Sloper &amp; Turner, 1993 U.K.</td>
<td>107</td>
<td>Severe physical disability</td>
</tr>
<tr>
<td>Garwick et al., 1995 U.S.</td>
<td>43</td>
<td>Down syndrome and/or congenital heart disease</td>
</tr>
<tr>
<td>Hasnat &amp; Graves, 2000b AUS</td>
<td>23</td>
<td>A variety of disabilities</td>
</tr>
</tbody>
</table>

3.3.1 Dissatisfaction with Manner and Communication Skills of Professionals

Parents are most frequently dissatisfied with manner and communication skills of professionals involved in the interview informing of their child’s disability. They often remember vividly the way in which the diagnosis was imparted, and some are preoccupied with this for many years to come. Mothers of children with Down syndrome described their experience with professionals at the informing interview as follows:

“After I received the news, I secretly prayed that the genetic specialist was wrong. Even when she announced the diagnosis, I insisted that she explain to me just how sure she was. She explained that, based on her expertise, she was 98% certain of her initial diagnosis. I clung desperately to that small
2% of uncertainty, but somehow in my heart I was afraid that she was right. The joy we felt briefly as new parents was extinguished by a person who never even bothered to introduce herself to us by name. My life, my husband’s life, our marriage, and the lives of our children would never be the same again. From the moment we received the diagnosis, we would never again be a ‘normal’ family... Strange doctors, including the nameless genetic specialists, outsiders to our family, had just given us brutal news, wounding our family in the most personal way. To us, their clinical language and impersonal talk of statistics were weapons that threatened an innocent baby—more important, our precious baby! We huddled together to protect ourselves against the intense pain and grief we were experiencing.”— A mother of a child with Down syndrome (Moeller, 1986, p.149-151)

“The doctor came into the recovery room and all he said was, “Hey, man, I hate to lay this thing on you now, but your child is Down syndrome. She probably won’t even be able to do any more than dress herself.” I do know I will never forget the way he told us. It is burned into my memory forever.”— A mother of a child with Down syndrome (Sharp et al., 1992, p.541)
Similarly, Wooley et al. (1989) in Oxford, U.K., found that all parents in their study remembered the manner of professionals involved in the informing interview and in some cases this lived on for years. A total of 70 families of children with life threatening illness were interviewed about their experience at the child's diagnosis. In a pilot study, semi-structured interviews were carried out with 25 families who were attending a hospice for children with a chronic life threatening condition. The interviews were then administered to a further 45 families in the main study. The children's illnesses included cerebral degenerative disorders, brain tumour, neuromuscular disease, and other neoplasms. In twenty cases only mothers were interviewed, while in the remaining cases both parents were present.

In the interview, once the topic had been presented many parents spontaneously talked about their experience at the informing interview. Parents reported that professionals' manner in which they were told had affected their ability to cope with the child's illness. They valued an open, sympathetic, and direct manner that had helped them at the time and in their subsequent coping, while they disliked an evasive or unsympathetic manner, which had been deeply distressing at the time and lived on afterwards. Parents also appreciated when professionals made eye contact with them, greeted or addressed them by name and felt this generated both trust and a feeling of being respected. The study,
however, failed to identify sampling procedures used, possibly reducing the applicability of the findings.

Professionals may worry about being excessively involved with parents because an excessive involvement is believed to impair their instrumental effectiveness (Darling, 1991b). They may also suppress their own emotions, since showing these is regarded as unprofessional behaviour and weakens trust that parents place in the professional as a whole (Buckman, 1992). Consequently, professionals may try to maintain some emotional distance from parents (Hasnat & Graves, 2000a). According to Jacobs (1979), such emotional distance may in turn serve as a defence mechanism, protecting them from anxieties resulting from interaction with parents in distress. A mother of a child with cerebral palsy described her experience with a doctor at the diagnosis of her child as follows:

"The doctor simply stated the diagnosis, handed us some papers with general information... told us to institutionalise him, and walked out the door. We would like to have been treated like human beings." (Sharp et al., 1992, p.544)
Parents in Hancock et al.'s study (1990) also seemed to feel that professionals involved in the informing interview were emotionally distant. To investigate sources of problems in parenting a child with a disability, semi-structured interviews were conducted with 6 mothers of children with a visual impairment in Edmonton, Canada. The mothers were recruited through a local organisation for individuals with a visual impairment. One of major themes that emerged was a problem about the relationship with professionals at the time around the child's diagnosis. All but one commented that professionals seemed to be insensitive and unfeeling.

Studies suggest that parents generally expect professionals not only to be technically competent but also emotionally sensitive, sympathetic, and caring. When professionals failed to show these qualities, parents tend to be dissatisfied with the service they received. Sharp et al. (1992) in North Carolina, U.S., carried out a large study of parents' preferences for professionals' behaviours at the informing interview. A self-administered questionnaire was developed to elicit parents' preferences for professionals' behaviours at the time, which included a series of behaviours derived from observations of videotaped paediatric residents' practice in a hypothetical situation (communicating a diagnosis of Down syndrome). The questionnaire was piloted on 36 parents of children with a disability, and then refined in wording and content based on
their feedback. Parents of 566 children with a disability enrolling in 15 developmental
day care centres were contacted and distributed the questionnaire through the directors
of these centres. The questionnaires were completed by 189 parents who were
predominantly mothers (93%). The children's disabilities included an intellectual
disability, cerebral palsy, Down syndrome, other genetic syndromes, and other
disabilities.

The parents' strongest preference for professionals' behaviours at the informing
interview was a caring manner (n=183, 97%), followed by allowing parents to talk
(n=180, 95%), and allowing parents to show their own feelings (n=176, 93%). The
parents also wanted professionals to share more feelings with them than they had done
at the time. The predominant inclusion of mothers and the use of the questionnaire that
had not been validated may, however, limit the applicability of the findings.

The level of parents' satisfaction with the informing interview seems to be related to
manner and communication skills of professionals involved. Sloper & Turner (1993) in
Greater Manchester, U.K., conducted a large study of 107 families of children with a
severe physical disability. A total of 147 families was contacted through referrals from
paediatricians, heads of special schools and specialist health visitors in the area, and

CHAPTER 3. LITERATURE REVIEW
asked to participate in the study. Of those contacted, 107 families (73%) agreed to participate and were interviewed. The families’ social-class distribution did not significantly differ from national norms, and 22% were single-parent households. Based on the literature, potentially important variables in informing practice were identified, and then relationships between these variables and the level of parents' satisfaction were examined.

Data on parents' satisfaction with the informing interview were collected at home through semi-structured interviews with 103 mothers as well as using a self-administered questionnaire completed by 98 mothers and 72 fathers. The results indicated that only 40 parents (37%) were satisfied with the informing interview. There was a significant relationship between the level of parents’ satisfaction and manner and communication skills of professionals involved. Parents tended to be satisfied if professionals were sympathetic, understanding, approachable, direct, open to questions and communicated well.

Clarkson et al. (1996) in Otago, N.Z., investigated fathers’ experience at the informing interview, and found that fathers were often dissatisfied with poor communication skills of professionals involved. Fathers of children with a severe disability were recruited...
through publicity in a paper as well as newsletters of community disability services. Of 26 fathers who initially volunteered, a smaller sample of 15 was selected to cover a range of geographical and family circumstances. Semi-structured, in-depth interviews with fathers were carried out at home. All the interviews were audiotaped, transcribed and analysed using a computer software package for qualitative data analysis.

A major area of the fathers’ negative comments was related to poor communication skills of professionals involved in the informing interview. Professionals were evaluated negatively when they failed to demonstrate appropriate communication skills at this time, even though they were perceived to be technically competent. This initial experience with professionals appeared to live in the fathers’ memories for many years and have a long-term negative effect on their perception of the service.

Formerly, communication skills of professionals were referred to as the “bedside manner” (Wolraich, 1982) and until recently, were not recognised as an important aspect of professional education and training. Yet, since the 1970s its importance has begun to attract attention in the literature. There has been an increasing awareness that better communication skills of professionals enable them to gain a more accurate understanding of parents’ needs (Sloper & Turner, 1991a), and enhance parents’
satisfaction with services (Sharp et al., 1992; Sloper & Turner, 1993; Clarkson et al., 1996). Professional education and training now emphasise communication skills of professionals to interact with patients and their families more than ever, and reported successes in improving this through specific programs.

Levinson & Roter (1993) in Oregon, U.S., evaluated effects of such programs to improve communication skills of 51 doctors. They found an improvement of communication skills in 20 doctors who attended a long program (a two and a half days session) compared to 31 doctors in a short program (a four and a half hours session) with no such improvement. Data were collected through 5 sequential interactions between the doctors and patients in their offices both one month before and one month after the programs, and were audiotaped and analysed in terms of content and affect of the interactions.

After the program the doctors who attended the long program used more open-ended questions, provided more medical information, and listened to more patients’ opinions than did those in the short program. There was also a decrease in negative affect in their interactions with patients, with fewer symptoms of distress demonstrated by patients during the interactions. The small sample size and the use of a non-random sampling
method may, however, reduce the ability to generalise the findings. There may also be a possible performance bias as the doctors were informed that their interactions with patients were being audiotaped and evaluated.

Similarly, Vaidya et al. (1999) in Washington, U.S., reported an improvement of communication skills in paediatric intensive care fellows through a one-day training program at a university hospital. Subjects included 7 paediatric intensive care fellows and 4 standardised parents (SPs) who had received fifteen hours training in role-playing, performance evaluation, and giving feedback to the fellows. The program consisted of two sessions during which the fellows interacted with 2 sets of the SPs using two case scenarios of children admitted to the intensive care unit with a serious condition. When the first session was completed, the fellows were given feedback from the SPs. During the second session, the fellows interacted with a different set of the SPs using the other case scenario.

There was a significant improvement in scores of the fellows' communication skills between the first and second sessions. This finding may, however, need to be taken with caution because the small sample size may reduce the ability to generalise the finding. Moreover, the study only shows a short-term outcome, thus also possibly limiting the
3.3.2 Professionals' Perception Adversely Affecting Their Practice

In addition to manner and communication skills, professionals' perception of families of children with a disability and informing practice can also affect their practice. This professionals' perception may result in their pessimistic attitude, assumptions of parents' inevitable emotional distress and resultant dissatisfaction with informing, and reluctance to give sufficient information to parents.

Professionals’ Pessimistic Attitude

Parents often complain about a pessimistic attitude of professionals shown in informing practice. Professionals in general have a more pessimistic attitude toward having a child with a disability than families themselves.

Among professionals, doctors appear to be most pessimistic about abilities of individuals with a disability. Wolraich & Siperstein (1983) in Iowa, U.S.A., compared professional groups in their prognostic impressions of individuals with an intellectual disability. The researchers assumed that such professionals' prognostic impressions closely relate to their attitudes toward these individuals, and affect parents' expectations
for their child with a disability and their decisions regarding placement in a program.

A total of 168 professionals took part in the study, including paediatric practitioners, developmental paediatricians, special educators, psychologists, social workers, physiotherapists, occupational therapists, and speech clinicians. According to the researchers, developmental paediatricians are different from paediatric practitioners: the former have specific training in developmental disabilities and limit their practice to children with developmental disabilities. The paediatric practitioners were recruited from the Iowa Chapter of the American Academy of Paediatrics and other professionals were approached through courses held at the University of Iowa or university affiliated programs. A scale was developed to examine professionals’ prognostic impressions of individuals with an intellectual disability. It consisted of 30 items that were associated with functional abilities of these individuals.

There was a difference between the paediatric practitioners and the other professional groups in the mean score of each item of the scale. This suggested that paediatric practitioners were significantly more pessimistic about abilities of individuals with an intellectual disability, in mastering tasks that require basic perceptual and sensory motor skills, than the other professional groups. Additionally, developmental paediatricians
and special educators scored higher on the scale than the other professional groups. This indicated that professionals with training in disability tended to be optimistic about abilities of these individuals. The use of a non-randomised sample may, however, reduce the ability to generalise the findings, and the use of a scale that had not been validated may further reduce the applicability of the findings.

It is possible that doctors have a high value placed on competency and intellect because of their higher level of education. This may make it difficult for them to understand that a child with an intellectual disability may be wanted, may enhance the life of a family, and may lead a worthy life:

"It’s somebody’s tragedy. I can find good things in practically everything—even dying—but birth defects are roaring tragedies... There’s nothing interesting about it... Death doesn’t bother me, but the living do.” – A paediatrician (Darling, 1979, p.166)

This attitude contrasts to that of a mother’s:

"They told me it would be a long, hard road with nothing but heartaches...
It hasn’t been that way at all... She’s my baby, and I love her and I wouldn’t trade her for another baby.” – A mother of a child with Down syndrome (Darling, 1979, p.169)

However that may be, professionals tend to predict adverse effects of a child with a disability on the family, underestimate parents’ abilities in coping and presume that the child inevitably creates difficulties in the family. Such a professionals’ pessimistic attitude can be a source of parents’ dissatisfaction with the service, and as discussed in Chapter 2, further makes parents’ adaptation process unnecessarily difficult (McCubbin & Patterson, 1983; Patterson, 1995).

The literature found professionals’ overestimation of the negative impact of a child with a disability on the family. Blackard & Barsh (1982) in Seattle, U.S., conducted a questionnaire survey of 101 professionals and 43 parents of children with a severe disability. The professionals all worked with children with a severe disability, and included teachers, social workers, speech and language therapists, counsellors and psychologists.

There was significant disagreement between the groups. As compared with the parents’
responses that few changes had actually occurred in the family, the professionals overestimated the negative impact of the child on aspects of family functioning, including marital and family relationships, family goals, family activities, and financial costs. They also overestimated the degree of community rejection and lack of support, and underestimated parents’ ability to teach the child. The researchers concluded that professionals should not automatically assume the negative impact of a child with a disability on the family, and pointed out the importance of parent-professional communication to gain a more accurate understanding of parents’ perspectives. The findings of this study may, however, need to be seen cautiously due to the use of self-reported data from the parents with a possible response bias.

Similarly, Urey & Viar (1990) in Kentucky, U.S., found parents and paediatricians had different perceptions of parents’ abilities to cope with problems in the family, with the paediatricians’ underestimation of parents’ abilities. Fifty families of children with spina bifida who were randomly selected from the membership of a local spina bifida association were sent a questionnaire on the family’s needs. A modified version of the questionnaire was sent to 50 randomly selected paediatricians in private practice. Of those who were sent the questionnaire, 21 parents and 23 paediatricians completed and returned it. The questionnaire asked the parents to rate the degree of distress that they
were experiencing in 15 family problem areas, and asked the paediatricians to rate the degree of distress that they perceived that families of children with a disability in general are experiencing in the same problem areas.

The paediatricians regarded these families as significantly more distressed than did the parents in 13 out of 15 problem areas. The paediatricians, for example, supposed that these families have greater problems in depression, parenting skills, and family and marital relationships, while the parents reported that they have greater problems in social isolation and anxiety. The use of a questionnaire that had not been validated may, however, reduce the applicability of the findings.

Doctors in the literature appeared to have a more pessimistic attitude than did parents themselves. Nursey et al. (1990) in London, U.K., investigated differences in attitude toward people with an intellectual disability between 73 doctors and 81 parents of children with an intellectual disability. A total of 132 parents of children with an intellectual disability were approached through a local planning register for people with an intellectual disability, and were sent a questionnaire to investigate their attitudes toward people with an intellectual disability. A total of 197 local doctors who were likely to have some involvement with people with an intellectual disability, were
contacted through the register and sent a modified version of the questionnaire. The questionnaire presented a series of statements about people with an intellectual disability in relation to four aspects of their lives: the effect on the family, place in society, quality of life, and independence and autonomy.

The results showed that the doctors were more pessimistic than the parents except in the area of independence and autonomy, where the doctors were more optimistic. However, the findings of this study should be taken with caution due to the failure to establish validity and reliability of the questionnaire and the relatively low response rates, especially in the doctors.

The literature reported that paediatricians tended to overestimate the family’s need for help. Sloper & Turner (1991a) in Greater Manchester, U.K., investigated differences in perceptions regarding the family’s need for help between paediatricians and parents of children with a severe physical disability. A total of 147 parents were contacted through referrals from paediatricians, heads of special schools and specialist health visitors in the area, and were asked to participate in the study. Twenty-eight paediatricians who were working with children with a physical disability were identified in all the thirteen hospitals with a paediatric department in the area, and were asked to participate in the
study. Of those, 107 parents (73%), 105 mothers and 2 fathers, and 24 paediatricians (86%) agreed to participate and were interviewed. Semi-structured interviews, using a scale of the family’s need for help, took place with the parent at home and with the paediatrician at a place of his/her choice. The paediatricians were asked to estimate the degree that they felt families of children with a physical disability would need help in potential problem areas related to the child. Their responses were then compared with the parents’.

The groups, to a large degree, agreed on some areas of the family’s greatest need for help (e.g. discussion of the child’s progress, information about services, improving the child’s mobility, and information about the child’s condition). Yet, in the other areas the paediatricians overestimated the family’s need for help (e.g. coming to terms with the child’s disability, teaching self-help skills, and assistance with childcare tasks at home). Overall, the paediatricians tended to overestimate the family’s need for help in all the areas compared to the parents themselves. Interestingly, paediatricians who had a longer professional experience or who regarded the provision of continual family support and information about services as important, tended to estimate the family’s need for help more accurately. The findings of this study may, however, need to be seen with caution because the use of non-random sampling method for the parents and the small sample

CHAPTER 3. LITERATURE REVIEW
size for the paediatricians possibly limit the ability to generalise the findings.

The professionals’ pessimistic attitude toward individuals with a disability may be fostered by several factors. It may reflect the view prevalent in society because professionals are exposed to the same social influences as others in society. From the time they were small they have seen biased images of people with a disability through the media, read biased accounts in books, or heard unfavourable epithets, such as ‘retard’ (Darling, 1991b). In addition, many professionals grew up with little personal contact with individuals with a disability (Wolraich, 1980), and generally receive less education or training in disability than in other areas since many disabilities occur with relatively low frequency (Wolraich, 1982). For example, 9 out of 24 paediatricians (37%) in Turner & Sloper’s study (1992) did not receive any education or training in disability. Many, as a result, enter their professions without opportunities to reconstruct their stereotyped or biased views toward individuals with a disability.

The professionals’ pessimistic attitude may be reinforced through the traditional professional education or training. Despite the advent of palliative medicine, many doctors who are practicing now were formerly taught to find cures. Consequently, they may feel helpless or inadequate about themselves in providing care to individuals with a
life-long incurable condition:

"I don’t enjoy it... I don’t really enjoy a really handicapped child who comes in drooling, can’t walk, and so forth... Medicine is geared to the perfect human body. Something you can’t do anything about challenges the doctor and reminds him of his own inabilities.” – A paediatrician (Darling, 1979, p.215)

Furthermore, differences in the nature of involvement with a child with a disability between parents and professionals may also contribute to the professionals’ pessimistic attitude (Nursey et al., 1988). For the professional, it is often his/her job to be involved because of the child’s disability which may lead him/her to focus on this aspect of the child. On the other hand, the parent is involved just because the child is his/hers regardless of the disability. Professionals’ experience with the child may be limited to negative aspects of the child’s life since most of their involvement may occur at the time when the child is unwell, while those of parents may be a “much more balanced mixture” of positive and negative aspects (Nursey et al., 1988).

The professionals’ pessimistic attitude may have some adverse impacts on families of
children with a disability. First, it may influence parents’ perception of the situation as well as the child because the information they receive is likely to reflect the professionals’ pessimistic view. If parents perceive the situation unnecessarily pessimistically, this can intensify their grief and interfere with their adaptation to the child’s disability. For example, parents who are given pessimistic accounts regarding the child’s developmental potential may be less likely to work toward the child’s developmental goals. Second, it may result in professionals’ failure to provide services appropriate to parents’ needs during this period. Nursey et al. (1988) stated:

“...if doctors perceive mental handicap in a more negative light than parents, and fail to recognize this, their reluctance to tell parents fully, clearly and at an early stage that they think their child has a mental handicap will be increased because they think this is in the best interests of the parents. (p.3)”

The professionals’ pessimistic attitude may consequently increase parents’ dissatisfaction with the service and strain the parent-professional relationship.
Professionals' Assumptions of Parents' Inevitable Emotional Distress and Resultant Dissatisfaction with Informing

Professionals in the literature often appear to assume that parents' dissatisfaction with the informing interview is inevitable because of their intrinsic emotional distress. Such a professionals' assumption can result in their failure to provide appropriate services to these parents at the time around the child's diagnosis.

Jacobs (1977) in Sussex, U.K., carried out an early study in this area, and reported professionals' inattention to informing practice. With an awareness of difficulties experienced by parents in obtaining information about their child's disability, the researcher investigated the quality and sources of the information parents had received.

All 250 parents whose children attended three special schools for children with a disability in the district were sent a questionnaire, and 120 replied (48%). The children had an intellectual or physical disability, or a combination of both.

The results indicated that, for 43% (n=52) of the parents, hospital doctors were the most important source of information about their child's disability, while 40% (n=48) reported receiving no satisfactory information of this kind from them. About half the parents (n=59, 49%) were dissatisfied with the informing interview due to inadequate
information, lack of information, language used, and lack of interest shown by doctors.

A surprising point of the study, however, was not these findings but the reaction of health authorities. When the researcher recommended the health authorities to set up a working party in order to examine problems in informing practice, they declined. The reasons for this were that they believed that they already gave full and adequate information, that parents often did not want to hear the truth, or that parents were dissatisfied with any information they were given because of their anger. This suggests that there was a serious mutual misunderstanding between parents and doctors, and that some doctors were unaware that parents’ need for information was unmet.

In contrast, the findings of McDonald et al.’s study (1982) conducted in Texas, U.S., seem to provide an alternative view. Using a list from a state medical association directory, a random sample of 150 doctors was obtained. An additional 150 doctors were recruited because of a low response rate of the random sample. The researchers then called these 300 doctors of whom 69 (23%) agreed to be interviewed on the phone. Of those interviewed, 25% were general practitioners, 33% family practitioners, and 39% paediatricians. In structured telephone interviews, the doctors were asked about their informing practice for parents of children with a disability.
Most doctors (n=63, 91%) saw themselves as the initial informant to parents of their child’s disability. Eighty-eight percent (n=61) of the doctors stated that they provided information immediately after the child’s birth to both parents with specific diagnostic labels when available, moreover, 97% (n=67) included additional information such as possible causation, prognosis, and community resources for the family. Many (n=30, 44%) considered that information they give to parents would be mediated by prognosis, severity of the child’s disability, parents’ social class and race/ethnicity, availability of outside resources, and their perception of parents’ emotional stability, while others (n=23, 34%) noted that they would provide all the information available regardless of these factors. Some others emphasised the importance of language that parents can understand and the pace at which they can absorb information, and evaluation of their emotional state and understanding.

The findings indicated that the doctors were well aware of parents’ need for information and aspects of informing practice, and were making considerable efforts to deal with parents. Pointing out that these findings contradicted the literature reporting parents’ dissatisfaction with informing practice, the researchers presumed that no matter how sensitive or supportive doctors might be, parents may still fail to recognise support from doctors due to their emotional state. The applicability of the findings may, however, be
limited because of the use of self-reported data from the doctors with a possible social desirability bias. That is, the doctors’ responses may not have reflected their actual practice, rather it was likely to be biased toward what they felt as ideal. The use of a non-random sampling method and the low response rate may further reduce the ability to generalise the findings.

In response to a prevalent assumption that parents’ dissatisfaction is an inevitable consequence of informing, Cunningham et al. (1984) in Manchester, U.K., demonstrated that, when a model procedure was followed, parents’ dissatisfaction could be avoided. The model procedure for informing practice was established based on the literature as well as data from 59 families of children with Down syndrome during a preliminary survey. The procedure included parents being told: by a paediatrician; as soon as possible; together; with the child present; in a private place without interruptions; in a direct manner; with time for questions; and having access to professionals who can provide information and practical support after the informing interview.

Following the survey, a comparison study of 32 families of children with Down syndrome took place to test the model procedure. Of these, 7 families received the
model service when they were told of their child’s diagnosis, and the remaining 25 families were told this in a customary manner. The families were recruited through referrals made by paediatricians and health visitors. The children included were born in the area during 1976 to 1980, were all receiving an early intervention program, and were thought to cover 80 to 90% of such births in the area during this period. The parents in the model service were interviewed at home 6 months after the child’s diagnosis, and those in the control group were interviewed at home between 1 week and 8 months (mean 15 weeks) after the child’s diagnosis. In two-parent households both parents were included.

The parents in the model service showed 100% satisfaction with the service compared to 20% (n=5) satisfaction of the parents in the control group. The parents who received the model service commonly displayed more positive attitudes toward the service generally. The researchers concluded that parents’ dissatisfaction was not an inevitable consequence of informing. The small sample size of the model service group, and the sole inclusion of parents of children with Down syndrome may, however, reduce the ability to generalise the findings. It is possible that parents of children with Down syndrome are generally more satisfied with informing than parents of children with other disabilities. This is because Down syndrome is identifiable at, or soon after birth,
and more prognostic information and resources are available for the former than the latter (Cottrell & Summers, 1990).

The finding of Cunningham et al.'s study that parents' dissatisfaction with informing is not inevitable was supported by later studies in this area. Krahn et al. (1993) in Oregon, U.S., conducted structured interviews with parents of 24 children with a disability regarding their experience at the informing interview. The parents were recruited through birth centres, cytogenetic laboratories, and programs serving young children with a disability. The children's disabilities included a variety of congenital malformations or chromosomal abnormalities. Where available, both parents in the family were included and interviewed together (71%). In the structured interviews, the parents were asked about their preferences for how to be told of their child's disability. Their responses were transcribed and coded by two raters. To test reliability of the procedure, comparisons were made between raters, with no discrepancies found.

The parents' preferences for informing concurred with themes previously discussed in the literature, but also included additional ones. They wanted to be told: as soon as possible; by a familiar person/professional; together; with support persons for single-parents; with the child present; in a private place without interruptions; in a direct but
caring manner; at a pace that they can follow; with time for questions; with information about community resources and positive aspects of the child; and with physical contact with the child. The parents appeared to be able to distinguish their own emotional reactions to the diagnosis from their impressions of how professionals told them. They were personally upset by the diagnosis, but felt being supported by professionals who were sensitive to their feelings was important. The researchers supported the claim that parents' dissatisfaction is not an inevitable consequence of informing practice. The use of a non-random sampling method and the small sample size may, however, reduce the ability to generalise the findings.

An Australian study conducted by Hasnat & Graves (2000b) in Victoria, also supported Cunningham et al.'s claim. The researchers interviewed families of children with a disability to investigate the level of their satisfaction with informing practice and determinants of their satisfaction. Eighty families were selected from a patient list of a disability clinic at a university medical centre, and were asked to take part in the study by letter. Of those sent a letter, 23 families (29%) agreed to participate. The majority of the children had autism (57%) or an intellectual disability (17%), and the remainder were diagnosed with other disabilities, such as learning disability, epilepsy, hearing impairment, or cerebral palsy. Data were collected through interviews with the parents.
at home or by telephone. Most interviews (87%) involved only the mother, but in the remaining interviews both parents were present.

A high proportion of the parents (n=19, 83%) expressed overall satisfaction with informing practice. Their satisfaction was significantly related to the amount of information and attributes of professionals involved in the informing interview. The parents tended to be satisfied if they were given a large amount of information. This suggests that parents generally want as much information as possible at the informing interview, even though they cannot absorb it all due to their emotional state. The level of parents’ satisfaction was also found to be higher when professionals were direct in manner, understood their concerns, and communicated well with them. With the high level of overall parents’ satisfaction, the researchers supported the claim that parents’ dissatisfaction with informing is not inevitable.

The ability to generalise the findings may, however, be reduced due to the low response rate, the small sample size and the predominant inclusion of families of children with autism. There may also be a possible interviewer bias regarding the level of parents’ satisfaction because the researchers were closely related to the disability clinic where the study took place. Thus, the parents might have hesitated to express negative
comments on the services they received, possibly resulting in the somewhat exceedingly high level of parents' satisfaction compared to those of other studies as shown in Table 3.1 on p.61.

Professionals' assumptions of parents' inevitable emotional distress and resultant dissatisfaction with informing may reduce professional efforts to make parents feel better at the informing interview. If professionals think informing inevitably causes distress or anger in parents, they are less likely to worry about their manner or communication with parents, behaving in the way where parents see them as insensitive and unfeeling.

**Professionals' Reluctance to Give Sufficient Information to Parents**

Professionals' reluctance to give sufficient information to parents may also affect their informing practice. Parents often reported that professionals appeared to be reluctant or evasive when asked for information. Though, such professionals' attitudes, rather than being a sign of lack of sympathy, can be attributed to lack of diagnostic information, lack of confidence in informing, reluctance to cause pain and distress in parents, and anxiety about parents' emotional reactions.
Professionals may delay informing if the cause of the child's disability is unknown or enough diagnostic information is not available. The timing of informing appeared to be significantly related to the availability of diagnostic information about the child's condition. Quine & Pahl (1987) in Canterbury, U.K., carried out structured interviews with parents of children with an intellectual disability regarding their experience of informing practice. A total of 190 parents included was a stratified sample of 399 families from a larger population study and was matched for age and sex with the total population from which it was drawn. The larger study covered all children under 16 years of age in two districts, who had been, or were likely to be, eligible for special education for children with an intellectual disability based on assessment by the research team. The children were divided into four groups by diagnoses, which were Down syndrome (n=62), cerebral palsy (n=21), other disabilities of known causes (n=32), and other disabilities of unknown causes (n=66).

The results indicated that 68% of parents (n=45) of children with a disability of unknown cause were not informed of their child's diagnosis until the second year or later of the child's life, while 63% of parents (n=39) of children with Down syndrome were informed of their child's diagnosis at birth. A majority of parents (n=42, 55%) of children with Down syndrome or a disability of known cause were satisfied with

CHAPTER 3. LITERATURE REVIEW
informing, while fewer parents (n=26, 30%) of children with cerebral palsy or a
disability with unknown cause were satisfied with this. In the study, cerebral palsy was
classified as a disability of unknown cause as its cause often cannot be ascribed. The
findings suggest that a higher satisfaction among parents of children with Down
syndrome or a disability of known cause can be ascribed to both earlier informing and
the availability of diagnostic information about the child’s condition.

Parents often see professionals who appear to avoid or delay informing as evasive since
they have already suspected that something is wrong with their child before they are
informed. The result of this is parents’ bitter feelings toward professionals:

“The doctor did not say anything at all when the baby was born. Then he
said, ‘It’s a boy,’ and the way he hesitated, I immediately said, ‘Is he all
right?’ And he said, ‘He has ten fingers and ten toes,’ so in the back of my
mind I knew there was something wrong.” – A mother of a child with Down
syndrome (Darling, 1979, p.129)

Wolraich (1982, p.325) stated “medical training often neglects to teach physicians how
to say ‘I don’t know’ in a manner that will not reflect poorly on their competence.” In
addition, professionals sometimes receive little education or training in informing, and may not feel confident enough to perform this task.

There are only a few studies, the researcher is aware of, that investigated professionals’ informing practice by asking them directly. Turner & Sloper (1992) in Manchester, U.K., conducted a study of paediatricians regarding their training in informing and their informing practice related to the diagnosis of a child’s disability. Twenty-nine paediatricians working with children with a physical disability were identified in all the thirteen hospitals with a paediatric department in the area, and were sent a letter asking for their participation in the study. Of those contacted, 24 paediatricians (83%) agreed to participate and were interviewed in a semi-structured manner either in their office or an interview room.

In relation to their training, 15 paediatricians (63%) had received some form of training in disability but only 5 (21%) had received training in counselling or communication skills. With regard to their practice, only one (4%) had standard procedures for informing in his hospital, six others (25%) had developed an informal policy with their colleagues, and the reminder of 17 (71%) had developed their practice individually.

When asked if they expected any changes in medical training in the area of childhood
disability, all but one (n=23, 96%) said they did. The most frequently mentioned point was the need for training in counselling (n=13, 54%), followed by training in informing technique (n=4, 17%) and more emphasis on social medicine rather than a disease-oriented approach (n=4, 17%). This study was conducted in a relatively limited area of the U.K. and had a relatively small sample size, which may reduce the ability to generalise the findings. However, these may, to some extent, be offset by the high response rate and covering all the hospitals in the area.

A recent study conducted by Hasnat & Graves (2000a) in Victoria, Australia, also investigated paediatricians’ practice in informing. Thirty-two paediatricians were recruited through a list of members of the Australian College of Paediatrics, a mailing list of a university medical centre children’s program, and paediatric practitioners in the area who were known to the researchers or their colleagues. All were sent a letter asking for their participation in the study, and 26 agreed (81%). Data were collected through interviews and questionnaires. The interviews were conducted in the place of paediatricians’ choice, including their consulting rooms, outpatient clinics, or an office in a university department. At the end of the interview, they were given a questionnaire to be completed and returned by mail. The paediatricians identified factors that were thought to operate against their ideal informing practice. The most common factor

CHAPTER 3. LITERATURE REVIEW
mentioned was lack of time (n=13, 50%), followed by lack of experience, training or knowledge about the area (n=4, 15%). The findings of this study may, however, need to be used cautiously because the use of a non-random sampling method and the small sample size possibly limit the ability to generalise the findings.

Although there is little evidence in the empirical literature, professionals may also feel awkward being with parents in distress in the aftermath of informing. This is more likely when they are unfamiliar with possible parents’ emotional reactions to the diagnosis of their child’s disability. This may put professionals in a situation where they feel uncertain or interpret parents’ negative feelings personally (Bloch, 1996). Conversely, professionals may also be reluctant to inform parents of their child’s disability if they think this will cause pain and distress in parents:

[The neurologist said] "'I think I know what’s wrong with your son but I’m not going to tell you because I don’t want to frighten you.' Well, I think that’s about the worst thing anyone could say... We didn’t go back to him... We wanted the truth."— A mother of a child with cerebral palsy (Darling, 1979, p.147)
Professionals' reluctance to give sufficient information to parents may interfere with their communication with parents. If professionals are reluctant to inform parents of their child's diagnosis for any of the above reasons, they may interact with parents in a distant manner and fail to take enough time with parents. It is also less likely that they provide parents with full and clear information at an early stage of discovery of the child's disability. Such professionals' behaviour is opposed to parents' preference for informing identified in the literature, and thus tend to increase parents' dissatisfaction with the service.

### 3.3.3 Dissatisfaction with Information

As discussed previously, among different professional disciplines, health care professionals are often the first to come into contact with these families. As a result, they not only have to be the informer of the child's diagnosis but also the provider of information. Parents commonly indicate the most important type of support they receive from professionals during this period is information, and in some cases, this is even more important than emotional support (Baxter, 1986). The provision of emotional support is generally available from the informal support network, i.e. relatives and friends. In contrast, the most appropriate source of information is usually the formal support network, i.e. professionals (Pain, 1999). In order to provide adequate support to
these families, professionals must have sufficient knowledge to give useful information to parents (Turnbull & Turnbull, 1990). Meeting parents’ need for information at the time around the child’s diagnosis is essential because the basic factor underlying their concerns is uncertainty, and parents see uncertainty as a source of additional stress (Baxter, 1986).

Conversely, adequate information seems to maintain family functioning and assist the family’s adaptation to the child’s disability. Taanila et al. (1996, for details of this study, see p.33) carried out a study of 89 families of children with a disability, and found that adequate information about the child’s disability had a protective impact on family functioning. The parents reported that when they had had a realistic understanding of the child’s disability, it had helped them support each other and cope with the child’s disability.

Pain (1999) in Southampton, U.K., conducted a study of families of children with a disability to examine the usefulness of information. Families of 80 children with a disability who were seen by the same paediatric consultant were contacted by letter asking for their participation in the study. The children’s disabilities included an intellectual or physical disability, or a combination of both. Of 37 families who agreed
to participate, 15 were selected to give a spread of disabilities, and were interviewed in
a semi-structured manner at home. In most interviews only the mother was included,
while in five cases both parents were present. The parents were asked to describe
difficult periods, and whether information had helped them. The interviews were
audiotaped and transcribed, and then coded and analysed in relation to parents’
judgement of the usefulness of the information they had received. It appeared that the
information had enabled parents to access appropriate services, to enhance their
management of the child’s disability, and to adjust emotionally to their child’s disability.
The ability to generalise the findings of this study may, however, be limited because the
subjects were selected from a patient list of the single paediatrician.

Information also provides parents with a sense of control over their lives:

"Our first step in protecting ourselves from further pain was to become
informed about our child’s disability. This information not only protected us
from the fear and confusion we experienced in our encounter with medical
professionals, but it also made us feel a sense of control. We read everything
possible on the subject. We prepared ourselves with information on the very
best we could expect for our son’s life, and the very worst. As we broke the
news to friends and family, we felt we had sufficient information to answer any and all of their questions.... The more we got to know our son and become knowledgeable about his disability, the more the pain eased.”— A mother of a child with Down syndrome (Moeller, 1986, p.150)

Two important issues regarding information given to parents at their child’s diagnosis are the amount and content of information.

**Amount of Information**

The amount of information that parents can initially absorb may vary, and there seems to be different opinions about how much information should be given at the time of diagnosis (Woolley et al., 1989). The amount of information needs to be tailored to the family’s situation, understanding, emotional state, and concerns. For example, if parents have already become aware and worried about their child’s developmental delay for a long time before diagnosis, they are likely to be prepared to receive details of information (Garwick et al., 1995). Despite individual preference, it is generally acknowledged that parents’ dissatisfaction with informing most frequently results from lack of information rather than from excessive information.
McKay & Hensey (1990) in Dublin, Eire, interviewed families of children with cerebral palsy regarding their early experience with health care professionals. Parents of children, aged 6 to 10 years, who had been diagnosed with cerebral palsy, had attended a disability clinic more than 5 years, and had been referred before 4 years of age, were asked to participate in the study. All the parents agreed to participate, consisting of 33 mother-father pairs, 47 mothers and 4 fathers. One of the researchers conducted semi-structured interviews with the parents, which were tape-recorded and transcribed.

The results showed that 70% (n=59) of the parents were dissatisfied with some aspects of their early contact with health care professionals. Lack of information about the child's condition was the most commonly mentioned complaint by the parents (n=49, 58%), followed by having their worries dismissed by doctors (n=43, 51%). Many related that they had been referred to the clinic or asked to attend for follow-up without any reasons being given, or that they had to visit their doctor or several different doctors repeatedly before their concerns were listened to and the child's problem was recognised. The findings of the study may, however, need to be used cautiously because it is unknown whether experience of parents of children with cerebral palsy are the same as that of parents of children with other disabilities.
A large study of 189 parents of children with a disability conducted by Sharp et al. (1992, for details of this study, see p.65) investigated parents’ preferences for professionals’ behaviour at the informing interview. Many (n=79, 42%) said that they would have preferred being given more information than they had, despite the fact that they could take in relatively little information at this time.

Similar findings were reported by other studies. Sloper & Turner (1992) conducted a study of 107 families of children with a severe physical disability to investigate the family’s needs in relation to informing practice. Sampling procedures, characteristics of subjects and measurement procedures were the same as those in the study discussed earlier (Sloper & Turner, 1993, for details of this study, see p.66). Parents reported that their least fulfilled need was the area of the provision of information. A majority would have preferred being given more information about services (n=63, 59%) or about the child’s condition (n=46, 43%) than they had.

Quine & Rutter (1994) interviewed 166 parents of children with a severe intellectual disability, regarding their experience at the child’s diagnosis. A detailed description of sampling procedures, characteristics of subjects and measurement procedures were the same as those in the study discussed earlier (Quine & Pahl, 1987, for details of this
A majority of parents (n=123, 74%) also reported that they would have preferred being given more information about their child’s condition than they had.

An Australian study of parents’ satisfaction with informing cited earlier (Hasnat & Graves, 2000b, for details of this study, see p.88) found a statistically significant relationship between the amount of information given and the level of parents’ satisfaction with informing: parents who had received more information were more satisfied.

Content of Information

Parents appear to require information about the child’s condition and services available, at the time of their child’s diagnosis. From the findings of the studies above, it is evident that a high level of parents’ dissatisfaction with informing frequently relates to the provision of information in these areas.

Information about the child’s condition may refer to specific diagnosis, prognosis, and possible causation. Beavers et al. (1986) in Texas, U.S., carried out a study of 40 families of children with a disability, and found that families who had received a clear diagnosis of their child’s disability have coped better than those who had not.
When parents fail to receive prognostic information about their child’s disability, they may worry about the child’s and their future. Baxter (1986) stated that the basic factor underlying parents’ concerns is uncertainty. Parents are particularly anxious about whether the child will be able to walk, talk, or go to school, or play normal adult roles in occupation and marriage (Darling, 1991a).

In addition to diagnosis and prognosis, parents often look for information about a possible cause of the child’s disability in order to be relieved of a feeling of guilt (Wolraich, 1986). It was found that parents of children with known causes showed a significantly higher satisfaction with informing than those of children with a disability of unknown causes (Quine & Pahl, 1987). Parents, especially mothers, frequently experience a feeling of guilt that persists for an extended period of time after the child’s diagnosis. This feeling is experienced as mothers wonder what they did wrong during their pregnancy. Mothers are prone to seek factors that has caused their child’s disability in their immediate known environment, yet this is sometimes unrealistic:

“When something was wrong with her, then I thought maybe I did do something that I shouldn’t have done. My mother-in-law told me not to wash ceilings, I washed ceilings.” (Cameron et al., 1992, p.99)
Within the family stress and coping models discussed in Chapter 2, families who have experienced a stressful life event often develop meanings of the event as a way to cope with it (McCubbin & Patterson, 1983; Patterson, 1988). For example, Taylor et al. (1984), in a study of breast cancer patients conducted in Los Angeles, U.S., found that 74 out of 78 subjects (95%) seemed to have attributed causes to their cancer in order to regain a sense of control. Similarly, families of children with a disability may seek a cause or a meaning of having a child with a disability as a part of coping mechanism.

Affleck et al. (1985) in Connecticut, U.S., found that finding causes or meanings of having a child with a disability related to a better outcome of the family’s adaptation to the event. A total of 42 mothers of infants who had been treated for severe perinatal medical problems in a newborn intensive care unit, took part in the study. The infants’ medical problems included severe asphyxia, seizures, intrauterine growth retardation and prematurity. To examine their ways of coping with the event, the mothers were interviewed and completed scales of mood disturbances and stress of an aversive life event at home shortly after the hospital discharge of the infant. The level of the mothers’ stress was measured in terms of their preoccupation with, and avoidance of disturbing thoughts about the child’s birth and hospitalisation. The results indicated that the occurrence of the mothers’ preoccupation and avoidance of thoughts decreased as they
found causes or meanings of the event. The findings of this study may, however, need to be seen cautiously as the data resulted from a single interview and only showed a correlation, not a causality, between the variables.

Besides the cause of the child’s disability, parents also seek information about treatment options in order to alleviate a feeling of helplessness by knowing there is something they can do for the child (Darling, 1991a).

Parents sometimes complain that they were given outdated or inaccurate information about their child’s condition. In the literature this has most frequently happened in the case of children with Down syndrome. Social and medical situations around these children dramatically changed in the latter half of the twentieth century due to advances in medical technology and the move from institutional care to the child remaining in the family home. As a result, children with Down syndrome are now able to survive for a longer period with less medical complications than they were expected to in past, and are more likely to be cared for at home, enabling them to have a more normalised life than they had previously. Despite these changes, parents of children with Down syndrome still report that they are given outdated or inaccurate information from professionals.
Garwick et al. (1995) in Minnesota, U.S., investigated parents' experience at the time of their child's diagnosis. The study included 43 families of children with chronic illness and disability who were drawn from a larger longitudinal study. The families had been contacted through health organisations, hospitals, and birth defects registries in the area. The children were diagnosed with Down syndrome (n=12) or congenital heart disease (n=25) or a combination of both (n=6). Semi-structured interviews were conducted with 38 mother-father pairs, 2 mother-grandmother pairs, and 3 mothers at home. The interviews were audiotaped and transcribed verbatim and then coded by two raters. The major complaints reported by the parents included receiving outdated or inadequate information. Most parents (n=16/18, 90%) of children with Down syndrome were dissatisfied with services in this area. Several parents reported that they had received outdated written materials about Down syndrome at the time of diagnosis:

"Well they gave us a book – Mongolism, You and Your Baby— written in 1956… The book said they should be institutionalised… There should have been a specialist there that said, ‘There is what you probably may be going through…’ There was no support at the hospital… All we had was total ignorance on what it was about.” (Garwick et al., 1995, p.996)
Parents are also frequently dissatisfied with professionals' lack of knowledge of community resources (Krahn et al., 1993), and commonly express difficulty in obtaining this kind of information on their own. Community resources may include local disability services and organisations, specialty services, counselling services, support groups, and parent-to-parent referrals (i.e., parents of children with a disability to whom newly informed parents may be referred).

Professionals tend only to tell parents about their own services (Jacobs, 1977). That is, hospital doctors were the source of information about medical treatment or therapies, and social workers were the source of information about social services.

Later studies suggest that this is still the situation. Parents in the literature appear to be unaware of the existing community resources, and this seems to result in their failures to
receive services appropriate for their needs. Kornblatt & Heinrich (1985) in Virginia, U.S., interviewed 24 families of children with a disability to examine their utilisation of services. The families were recruited through a patient list at an institution, which located in the centre of a large city and concerned with diagnostic assessment and treatment for children with a disability from birth to 21 years. The children were selected from those who had been seen for in-patient admission, clinic, diagnostic, or evaluation services, and had been diagnosed with cerebral palsy, intellectual disability, seizure, and other physical disabilities. The families came from a range of socioeconomic classes, and were stratified by geographic residence, child’s age, and race. Semi-structured interviews were conducted with the families at home using a scale of need and coping to investigate the child’s specific care needs and their coping abilities with these needs.

Eighty-three percent (n=20) of the families reported a high level of care needs of the child, and 67% (n=16) appeared to be coping with these needs at a low level. From the families’ responses in the scale and the interviewer’s observation, all the families were judged to be in need of at least one referral to community services. The researchers stressed a need for closer linkages between institutions and community service systems. The findings of the study may, however, need to be seen cautiously because the sample
was recruited from a single institution by using a non-random sampling method, and the scale had not been validated.

Similarly, Urey & Viar (1990) found that 5 out of 11 parents, who sought counselling services during the previous year, were unable to find such services on their own.

Within the family stress and coping models, the use of community resources can be seen as a coping strategy. That is, parents use community resources in order to alleviate stressful demands in their lives. Community resources may include early contact with other parents of children with a similar condition. This kind of contact is usually sought in parent-to-parent referrals or parent support groups, and often becomes an important source of information and emotional support. Gottlieb (1981, p.221) indicated that people who experience a crisis in their lives “need to share and compare their own reactions and beliefs with others; preferably with persons currently or recently experiencing similar events”.

Studies confirm that contact with other parents is a major source of support for parents to cope with their child’s disability. Koroloff & Friesen (1991) in Portland, U.S., conducted a large study of 834 parents of children with emotional disorders to examine
the effectiveness of participation in parent support groups. A questionnaire was developed to collect data from parents regarding their coping with the child’s condition and their participation in parent support groups. The questionnaires were distributed to parents of children with emotional disorders through regional conferences targeting these parents, parent organisations listed in a national directory, and state mental health departments. These departments further forwarded the questionnaires to mental health agencies, child welfare or public school programs in order to distribute them to parents.

Of 834 parents who returned the questionnaire, 315 parents (38%) were members of parent support groups and 519 (62%) were not.

Parents were asked to indicate which of resources was most helpful in coping with the child’s disability. The resources included were: religion; involvement with other parents; own career; own hobbies; community volunteer activities; recreation; and involvement in advocacy. Parents who were members of parent support groups mentioned involvement with other parents as the most helpful resource (n=158, 50%), followed by religion (n=50, 16%) and career (n=38, 12%). On the other hand, parents who were not members of parent support groups mentioned religion as the most helpful resource (n=166, 32%), followed by career (n=104, 20%) and involvement with other parents (n=67, 13%). Overall, 27% (n=225) of all the parents identified involvement
with other parents as the most helpful resource in coping with their child’s disability.

The findings of this study may, however, need to be seen cautiously due to a possible sample bias: the subjects were found to be more educated and earn a higher income than the general population.

Similar findings were reported by Smith et al. (1994) in Los Angeles, U.S. The researchers conducted a mail survey of families of children with special medical needs to examine families’ participation in parent support groups and what they liked best about participating in such groups. The questionnaires were mailed to families of a random sample of 300 children drawn from client lists at county services for children with special medical needs, such as orthopaedic problems, cleft lip and palate, central nervous system problems, or malignancies. Fifty-two questionnaires were sent back because families had changed addresses. Of the remaining 248 questionnaires delivered, 45 (18%) were returned.

Forty-two percent (n=19) of the parents reported that they had participated in parent support groups. These parents identified meeting other parents as the most preferred support they had received from the group (n=17, 89%). This was followed by sharing feelings (n=15, 79%), receiving information about resources (n=13, 68%) and receiving
information about the child’s illness or disability (n=12, 63%). However, the findings of this study should be seen cautiously because of the low response rate and the use of a questionnaire that had not been validated.

Other researchers suggest that parents also want information about other issues. For example, Lynch & Staloch (1988) reported that 44 out of 50 parents (88%) of children with a disability in their study indicated that suggestions on how to tell of the child’s diagnosis to relatives and friends would be helpful. Parents may look for information on educational options such as physical or speech therapies that begin shortly after birth in order for their child to attain optimal development (Darling, 1991a).

If professionals who interact with parents at the time around the child’s diagnosis fail to provide appropriate information on community resources, or fail to make referrals to appropriate services or programs, parents may engage in an extensive search on their own, spending considerable time and energy (Drew et al. 1992). In this search, they may find outdated or inaccurate information. One way to provide parents with appropriate information would be the distribution of written materials at the informing interview. For example, Quine & Pahl in U.K. (1989 cited in Sloper & Turner, 1992) found that the distribution of a booklet with available community resources to parents reduced the
level of parents’ dissatisfaction with information, with a decrease from 47% to 18%.

Written materials should, however, be used as a back up rather than a primary source of information. Pain (1999) suggests covering all the necessary information verbally first before the provision of written materials because parents indicate personal communication as the best medium of information. Materials would need to be reviewed and updated on a regular basis before they are given to parents.

3.3.4 Dissatisfaction with Circumstances of Informing

Circumstances of informing can be other sources of parents’ dissatisfaction. It appears in the literature that parents tend to stress the importance of circumstances when they were informed of the child’s diagnosis in unsatisfactory circumstances rather than in satisfactory circumstances (Sharp et al., 1992). That is, if parents were informed alone, they tend to mention the importance of parents being told together or the involvement of support persons. Likewise, if they were informed by phone, they tend to emphasise the importance of being told in person. From the available literature, circumstances that appear to influence parents’ satisfaction with informing include timing, persons present, professionals present, follow-up, and strategies used.
Timing

Timing of informing generates conflicting opinions within individual parents and within families. Studies report that a majority of parents prefer to be told as soon as possible if there is something wrong with their child, while a minority prefer not to be told until a firm diagnosis is made. Krahn et al. (1993, for details of this study, see p.87) interviewed 24 parents about their preferences for informing. Following to the provision of information (n=21, 86%) and professionals’ manner (n=15, 64%), the third most frequently mentioned parents’ concern was timing of informing (n=12, 50%). Of 12 families who mentioned this as important, 9 (75%) indicated they wanted to be told earlier than they had been or as soon as staff suspected that something was wrong with their child. However, one family wanted to be told later than they had been in order to recover from a difficult delivery. For another family, the mother appreciated being told as soon as there was a suspicion while the father said he would have preferred to wait until a firm diagnosis was made.

Other researchers found that an earlier informing was related to a greater level of parents’ satisfaction. Quine and his colleagues (Quine & Pahl, 1986; Quine & Pahl, 1987; Quine & Rutter, 1994) in the U.K., conducted a series of studies to investigate parents’ experience at the informing interview. Sampling procedures, characteristics of
subjects and measurement procedures were discussed earlier (Quine & Pahl, 1987, for
details of this study, see p.91).

The studies included 181 children who had been diagnosed with Down syndrome
(n=62), cerebral palsy (n=21), other disabilities of known causes (n=32), and other
disabilities of unknown causes (n=66). Structured interviews were conducted with
primary caregivers of the children. There appeared to be a significant relationship
between timing of informing and the level of parents’ satisfaction. Parents who were
told at birth or early in the child’s life were more satisfied than those who were told
later. This result may, however, be compounded with the fact that parents of children
with a disability of known cause (i.e. Down syndrome and disabilities of known causes)
were likely to be informed earlier than parents of children with a disability of unknown
cause (i.e. cerebral palsy and disabilities of unknown causes). It was suggested that the
former were significantly more satisfied (n=52, 55%) with informing than the latter
(n=26, 30%), not only because of an earlier informing but also because of the
availability of causal information about the child’s disability.

A substantial minority (n=8, 24%) of parents of children with Down syndrome,
however, still felt that they had been faced unnecessary delay, denial and evasion in
professionals, although they had been told relatively early. This appeared to have an adverse effect on the parent-professional relationship:

"I knew immediately that something was wrong, the minute she was born. They all gathered round to look at her. Then they wrapped her up and took her away. I kept asking 'Is she all right?' and they would say 'Yes, she's fine, don't worry.' But they must have realised I knew, so why didn't they tell me the truth straight away?" (Quine & Pahl, 1986, p.57)

About half of parents of children with a disability of unknown cause had already suspected that something was wrong with the child, and had a long period of anxiety and uncertainty before a firm diagnosis was made. Many felt that their anxieties had been discounted by professionals, or that the diagnosis could have been made earlier.

Parents in another study who had already worried about their child's development for a long time before diagnosis, reported that informing relieved them from suffering:

"When the doctor told us, he couldn't believe how well we accepted the diagnosis. All I can say is that it was such a relief to have someone finally
just come out and say what we had feared for so long! We felt that now we could move ahead and do the best we could for Timmy.” (Dickman & Gordon, 1985, p.31)

These findings suggest that gauging the family’s individual situation, such as the mother’s health, parents’ emotional state, and the length of parents’ suspicion, helps professionals decide appropriate timing of informing.

**Persons Present**

Parents generally prefer to be told their child’s diagnosis together, yet the literature reports that parents are often told separately. Sloper & Turner (1993, for details of this study, see p.66) found that a substantial minority of mothers (n=32/83, 38%) in two-parent families were given the child’s diagnosis without fathers being present.

When a parent is told alone, he/she may feel too distressed to communicate the diagnosis to the spouse, or may find it difficult to relay information to the spouse accurately (Woolley et al., 1989). Parents, especially single parents, should be offered an opportunity to have a relative or friend as a support person at the time of diagnosis (Ahmann, 1998).
The presence of the child at the informing interview is thought to facilitate parents’ acceptance of the child (Cunningham et al., 1984). Parents report that the availability of physical contact with the child during the informing interview is important, and appreciate professionals’ touching or holding the child in a positive and caring manner during this time (Krahn et al., 1993).

**Professionals Present**

For most parents, it is the hospital doctor who informs them of their child’s disability. For example, in a study conducted by Sloper & Turner (1993), most mothers were told of their child’s disability either by paediatricians (n=85/107, 79%) or obstetricians (n=11, 10%), with the remainder (n=12, 11%) being told by general practitioners, midwives or hospital nurses.

Traditionally, doctors are exclusively responsible in providing medical information to clients and their families. Medical information includes diagnoses of clients, as a result, doctors inevitably assume a primary responsibility for informing practice. Other professionals, especially nurses, are educated to assist doctors in this responsibility, and only required to explain or reinforce the information given by doctors (Quine & Pahl, 1986).
Despite the doctor’s exclusive responsibility in informing, the involvement of other health care professionals is advantageous. These professionals can play an important role in arranging an appropriate setting, encouraging effective communication with parents, and helping parents find information they need (Ahmann, 1998). Diggins & Lennox (1999) also recommend the involvement of two types of health care professionals in the informing interview, one to provide factual information, that is a doctor, and the other available to work with parents toward adaptation, that is a nurse, social worker, or other professionals. The role of nurses generally comes into the area of support to parents in the aftermath of the informing interview as well as on an ongoing basis. They are regarded as ‘front-line workers’ with clients and their families (Hitch & Murgatroyd, 1983), and are skilled in interpersonal communication, since they are likely to be around clients and their families at the time of distress. The involvement of other professionals such as social workers and psychologists is also beneficial, because these professionals tend to be knowledgeable about aspects of family dynamics, coping with stressful events, and information about community resources.

Follow-Up

It may be difficult for parents to take in all the information given at the informing interview due to their emotional state, and what they can recall may be inaccurate.
Follow-up after the informing interview enables parents to take in further information and ask questions that may arise after the informing interview (Firth, 1983). Follow-up also allows professionals to check parents’ understanding of the information, correct any misunderstandings, and check parents’ use of resources after the informing interview (Olson et al., 1987).

Parents often fail to receive appropriate follow-up after diagnosis and this appears to be a source of their dissatisfaction with informing. Sloper & Turner (1992, for details of this study, see p. 101) interviewed 107 families of children with a severe physical disability regarding their experience of informing practice. A majority of parents complained that they were not given appropriate follow-up after the informing interview (43%) or enough opportunities to ask questions during or after the interview (39%).

Similarly, in a study conducted by Hasnat & Graves in Australia (2000b, for details of this study, see p. 88), parents most commonly mentioned follow-up as a source of their dissatisfaction with informing. Compared with a high level of overall satisfaction with informing (83%), only 52% of the parents were satisfied with follow-up. This was much lower than their satisfaction with the information given (83%) and manner of professionals (96%).
It is common that professionals tell parents to make contact when they need further help. However, according to Firth (1983), with such a loose offer of help, none of parents in his study took action for further contact even when there were things they wanted to discuss. Therefore, it should be professionals who schedule and initiate follow-up interviews.

**Strategies Used**

In the literature, there is general agreement that certain strategies for informing are commonly preferred by parents. The use of these strategies is of absolute importance in enhancing parents' satisfaction with informing. These include telling parents: in a private setting without interruptions; in person; in a simple and direct language without medical jargon; and allowing enough time for questions.

People usually feel at ease discussing important issues in a private setting without interruptions. This principle should be applied when informing parents of their child's disability. Such a setting also allows parents to release emotions at the initial shock of their child's diagnosis. To arrange an appropriate environment for the informing interview, professionals should avoid interruptions by, for example, “hanging a note on the door saying ‘interview in progress’, leaving the bleep with somebody else and taking
The number of people involved in the informing interview should be kept to a minimum. Ideally this should consist of a doctor, a support professional, parents, or a support person for a single parent, and the child. Parents often complained when they were given the child’s diagnosis in the presence of strangers, such as medical students, unknown staff or other parents (Garwick et al., 1995). In one case, parents felt that the informing interview was like a teaching seminar in which they were dealt with as if they were subjects of a demonstration (Woolley et al., 1989).

One might take it for granted that parents are told the child’s diagnosis in person. However some parents did report that they were given the diagnosis by phone (Krahn et al., 1993). Such an impersonal practice appears to have hurt their feelings. In one case, a father was informed about his child’s diagnosis of Down syndrome by phone when he was at work, during his wife’s absence on a business trip. In another case, parents were informed of their baby’s heart problem from a message left on an answering machine.

Language used at the informing interview needs to be considered carefully. Parents sometimes report that they were unable to understand terms and explanations given at
the interview (Cunningham et al., 1984; Wooley et al., 1989), and emphasise the importance of the use of simple and direct language without medical jargon (Krahn et al., 1993). In Lynch & Staloch’s study (1988), 44% of parents (n=22/50) recalled that the information given was unclear, leaving confusion regarding implications of the child’s condition. Conversely, when parents were given information in simple and direct language, they tended to be more satisfied (Krahn et al., 1993), and were better able to accept the diagnosis (Wooley et al., 1989).

Parents indicate that they dislike communication that involves medical jargon (Krahn et al., 1993). The use of medical jargon may convey little meaning to parents, and thus interrupt communication between parents and professionals. Wolraich (1986) suggests that parents may make little effort to clarify terms themselves unless they are asked, because they may be intimidated or afraid to be seen as ignorant.

The diagnosis of the child’s disability is likely to bring about intense feelings and concerns to parents. Allowing enough time at the informing interview is important in order for parents to release such feelings and concerns. Without professionals’ assistance, parents may need to devote considerable energies to suppressing such feelings and concerns, and may not be able to concentrate on subsequent discussion.
Parents in Wooley et al.'s study (1989) reported that when professionals paced information, allowed sufficient time, and used repetition and clarification, they could take in and remember the information initially given. Professionals can encourage parents to write down questions that they want to ask at the next interview (Firth, 1983). Any concerns that cannot be immediately responded to should be openly acknowledged and clarified as soon as possible.

3.4 Factors Affecting Professionals’ Preparedness for Informing Practice

It is important to investigate professionals’ preparedness for informing practice to improve the service provision for parents of children with a disability at the time around the diagnosis of their child’s disability. From the literature, factors that possibly affect professionals’ informing practice include professionals’ attitudes toward having a child with a disability, knowledge to give sufficient information to parents, and skills necessary in informing practice. Major points of discussion about these factors may inevitably overlap previous sections as these factors in turn closely relate to parents’ satisfaction with services, therefore, only brief discussion about these factors is presented in the following section.

The majority of data on professionals’ preparedness for informing practice are obtained
indirectly through parents’ reports on services that they received, and only a few studies have examined this issue by asking professionals directly. Moreover, most of the latter studies have investigated only a particular variable of professionals’ preparedness. The remaining studies investigated more than one variable of professionals’ preparedness but only among doctors.

There is no study, the researcher is aware of, that investigated professionals’ preparedness for informing practice in the areas identified among different health care professionals. Although doctors generally assume the primary and often sole responsibility in informing practice, the advantage of involvement of other health care professionals should not be discounted because these other professionals may have unique expertise relating to their own professions.

**Attitudes toward Having a Child with a Disability**

Professionals’ attitudes toward having a child with a disability may have an effect on their informing practice. Studies report that professionals tend to overestimate the negative impact of the child on the family unit (Blackard & Barsh, 1982) as well as the family’s need for help (Sloper & Turner, 1991a), and tend to underestimate potential abilities of the child (Nursey et al., 1990) as well as coping abilities of parents (Urey &
Doctors appear to be more pessimistic about abilities of individuals with an intellectual disability than other disciplines (Wolraich & Siperstein, 1983).

Professionals’ attitudes may be conveyed both verbally and non-verbally to parents, and influence parents’ perception of the situation and the child. For example, in Krahn et al.’s study (1993, for details of this study, see p.87), a parent of a baby with a severe cleft lip and palate painfully recalled a staff member gasping and covering the baby’s face at the time of delivery. Such professionals’ attitude can intensify parents’ grief and interfere with their subsequent adaptation to the child’s disability.

Professionals’ attitudes can also influence the provision of services for these families at the time around the child’s diagnosis. If professionals are unnecessarily pessimistic about the family’s situation, they are less likely to give information to parents ‘fully, clearly and at an early stage’ (Nursey et al., 1988).

Knowledge to Give Sufficient Information to Parents

Professionals’ knowledge to give sufficient information to parents may have an impact on their informing practice. The literature suggests that parents generally want information about the child’s condition (Quine & Rutter, 1994) and community
resources (Kornblatt & Heinrich, 1985) at the time around their child’s diagnosis. Such information is thought to alleviate parents’ feeling of uncertainty (Moeller, 1986), and direct them to appropriate services that facilitate their adaptation to the child’s disability (Pain, 1999).

Parents often express difficulty in obtaining information on their own, and expect professionals to provide sufficient information to them (Baxter, 1986). In order for professionals to meet this parents’ expectation, they must have sufficient knowledge to give useful information to parents. In this respect, the inclusion of different health care professionals in informing practice would be extremely beneficial. Studies suggest that professionals tend to have knowledge of a particular area relating to their own practice (Kornblatt & Heinrich, 1985). That is, doctors are usually familiar with the child’s condition, while other professionals (e.g., social workers) tend to be familiar with community resources.

Skills Necessary in Informing Parents of Their Child’s Disability

Professionals’ skills pertaining to informing are thought to affect their informing practice. Such skills may be developed from education and/or training that they received, and their experience and knowledge of issues relevant to informing practice.
The literature suggests that there is relatively little education and/or training to teach professionals necessary skills in informing practice. The result of this appeared to be professionals' feeling of inadequacy about their ability to deal with clients and their families, and professionals' perceived need for such education and/or training. In Turner & Sloper's study (1992, for details of this study, see p. 93), most paediatricians (n=19/24, 79%) indicated that they had no training in counselling or communication skills. When asked, all but one (n=23, 96%) preferred some improvements in professional training. These included additional training in counselling (n=13, 54%) and in informing technique (n=4, 17%).

In Hasnat & Graves's study (2000a, for details of this study, see p.94), a minority of paediatricians (n=4/26, 15%) perceived lack of experience, training or knowledge as the second most common factor that restrains their practice in informing.

Morgan & Winter (1996) in Chicago, U.S., established a training program to teach communication skills to paediatric residents, which was initiated by the residents' discomfort and a sense of inadequacy in interacting with patients and their families. The program was designed to address difficult situations in physician-patient interaction, including how to deliver "bad news," deal with hostile parents, and talk to children.
about their serious illnesses, and the psychosocial aspects of death and dying. The program used various teaching techniques (e.g., interactions with volunteered families and patients), consisted of didactic sessions and seminars, and was delivered to the first-year residency group (n=70). To evaluate impacts of the program on the trainees’ performance, the researchers requested the trainees to fill out a program evaluation form, and also asked the volunteers to assess pre-post program effects in the trainees’ communication skills in videotaped interactions of a small sample of trainees (n=5) using a checklist.

The trainees’ attendance to the program was approximately 75% for the didactic sessions and 95% for the seminars. Their responses indicated that, despite no statistically significant improvement found in their communication skills, the program contributed to an increased awareness and confidence in their interactions with the volunteers. The trainees expressed relative comfort with the interactions, and commented that the program was valuable and effective. With the trainees’ perceived effectiveness of the program, the finding of no improvement in their communication skills may need to be seen cautiously because the small sample size and an invalidated instrument might have resulted in a failure to demonstrate effects of the program.
In contrast, Greenberg et al. (1999) in Washington DC, U.S., successfully proved beneficial effects of a training program on communication skills of trainees. The researchers developed and evaluated a training program to teach medical students communication skills and content issues necessary in informing. All second and third year paediatric residents (n=51) and emergency department fellows (n=4) in a university were asked to participate in the program, of whom 27 were agreed, generating a 49% of response rate. The program also included 4 standardised patients (SPs) who had received 15-hour of training in role-playing, performance evaluation, and giving feedback to the trainees.

The program consisted of two interviews during which the trainees interacted with 2 sets of the SPs using two case scenarios of unexpected death of children on arrival to an emergency department. The interviews were conducted in an emergency department counselling room, and were videotaped and evaluated in terms of communication skills and content issues covered using two validated instruments. When the first interview was completed, the trainees and the SPs completed an assessment of the trainees' performance, and then the trainees were given feedback from the SPs. The trainees were presented with the other case scenario with a different set of the SPs 4 to 10 weeks later.
The results indicated that the trainees significantly improved their skills in counselling and in informing, and showed a significantly increased level of comfort and confidence in their skills after the interviews. Interestingly, as the trainees’ scores on communication skills increased, their ability to give sufficient information increased. The researchers attributed this to an assumption that as the trainees’ knowledge about information increased, they became more comfortable in this difficult situation and thus their communication skills improved. The findings of this study may, however, need to be seen with caution because of the low response rate and the only fair agreement among the SPs’ performance evaluation. Moreover, the study only shows a short-term outcome, possibly limiting the applicability of the findings.

It is quite possible that professionals’ experience with families of children with a disability, their knowledge of these families’ perspectives of having a child with a disability, and their knowledge of families’ emotional reactions to the child’s diagnosis generate professionals’ confidence and comfort in their abilities to deal with these families. With the same grounds of Greenberg et al.’s assumption, such professionals’ experience and knowledge may enhance their communication with these families. Similarly, professionals’ awareness of issues relevant to informing practice may have positive effects on their practice in informing. Morgan & Winter (1996) suggest that
there is likely to be a positive effect in this area by merely increasing such awareness of professionals.

**Demographic Variables**

Besides the factors discussed above, some demographic variables of professionals are also thought to affect their informing practice. These may include gender, academic and language background, age, length of clinical experience, presence of child, and personal contact with individuals with a disability.

The gender of professionals may influence their sensitivity toward parents’ emotional reactions to the child’s diagnosis. Females are generally more sensitive to others’ emotional state than males (Berk, 1997), and express feelings more freely, using language, facial expressions and body gestures (Hall & Halberstadt, 1981).

The length of clinical experience of professionals may also have an impact on the level of their understanding of the family’s needs. Sloper & Turner (1991a, for details of this study, see p.77) found that paediatricians who had longer clinical experience tended to be more accurate in their estimation of the family’s need for help in areas related to a child with a disability.
Hasnat & Graves (2000a, for details of this study, see p.94) also found a relationship between the length of clinical experience of professionals and the level of their understanding of the family’s needs. Paediatricians with longer clinical experience were more likely to be aware of the importance of informing both parents together and having a support person present.

Although there is little evidence in the empirical literature, it is quite feasible that professionals’ preparedness for informing practice relates to other variables. For example, academic background of professionals may have relation to the level of their familiarity with parents’ emotional reactions to the child’s diagnosis, or their familiarity with parents’ perspective of having a child with a disability. Language background of professionals may also have an effect on their ability to communicate with parents. Professionals who have children may be better able to imagine the family’s situation in parenting a child with a disability than those who do not. Professionals who have personal contact with individuals with a disability may have a more accurate understanding of the family’s life than those who do not.

3.5 Conclusion

The parent-professional relationship can be a major resource for families of children
with a disability because these families generally need to establish long-term relationships with a variety of professionals due to the nature of the child’s disability. Despite this importance, parents often regard the relationship with professionals as a source of additional stress. This is more likely when they have had negative experience with professionals in the past. For the majority of parents, the relationship with professionals is initiated at the time of their child’s diagnosis. Among different professional disciplines, health care professionals are often the first to come into contact with these families and are thus likely to be the informer of the child’s diagnosis.

Professionals who are involved in the informing interview take an important position because this event may affect the future parent-professional relationship, and parents’ adaptation to the child’s disability. If parents have negative experience with professionals at this time, they may fail to trust professionals as a whole and become reluctant to utilise them as a resource (Lian & Aloia, 1994). In this respect, professionals must be skilled at inspiring trust, have sufficient knowledge to give useful information to parents, and must be aware of parents’ preferences for informing practice.

Studies often report a relatively high level of parents’ dissatisfaction with informing
practice. Parents tend to be dissatisfied when professionals involved in the informing interview fail to meet expectations that they be emotionally available, communicate well, provide sufficient amount and quality of information, and arrange satisfactory circumstances in which the interview takes place.

There appear to be different opinions expressed by individual parents and individual families, especially in relation to the amount of information and the timing of informing. Some professionals assume that parents are unable to take in what they are told at the informing interview due to their emotional state (Jacobs, 1977). Studies, however, report that parents tend to be satisfied when they are given a large amount of information (Hasnat & Graves, 2000b). Other studies indicate that parents are better able to absorb information when professionals use certain strategies, such as using language that parents can understand (Krahn et al., 1993), pacing information, and using repetition and clarification (Wooley et al., 1989).

For the timing of informing, a majority of parents prefer to be told as soon as possible if there is something wrong with their child, while a minority do prefer not to be told until a firm diagnosis is made (Krahn et al., 1993). However, other researchers report that parents who are given a relatively early diagnosis are still dissatisfied when they face
unnecessary delay, denial and evasion in professionals (Quine & Pahl, 1986).

On the other hand, there are considerable consistencies in parents' preferences for other aspects of informing. For example, parents commonly prefer to be told: together; with the child present; in a private setting without interruptions; in person; in simple and direct language without medical jargon; with professionals' tolerance for parents' emotional expressions; in a sympathetic and caring manner; with time for questions; and with early opportunities for follow-up. Cunningham et al. (1984) successfully demonstrated that when the model procedure similar to the above was followed parents' dissatisfaction with informing could be avoided.

The major support that parents expect from professionals is the provision of information. Parents require information about the child's condition and community resources at an early stage after the child's diagnosis. Information can help them alleviate a feeling of uncertainty and direct them to appropriate services without an extensive search on their own. The use of community resources, such as local disability services and organisations, specialty services, counselling services, support groups, and parent-to-parent referrals, may reduce stressful demands in the family's life and assist their adaptation to the child's disability. Parents especially value early contact with other
parents of children with a similar condition. This contact often serves as an important source of information and emotional support.

Professionals can be an important resource for families of children with a disability. It is, therefore, regrettable if parents see the relationship with professionals as a source of additional stress. Professionals need to make all possible efforts to establish a good relationship with parents in order to support them effectively. In this regard, investigating professionals’ preparedness for informing practice is of great importance because parents’ early experience with professionals at the time of the child’s diagnosis is thought to affect their future relationship with professionals and their adaptation to the child’s disability.

Factors that possibly affect professionals’ preparedness for informing practice include their attitudes toward having a child with a disability, knowledge to give sufficient information to parents, and skills necessary in informing practice. The current study investigates professionals’ preparedness for informing practice in these areas. A specific focus of the study is placed on the investigation of differences in preparedness among different professional disciplines. This is because the researcher assumes that there is likely a beneficial effect by involving different professions in informing practice.
Although doctors generally have the primary and often sole responsibility in informing, the advantage of the involvement of other professionals should not be discounted as these professionals may have unique expertise relating to their own professions.
CHAPTER 4 METHODOLOGY

4.1 Introduction

In this chapter, research design, participants and methods of data collection of the current study are reviewed. This is followed by discussion about data analysis, validity and reliability of procedures, and ethical considerations.

4.2 Research Design

The current study used a survey design that is defined as “a method of gathering information from a number of individuals, a ‘sample’, in order to learn something about the larger population from which the sample is drawn” (Ferber et al., 1980, p.3). The purpose of the study was to measure attitudes, knowledge and skills of a number of health care professionals through the questionnaire in order to identify characteristics which may indicate their preparedness in informing practice.

4.3 Subjects in the Study

Location of the Study

Hospitals were chosen from a variety of locations, including rural, regional and city areas. Of these, one hospital declined to participate and another hospital was deleted from the list because a lengthy process was anticipated to obtain ethical approval. Participating hospitals, thus, included Shoalhaven District Memorial Hospital, Shellharbour Public Hospital, and Illawarra Regional Hospital Wollongong Campus in the Illawarra area; The Sutherland Hospital Caringbah, and St George Hospital in the South Eastern Sydney area; and Liverpool Health Service in the South Western Sydney area.
Population

The population of interest is all health care professionals who are working in paediatric or obstetric areas in NSW. These people are likely to be involved when parents are first informed of their child's disability. Potential subjects consisted of paediatricians, obstetricians, midwives, registered nurses, social workers, and other health care professionals.

The study included a variety of health care professionals, as it would be informative to investigate and compare preparedness in informing practice among different professional groups. As discussed previously, the literature suggests the advantage of involvement of different professional groups in informing practice. These professionals may have unique expertise related to their own professions, and thus, their collaboration may result in improved services for families of children with a disability. The main purpose of the current study was to investigate differences in preparedness in informing practice among different professional groups in order to demonstrate a benefit of involvement of different professional groups in this practice.

Sampling Procedure

A convenience sample was obtained by recruiting subjects in three ways. First, after ethics approval had been obtained from both the University of Wollongong and the Area Health Services involved, the Director of Nursing of each hospital was approached and requested by letter to assist in the study. In the letter, they were asked to distribute questionnaires (for details, see Appendix 1) accompanied by a consent form (Appendix 2), an information sheet (Appendix 3) and an addressed envelope to relevant health care professionals working in paediatric or obstetric areas in the hospital. The professionals
were then requested to participate in the study through the information sheet describing the purpose of the study. Second, midwives and registered nurses who had attended a conference held at the University of Wollongong were asked to participate in the study and distributed with the questionnaire, information sheet, and consent form during the conference. Finally, paediatricians and obstetricians who were practicing privately in the Illawarra area were contacted by letter accompanied by the questionnaire, information sheet, consent form and addressed envelope.

4.4 Data Collection

The aim of the study was to investigate health care professionals' preparedness in informing practice among different professional groups. Areas that were thought to affect professionals' performance in informing practice included their attitudes toward having a child with a disability, knowledge to give sufficient information to parents, and skills necessary in informing parents of their child's disability.

As a result of an extensive search of the existing literature, it appeared that there were no research instruments available to investigate health care professionals' preparedness for informing practice in the areas identified, except for an attitude questionnaire. A questionnaire was consequently developed based on knowledge from the literature (for details of the questionnaire, see Appendix 1). Items in the attitude section of the questionnaire came from a scale developed by Nursey et al. (1990, for details of this study, see p.76). Of the 49 items of Nursey et al.'s scale, ten items were selected and modified to fit into the current study.
The questionnaire consisted of five sections: health care professionals' demographic characteristics; their attitudes toward having a child with a disability; knowledge to give sufficient information to parents; skills related to informing practice; and opinions about the guidelines for informing. A number of guidelines for informing that have been suggested in the literature were integrated for the current study. Issues pertaining to guidelines for informing were discussed in Chapter 3.

The term 'disability' was used throughout the questionnaire without specifying severity or nature of disabilities. This might have made content of some statements in the questionnaire awkwardly broad, yet it was felt important not to specify these aspects of disabilities as this might unnecessarily limit professionals' responses to the questionnaire. Based on their past experience in disability, professionals may define any disabling condition as 'disability' regardless of its severity and nature. This is such a subjective definition with which professionals have developed their attitudes toward children with a disability and their families. It is quite possible that these attitudes, in turn, have had impacts on their knowledge and skills in disability, and further influenced their practice in informing.

4.5 Data Analysis

Quantitative data were derived from the subjects' responses to the questionnaire, except for the final section consisting of an open-ended question (for details of the questionnaire, see Appendix 1).

The first section of the questionnaire investigated demographic characteristics of the subjects. Variables included were gender, education, language, presence of children,
presence of relationships with individuals with a disability, age and length of career. The subjects' responses to each category of the variables were compared across professional groups, including doctors, nurses and social workers.

The following three sections examined differences in health care professionals' preparedness for informing practice across the professional groups in areas of attitudes, knowledge, and skills. The second section presented a series of statements in relation to the subjects' perceived attitudes toward having a child with a disability. Ten out of 49 statements were selected and modified from the scale developed by Nursey et al. (1990, for details of this study, see p.76). The subjects were asked to respond to each statement by choosing their level of agreement on a 5-point Likert scale. Scores for each statement were added up to generate the sum score for this section, ranging on a continuum from most negative to most positive. The higher the score, the more positive attitudes to the statements a subject perceived he/she had.

The third section related to the subjects' perceived knowledge of information that parents are likely to require at the time of their child's diagnosis. This section consisted of ten knowledge items that had been identified in the literature. The subjects were asked to choose items about which they felt they were able to provide sufficient information to parents at this time. The number of items chosen was counted to generate the sum score for this section, ranging on a continuum from least knowledgeable to most knowledgeable. The higher the score, the more knowledge of the items a subject perceived he/she had.
The fourth section involved a series of statements in relation to the subjects’ perceived skills that are thought to be necessary in informing practice. Eleven statements pertaining to the skills were developed based on knowledge from the literature. The subjects were asked to respond to each statement by deciding their level of agreement on a 5-point Likert scale. Scores for each statement were added up to generate the sum score for this section, ranging across a continuum from least skilled to most skilled. The higher the score, the more skills in the items of the statements a subject perceived he/she had.

Mean scores for each item as well as means of the sum score for each section for the professional groups were compared and analysed. In comparisons, statistical analysis employing a one-way analysis of variance (One-way ANOVA) was carried out using a computer package, JMP version 3.2.1. (SAS Institute Inc. 1989-1997).

Qualitative data were derived from the subjects’ responses to the final section of the questionnaire, an open-ended question. The question asked the subjects’ their opinions about the guidelines for informing in order to investigate their awareness of aspects of informing, and to determine the relevance of the guidelines in actual practice. The guidelines were integrated from those that had been suggested in the literature. Frequencies with which subjects in each professional group mentioned aspects of informing that pertain to the guidelines were compared and analysed. In addition to the aspects pertaining to the guidelines, the subjects also mentioned additional aspects of informing. All of these aspects were once again coded manually into some major themes and were discussed.
4.6 Validity and Reliability of the Procedures

Few studies have investigated health care professionals’ preparedness in informing practice across different professional groups in the areas identified, and as a result, there were no research instruments available for the current study. The questionnaire was, therefore, developed based on knowledge from the literature as well as prior experience of the researcher in this area. Kidder (1981) defined validity and reliability as;

“Research is valid when the conclusions are true. It is reliable when the findings are repeatable. Reliability and validity are requirements for both the design and measurement of research. At the level of research design, we examine the conclusions and ask whether they are true and repeatable. At the level of measurement, we examine the scores of observations and ask whether they are accurate and repeatable.” (Kidder, 1981, p.7)

The questionnaire was used without being piloted or without testing its validity and reliability. This is because the researcher was advised by a statistician that neither of these procedures would add appreciably to the value of the study. This may be a weakness of the research instrument. However, its relevance was closely examined through several consultations with supervisors, a statistician and personnel of the university ethics committee. The researcher also believed the potential value of the study might have overridden this concern, especially if the findings of the study are informative.
4.7 Ethical Considerations

Ethics approvals have been obtained from the University of Wollongong as well as the Area Health Services involved, South Eastern Sydney Area Health Service, South Western Sydney Area Health Service, Illawarra Area Health Service.

In the information sheet, health care professionals were informed of the purpose of the study prior to giving consent, and were assured that their responses would be strictly confidential and used solely for research purposes. Informed consent was obtained from the professionals by delivering the consent form with the questionnaire. The professionals were then requested to return the completed questionnaire and the consent form together to the researcher. Issues of freedom to decide or discontinue participation and confidentiality were covered in the consent form. Returned questionnaires and consent forms have been stored separately in a locked filing cupboard. The study follows the guidelines for disposal time of research documents from the New Record Act in 1999 in the University of Wollongong. When the disposal time of five years has passed all completed questionnaires and consent forms will be shredded.
5.1 Introduction

This chapter presents the quantitative results of the study based on responses of the subjects to the first four sections of the questionnaire. These sections covered the subjects' demographic variables, their attitudes toward having a child with a disability, knowledge to give sufficient information to parents, and skills in relation to their practice in informing parents of their child’s disability.

5.2 Response Rate

A total of 281 questionnaires were sent to the Directors of Nursing of the participating hospitals or distributed to the attendants of the conference held at the University of Wollongong and the private practitioners in the vicinity (for details of the sampling procedures, see p.140). Of the questionnaires sent or distributed, 108 were returned to the researcher, this is likely to give a possible response rate of 38.4%. It should be noted, however, that there was a difficulty in estimating the actual response rate, since accurate information about the number of questionnaires that reached professionals from the Directors of Nursing was not available due to the nature of the sampling procedures. Of the 108 questionnaires returned, 3 were disqualified because of non-completion of the questionnaire, and the remaining 105 were included in data analysis.

5.3 Demographic Characteristics of the Subjects

The first section of the questionnaire related to demographic characteristics of the subjects (for details of the questionnaire, see Appendix 1). Demographic variables included were gender, education, language, presence of children, presence of
relationships with individuals with a disability, age and length of career. As discussed previously, these variables are thought to affect professionals' practice in informing parents of their child's disability. Data are summarised in Table 5.1.

Table 5.1 Demographic Characteristics of Subjects (n =105)

<table>
<thead>
<tr>
<th></th>
<th>DOCTOR</th>
<th>NURSE</th>
<th>SOCIAL WORKER</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>n (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>12 (11.4%)</td>
<td>85 (81%)</td>
<td>6 (5.7%)</td>
<td>105 (100%)</td>
</tr>
<tr>
<td>GENDER:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>9 (75%)</td>
<td>2 (2.4%)</td>
<td></td>
<td>11 (10.5%)</td>
</tr>
<tr>
<td>Female</td>
<td>3 (25%)</td>
<td>83 (97.6%)</td>
<td>6 (100%)</td>
<td>94 (89.5%)</td>
</tr>
<tr>
<td>EDUCATION:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Certificate</td>
<td></td>
<td>25 (29.4%)</td>
<td></td>
<td>25 (23.8%)</td>
</tr>
<tr>
<td>Bachelor</td>
<td>1 (8.3%)</td>
<td>14 (16.5%)</td>
<td>5 (83.3%)</td>
<td>21 (20%)</td>
</tr>
<tr>
<td>Post Graduate</td>
<td>11 (91.7%)</td>
<td>46 (54.1%)</td>
<td>1 (16.7%)</td>
<td>59 (56.2%)</td>
</tr>
<tr>
<td>LANGUAGE:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>English</td>
<td>12 (100%)</td>
<td>74 (87.1%)</td>
<td>6 (100%)</td>
<td>94 (89.5%)</td>
</tr>
<tr>
<td>Non-English</td>
<td></td>
<td>11 (12.9%)</td>
<td></td>
<td>11 (10.5%)</td>
</tr>
<tr>
<td>PRESENCE OF CHILDREN:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>9 (75%)</td>
<td>65 (76.5%)</td>
<td>4 (66.7%)</td>
<td>79 (75.2%)</td>
</tr>
<tr>
<td>No</td>
<td>3 (25%)</td>
<td>20 (23.5%)</td>
<td>2 (33.3%)</td>
<td>26 (24.8%)</td>
</tr>
<tr>
<td>KNOWING ANYONE WITH A DISABILITY*:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>1 (8.3%)</td>
<td>20 (23.5%)</td>
<td></td>
<td>21 (20%)</td>
</tr>
<tr>
<td>Yourself</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relative</td>
<td>6 (50%)</td>
<td>31 (36.5%)</td>
<td>1 (16.7%)</td>
<td>38 (36.2%)</td>
</tr>
<tr>
<td>Friend</td>
<td>4 (33.3%)</td>
<td>37 (43.5%)</td>
<td>6 (100%)</td>
<td>49 (46.7%)</td>
</tr>
<tr>
<td>Neighbour</td>
<td>1 (8.3%)</td>
<td>8 (9.4%)</td>
<td>1 (16.7%)</td>
<td>10 (9.5%)</td>
</tr>
<tr>
<td>AGE:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean ± SD</td>
<td>42.1 ± 11.3</td>
<td>42.5 ± 7.9</td>
<td>39.5 ± 10.8</td>
<td>42.2 ± 8.5</td>
</tr>
<tr>
<td>Range: year-old</td>
<td>27 - 70</td>
<td>22 - 60</td>
<td>24 - 51</td>
<td>22 - 70</td>
</tr>
<tr>
<td>LENGTH OF CAREER</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean ± SD</td>
<td>18.1 ± 11</td>
<td>21.6 ± 8.17</td>
<td>7.02 ± 7.12</td>
<td>20.2 ± 9.1</td>
</tr>
<tr>
<td>Range: years</td>
<td>3.5 - 45</td>
<td>2 - 41</td>
<td>2mths - 20</td>
<td>2mths - 45</td>
</tr>
</tbody>
</table>

*Respondents could choose more than one category.
Of the 105 participants, 12 were Doctors (11.4%), 85 were Nurses (81%), 6 were Social Workers (5.7%), and each one was Medical Administrator (1%) and Physiotherapist (1%).

"Doctors" consisted of paediatricians, obstetricians, a gynaecological oncologist, and an emergency registrar. "Nurses" consisted of midwives, registered nurses and an enrolled nurse. Because of the small number of doctors from each department, they were categorised together in the doctor group. Similarly, the number of midwives recruited was extremely small, and therefore, it was decided not to treat this group separately but include them in the nurse group. An enrolled nurse was included because she had a son with a disability and more than 20 years clinical experience, and thus was thought to be familiar with this area. It was, however, well acknowledged that enrolled nurses and registered nurses have totally different education/training in relation to their professions.

Data from the medical administrator and physiotherapist are included in the total data but excluded from comparisons across professional groups. Because these two subjects are the sole representative of their categories it was felt there was no point in using their data for comparisons with the other professional groups.

GENDER

Most subjects (90%) and most nurses (98%) were females. All the social workers were females, while only 25% of the doctors (n=3) were females.
EDUCATION

A majority of the subjects (56%) had a post graduate qualification, 24% had a certificate or diploma, and 20% had a bachelor’s degree. All but one doctor (92%) had a post graduate qualification, while the registrar had a bachelor’s degree. A majority of the nurses (54%) had a post graduate qualification, 29% had a certificate or diploma, and 17% had a bachelor’s degree. All but one social worker (83%) had a bachelor’s degree, while the one had a post graduate qualification.

LANGUAGE

English was the first language for all the doctors and the social workers and for 87% of the nurses.

PRESENCE OF CHILDREN

Most subjects (75%) had at least one child. All male doctors were fathers while none of the female doctors had a child. Most nurses (77%) and social workers (67%) had at least one child.

PRESENCE OF RELATIONSHIPS WITH INDIVIDUALS WITH A DISABILITY

No subjects reported that they had a disability themselves. Eighty percent of the subjects knew at least one individual with a disability. Many subjects had either a relative with a disability (36%), a friend with a disability (47%), or a neighbour with a disability (10%).

All but one doctor (92%) knew at least one individual with a disability. Half the doctors had a relative with a disability, four (33.3%) had a friend with a disability, and one (8%)
had a neighbour with a disability. Most nurses (77%) knew at least one individual with a disability, and many had either a relative with a disability (37%), a friend with a disability (44%), or a neighbour with a disability (9%). All the social workers had a friend with a disability. One social worker (17%) had a relative with a disability, and another (17%) had a neighbour with a disability.

AGE

The subjects were between 22 and 70 years of age (mean age: 42.3 ± 8.5 years). There was no significant difference in age among the professional groups: the doctors were between 27 and 70 years of age (mean age: 42.1 ± 11.3 years), the nurses were between 22 and 60 years of age (mean age: 42.5 ± 7.9 years), and the social workers were between 24 and 51 years of age (mean age: 39.5 ± 10.8 years).

LENGTH OF CAREER

Mean length of career of the subjects was 20.3 ± 9.1 years with a range of 2 months to 45 years. Mean length of career of the social workers was significantly shorter than that of the other professional groups (p<0.05). The doctors’ mean length of career was 18.1 ± 11 years, the nurses’ was 21.6 ± 8.17 years, and the social workers’ was 7.02 ± 7.12 years.

5.4 Attitudes toward Having a Child with a Disability

The second section of the questionnaire presented a series of statements regarding the subject’s perceived attitudes toward having a child with a disability. Ten out of 49 statements were selected and modified from the scale developed by Nursey et al. (1990, for details of this study, see p.76). In this section, the subjects were asked to respond to
each statement by indicating their level of agreement on a 5-point Likert scale. Responses were indicated by circling appropriate initials alongside the statements (SA: Strongly Agree, A: Agree, NC: Not Certain, D: Disagree, SD: Strongly Disagree).

The statements were either positive or negative. A positive statement was, for example, “I believe that having a child with a disability gives parents a special sense of purpose in their lives”, and negative one was, “I feel that having a child with a disability is a terrible thing for most families”. In each statement, the highest point of 5 invariably indicated a subject’s most positive attitude, and 1 as the most negative attitude. That is, one who strongly agreed with a positive statement received a score of 5, indicating the most positive attitude, and the other who strongly disagreed with this received a score of 1, indicating the most negative attitude. Scores were concomitantly reversed between positive and negative statements. That is, one who strongly agreed with a negative statement received a score of 1, indicating the most negative attitude, and the other who strongly disagreed with this received a score of 5, indicating the most positive attitude. For the sake of data analysis, a score above the midpoint of 3 was defined “positive attitude”, and a score below this was defined “negative attitude”. Scores for each statement were added up to generate the sum score for this section, ranging on a continuum from most negative to most positive. The higher the score, the more positive attitudes to the statements a subject perceived he/she had.

Table 5.2 gives mean scores for each statement for the professional groups in the attitude section. Figure 5.1 demonstrates comparisons of mean scores for each statement among the professional groups in the attitude section.
<table>
<thead>
<tr>
<th>Statement</th>
<th>DOCTOR</th>
<th>NURSE</th>
<th>SOCIAL WORKER</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I feel that having a child with a disability is terrible thing for most families</td>
<td>2.3 ± 1.0</td>
<td>2.3 ± 1.1</td>
<td>3.2 ± 0.8</td>
<td>2.4 ± 1.1</td>
</tr>
<tr>
<td>(Mean ± SD)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. I believe that having a child with a disability gives parents a special sense of purpose in their lives</td>
<td>3.8 ± 0.6</td>
<td>3.3 ± 1.1</td>
<td>3.3 ± 0.5</td>
<td>3.4 ± 1.1</td>
</tr>
<tr>
<td>3. I feel that having a child with a disability is worse for most parents than having a still-born baby</td>
<td>2.9 ± 1.1</td>
<td>3.4 ± 1.1</td>
<td>3.2 ± 1.2</td>
<td>3.4 ± 1.1</td>
</tr>
<tr>
<td>4. I think that the positive side of having a child with a disability outweighs the negative side for most parents</td>
<td>2.8 ± 1.0</td>
<td>3.0 ± 0.9</td>
<td>3.0 ± 0.9</td>
<td>3.0 ± 1.0</td>
</tr>
<tr>
<td>5. I think that having a child with a disability restricts most families socially</td>
<td>2.5 ± 1.1</td>
<td>2.2 ± 0.9</td>
<td>2.5 ± 0.8</td>
<td>2.2 ± 0.9</td>
</tr>
<tr>
<td>6. It is possible for most parents to love their child with a disability as much as non-disabled child</td>
<td>4.7 ± 0.5</td>
<td>4.4 ± 0.7</td>
<td>4.5 ± 0.5</td>
<td>4.4 ± 0.7</td>
</tr>
<tr>
<td>7. I believe that most people with a disability are usually unhappy</td>
<td>4.0 ± 0.6</td>
<td>4.2 ± 0.6</td>
<td>4.5 ± 0.5</td>
<td>4.2 ± 0.6</td>
</tr>
<tr>
<td>8. I believe that most people with a disability can be helped to live virtually normal lives</td>
<td>2.8 ± 1.1</td>
<td>3.4 ± 1.0</td>
<td>3.5 ± 1.2</td>
<td>3.4 ± 1.1</td>
</tr>
<tr>
<td>9. I think that most people with a disability cannot make close independent friendships with other people</td>
<td>4.4 ± 0.5</td>
<td>4.0 ± 1.0</td>
<td>4.3 ± 0.5</td>
<td>4.1 ± 0.9</td>
</tr>
<tr>
<td>10. I believe that encouragement and care can help most children with a disability to do more than is initially expected of them</td>
<td>4.3 ± 0.5</td>
<td>4.2 ± 0.7</td>
<td>4.3 ± 0.9</td>
<td>4.2 ± 0.7</td>
</tr>
<tr>
<td><strong>SUM SCORE</strong></td>
<td><strong>Mean ± SD</strong></td>
<td><strong>Range</strong></td>
<td><strong>Mean ± SD</strong></td>
<td><strong>Range</strong></td>
</tr>
<tr>
<td></td>
<td>34.3 ± 4.1</td>
<td>28 – 43</td>
<td>34.5 ± 4.4</td>
<td>26 – 46</td>
</tr>
<tr>
<td></td>
<td>36.3 ± 5.2</td>
<td>29 – 43</td>
<td>34.7 ± 4.6</td>
<td>26 – 49#</td>
</tr>
</tbody>
</table>

# Medical Administrator had the highest score 49
Figure 5.1 Comparisons of Mean Scores for Each Statement among Professional Groups in Attitude Section (n = 105)

The Y-axis represents mean scores and crosses at point 3. A value above the line indicates "positive attitude" of subjects in each group to the statement, and a value below the line indicates "negative attitude" of subjects in each group to the statement. The X-axis represents the statements of the attitude section. The numerals 1 to 10 indicate each attitude statement (for details of the statements, see Table 5.2).

Overall, the subjects showed positive attitudes rather than negative attitudes to the statements, demonstrating positive attitudes to 7 out of 10 statements (Figure 5.1). The professional groups largely agreed in their attitudes to the statements. The subjects showed a high level of positive attitudes to Statement 6, 7, 9 and 10, with the most positive attitude to Statement 6. This indicates that the subjects tended to think it is
possible for most parents to love their child with a disability as much as a non-disabled child (Statement 6), deny that most people with a disability are usually unhappy (Statement 7), deny that most people with a disability cannot make close independent friendships with other people (Statement 9), and believe that encouragement and care can help most children with a disability to do more than is initially expected of them (Statement 10).

The subjects, on the other hand, showed negative attitudes to Statement 1 and 5, suggesting that they tended to think that having a child with a disability restricts most families socially (Statement 5), and, except for the social workers, feel that having a child with a disability is terrible thing for most families (Statement 1). The doctors were the only group that demonstrated negative attitudes to Statements 3, 4 and 8. This indicates that they tended to think that having a child with a disability is worse for most parents than having a still-born baby (Statement 3), deny that the positive side of having a child with a disability outweighs the negative side for most parents (Statement 4), and deny that most people with a disability can be helped to live virtually normal lives (Statement 8).

To compare the data among the professional groups, a one-way analysis of variance (One-way ANOVA) was conducted. There were no significant group differences in the mean score for each statement as well as the sum score in this section. There was, however, a suggestion of a group difference (p<0.1) in the mean score for Statement 8, although this failed to reach the statistically significant level (p<0.05). The doctors were the only group showing negative attitude to this statement, indicating that they were
unlikely to think that most people with a disability can be helped to live virtually normal lives.

When the focus was placed on the number of statements with scores below the midpoint of 3, indicating negative attitude (i.e., values below the line in Figure 5.1), the doctors demonstrated negative attitudes most frequently, 5 statements, compared to the nurses’ 2 statements and the social workers’ 1 statement. Interestingly though, the doctors showed the highest level of positive attitude to Statement 2 among the groups, indicating that they were more likely to think that having a child with a disability gives parents a special sense of purpose in their lives than the other groups.

5.5 Knowledge to Give Sufficient Information to Parents

The third section of the questionnaire related to the subject’s perceived knowledge of information that parents are likely to require at the diagnosis of their child’s disability. This section consisted of ten knowledge items that had been identified in the literature. The subjects were asked to choose items about which they felt they were able to provide sufficient information to parents at this time. Responses were indicated by choosing as many boxes alongside the items as were appropriate. The number of items chosen was counted to generate the sum score for this section, ranging on a continuum from least knowledgeable to most knowledgeable. The higher the score, the more knowledge of the items a subject perceived he/she had.

Table 5.3 demonstrates the percentage of subjects in each professional group who indicated they had sufficient knowledge of each item in this section. Comparisons of the
percentage of subjects in each professional group who indicated sufficient knowledge of each item in this section are given in Figure 5.2.

Table 5.3 Percentage of Subjects in Each Professional Group Indicating Sufficient Knowledge of Each Item in Knowledge Section (n = 105)

<table>
<thead>
<tr>
<th>ITEM</th>
<th>DOCTOR % (n)</th>
<th>NURSE % (n)</th>
<th>SOCIAL WORKER % (n)</th>
<th>TOTAL % (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>ITEM 1. Cause and history of the disability</td>
<td>91.7 (11)</td>
<td>64.7 (55)</td>
<td>16.7** (1)</td>
<td>63.8 (67)</td>
</tr>
<tr>
<td>ITEM 2. Accurate and up-to-date information of the disability</td>
<td>75 (9)</td>
<td>57.6 (49)</td>
<td>66.7 (4)</td>
<td>60 (63)</td>
</tr>
<tr>
<td>ITEM 3. Treatment and therapy options for the disability</td>
<td>91.7** (11)</td>
<td>54.1 (46)</td>
<td>16.7 (1)</td>
<td>56.2 (59)</td>
</tr>
<tr>
<td>ITEM 4. Educational options for the disability</td>
<td>50 (6)</td>
<td>35.3 (30)</td>
<td>16.7 (1)</td>
<td>36.2 (38)</td>
</tr>
<tr>
<td>ITEM 5. Informative materials for parents</td>
<td>83.3 (10)</td>
<td>72.9 (62)</td>
<td>83.3 (5)</td>
<td>75.2 (79)</td>
</tr>
<tr>
<td>ITEM 6. Counselling services</td>
<td>83.3 (10)</td>
<td>68.2 (58)</td>
<td>83.3 (5)</td>
<td>70.5 (74)</td>
</tr>
<tr>
<td>ITEM 7. Specialty services</td>
<td>91.7 (11)</td>
<td>56.5* (48)</td>
<td>83.3 (5)</td>
<td>61 (64)</td>
</tr>
<tr>
<td>ITEM 8. Community services</td>
<td>50 (6)</td>
<td>68.2 (58)</td>
<td>66.7 (4)</td>
<td>66.7 (70)</td>
</tr>
<tr>
<td>ITEM 9. Support groups and Parent-to-parent referrals</td>
<td>50 (6)</td>
<td>70.6 (60)</td>
<td>83.3 (5)</td>
<td>69.5 (73)</td>
</tr>
<tr>
<td>ITEM 10. Suggestions on how to inform friends and family</td>
<td>66.7 (8)</td>
<td>56.5 (48)</td>
<td>100# (6)</td>
<td>60 (63)</td>
</tr>
</tbody>
</table>

* p < 0.05   ** p < 0.01   # p < 0.1

The sum score for professional groups in this section are as follows (Mean±SD);

- Doctors: 7.3 ± 2.4
- Nurses: 6.0 ± 3.2
- Social Workers: 6.2 ± 1.7
The Y-axis indicates the percentage of subjects in each group who perceived they had knowledge to give parents sufficient information on each item in the knowledge section. The X-axis represents the items of this section. The numerals 1 to 10 indicate each knowledge item (for details of the items, see Table 5.3).

The data suggested that more than half the subjects perceived they had knowledge of all the items except for Item 4 “Educational options of the disability” (n=38, 36%). This was also the item of which the least subjects in all the groups indicated perceived knowledge. The highest proportion of the subjects indicated knowledge of informative materials for parents (n=79, 75%), followed by counselling services (n=74, 71%), and
support groups and parent-to-parent referrals (n=73, 70%). The data of the total subjects and the nurses agreed, probably because a large number of subjects in the nurse group had a great influence on the total data.

The groups varied in the proportion of subjects with perceived knowledge of each item. Compared to the other groups, a relatively modest proportion of subjects in the nurse group indicated knowledge of all the items. This group most frequently yielded the other groups (Items 2, 5, 6, 7 and 10). Of these items, they remarkably yielded the other groups on Item 7 “Specialty services”. They failed to show any superiority to the other groups, except for Item 8 “Community services” on which they barely exceeded the other groups.

The doctors most frequently (Items 1, 2, 3, 4 and 7) exceeded the other groups, suggesting a higher proportion of subjects in this group indicating knowledge of the items than in the other groups. Of these items, they strikingly exceeded the other groups on Item 1 “Cause and history of the disability” and Item 3 “Treatment and therapy options of the disability”. The proportion of subjects in this group with perceived knowledge of each item was never lower than 50%. They demonstrated the lowest proportion of subjects with perceived knowledge for Items 4, 8 and 9. These were “Educational options of the disability”, “Community services” and “Support groups and parent-to-parent referrals” respectively, on the latter two items they yielded to the other groups.

Compared to the other groups, the proportion of subjects in the social worker group with perceived knowledge of the items showed the largest variability. They yielded
considerably to the other groups on Items 1, 3 and 4. These were "Cause and history of the disability", "Treatment and therapy options of the disability" and "Educational options of the disability" respectively. The social workers, however, also demonstrated a relatively high proportion of subjects with perceived knowledge for the remaining items. They compared with the doctors on Item 5 "Informative materials" and Item 6 "Counselling services", and exceeded the other groups on Item 9 "Support groups and parent-to-parent referrals" and Item 10 "Suggestions on how to inform friends and family".

By employing a one-way analysis of variance (One-way ANOVA), there were statistically significant group differences in the proportion of subjects with perceived knowledge of Items 1, 3 and 7. As can be seen in Table 5.3, a significantly lower proportion of subjects in the social worker group indicated knowledge of Item 1 "Cause and history of the disability" than the other groups (p<0.01), a significantly higher proportion of subjects in the doctor group indicated knowledge of Item 3 "Treatment and therapy options of the disability" (p<0.01), and a significantly lower proportion of subjects in the nurse group indicated knowledge of Item 7 "Specialty services" (p<0.05). There was also a suggestion of a group difference in the data on Item 10 "Suggestions on how to inform friends and family" (p<0.1) of which all the social workers indicated knowledge, although this failed reach the statistically significant level of p<0.05.

5.6 Skills Necessary in Informing Parents of Their Child’s Disability
The fourth section of the questionnaire involved a series of statements in relation to subjects’ perceived skills in items that are thought to be necessary in informing parents of their child’s disability. Eleven statements pertaining to the skill items were developed based on knowledge from the literature. The subjects were asked to respond to each statement by deciding their level of agreement on a 5-point Likert scale. An example of the statements was “Your education/training in disability”. Responses were indicated by choosing appropriate words alongside each statement (e.g. Excellent; More than adequate; Adequate; Less than adequate, Poor). In each statement, the highest point of 5 invariably indicated a subject’s perceived skill in a given item as excellent, while the lowest point 1 indicated a subject’s perceived skill in the item as poor. For the sake of data analysis, a score above the midpoint of 3 was defined as “more than adequate”, and a score below this was defined “less than adequate”. Scores for each statement were added up to generate the sum score for this section, ranging a continuum from least skilled to most skilled. The higher the score, the more skills in the items of the statements a subject perceived he/she had.

Table 5.4 demonstrates mean scores for each item for the professional groups in the skill section. Comparisons of mean scores for each item among the groups in this section are given in Figure 5.3. The detailed responses of subjects in each group to each skill item are given in Appendix 5 and are discussed more extensively in Chapter 6.
<table>
<thead>
<tr>
<th>Item</th>
<th>Professional Group</th>
<th>DOCTOR</th>
<th>NURSE</th>
<th>SOCIAL WORKER</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Education/training in disability</td>
<td></td>
<td>2.7 ± 1.2</td>
<td>2.3 ± 0.9</td>
<td>2.8 ± 0.4</td>
<td>2.4 ± 0.9</td>
</tr>
<tr>
<td>2. Education/training in counselling and communication skills</td>
<td></td>
<td>2.9 ± 0.7</td>
<td>2.9 ± 0.9</td>
<td>4.5 ± 0.5***</td>
<td>3.0 ± 0.9</td>
</tr>
<tr>
<td>3. Education/training in parent-professional relationship</td>
<td></td>
<td>3.2 ± 1.0</td>
<td>3.0 ± 0.9</td>
<td>3.8 ± 0.8#</td>
<td>3.1 ± 0.9</td>
</tr>
<tr>
<td>4. Experience with parents of children with a disability</td>
<td></td>
<td>3.0 ± 1.0</td>
<td>2.7 ± 1.2</td>
<td>3.2 ± 0.4</td>
<td>2.8 ± 1.1</td>
</tr>
<tr>
<td>5. Familiarity with parents' perspective of having a child with a disability</td>
<td></td>
<td>2.8 ± 0.9</td>
<td>2.6 ± 1.1</td>
<td>3.3 ± 0.5</td>
<td>2.7 ± 1.0</td>
</tr>
<tr>
<td>6. Education/training in informing</td>
<td></td>
<td>2.9 ± 1.1</td>
<td>2.2 ± 0.9*</td>
<td>2.7 ± 0.5</td>
<td>2.3 ± 1.0</td>
</tr>
<tr>
<td>7. Experience in informing</td>
<td></td>
<td>3.1 ± 1.1**</td>
<td>2.1 ± 1.0</td>
<td>2.5 ± 0.8</td>
<td>2.2 ± 1.0</td>
</tr>
<tr>
<td>8. Frequency of observing other professionals' informing</td>
<td></td>
<td>3.8 ± 1.3</td>
<td>3.2 ± 1.1</td>
<td>3.5 ± 1.5</td>
<td>3.3 ± 1.2</td>
</tr>
<tr>
<td>9. Familiarity with parents' emotional reactions to the child's diagnosis</td>
<td></td>
<td>3.8 ± 0.7</td>
<td>3.6 ± 1.0</td>
<td>4.3 ± 0.8</td>
<td>3.7 ± 1.0</td>
</tr>
<tr>
<td>10. Confidence in informing</td>
<td></td>
<td>3.8 ± 0.9**</td>
<td>2.7 ± 1.1</td>
<td>3.0 ± 1.1</td>
<td>2.9 ± 1.1</td>
</tr>
<tr>
<td>11. Feeling additional education and/or training in the areas identified as beneficial</td>
<td></td>
<td>2.3 ± 0.9</td>
<td>2.0 ± 0.9</td>
<td>1.7 ± 0.5</td>
<td>2.0 ± 0.9</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SUM SCORE</th>
<th>Mean ± SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>DOCTOR</td>
<td>34.3 ± 8.8</td>
<td>18 – 49</td>
</tr>
<tr>
<td>NURSE</td>
<td>29.4 ± 7.0*</td>
<td>15 – 45</td>
</tr>
<tr>
<td>SOCIAL WORKER</td>
<td>35.3 ± 4.8</td>
<td>31 – 44</td>
</tr>
<tr>
<td>TOTAL</td>
<td>30.3 ± 7.2</td>
<td>15 – 49</td>
</tr>
</tbody>
</table>

# p < 0.1  * p < 0.05  ** p < 0.01  *** p < 0.0001
Figure 5.3 Comparisons of Mean scores for Each Item among Professional Groups in Skill Section (n = 105)

The Y-axis represents mean scores and crosses at the midpoint 3. A value above the line indicates a perceived skill in the item of subjects in each group as “more than adequate”, and a value below the line indicates a perceived skill in the item of subjects in each group as “less than adequate”. The X-axis represents the items of this section. The numerals 1 to 11 in the X-axis correspond to each skill item (for details of the items, see Table 5.4).

Overall, the subjects perceived their skills in the items was less than adequate rather than more than adequate, indicating a less than adequate level of skills in 7 out of 11 items. In the remaining three items the subjects perceived their skills as more than adequate. These were Item 3 “Education/training in parent-professional relationship”,
Item 8 “Frequency of observing other professionals’ informing” and Item 9 “Familiarity with parents’ emotional reactions to the child’s diagnosis”. Of these items, the groups, except the social workers, demonstrated the highest level of perceived skill in Item 9 “Familiarity with parents’ emotional reactions to the child’s diagnosis”, while the social workers indicated the highest level of perceived skill in Item 2 “Education/training in counselling and communication skills”.

The subjects demonstrated a lower level of perceived skill in Items 1, 6, 7 and 11. These were “Education/training in disability”, “Education/training in informing”, “Experience in informing”, and “Feeling additional education/training in the areas identified as beneficial”, respectively. Of these items, the subjects scored least for Item 11, indicating that they tended to agree with this statement.

The groups varied considerably in the level of perceived skill in each item. The doctors showed a more than adequate level of perceived skills in 5 items (Items 3, 7, 8, 9, and 10), with the highest score for Items 8, 9 and 10. These were “Frequency of observing other professionals’ informing”, “Familiarity with parents’ emotional reactions to the child’s diagnosis” and “Confidence in informing”, respectively. However, they also demonstrated a less than adequate level of perceived skills in 5 items (Items 1, 2, 5, 6 and 11). These were “Education/training in disability”, “Education/training in counselling and communication skills”, “Familiarity with parents’ perspective of having a child with a disability”, “Education/training in informing”, and “Feeling additional education/training in the areas identified as beneficial”, respectively. The doctors exceeded the other groups on Items 6, 7, 8, 10 and 11, and was the only group that
scored a *more than adequate* level for Item 7 “Experience in informing” and Item 10 “Confidence in informing”.

The nurses scored a *more than adequate* level for only two items. These were Item 8 “Frequency of observing other professionals’ informing” and Item 9 “Familiarity with parents’ emotional reactions to the child’s diagnosis”. This group most frequently scored least among the groups, with a remarkably lower level of skills in Item 1 “Education/training in disability” and Item 6 “Education/training in informing”. They were also the only group that indicated a *less than adequate* level of skills in Item 4 “Experience with parents of children with a disability” and Item 10 “Confidence in informing”.

The social workers most frequently scored a *more than adequate* level for the items, 6 items compared to 5 items for the doctors and 2 items for the nurses. They were also the only group that scored a *more than adequate* level for Items 2, 4 and 5. These were “Education/training in counselling and communication skills”, “Experience with parents of children with a disability” and “Familiarity with parents’ perspective of having a child with a disability”, respectively. This group exceeded the other groups on 5 items (Items 2, 3, 4, 5 and 9), most prominently on Item 2 “Education/training in counselling and communication skills” and Item 3 “Education/training in parent-professional relationship”. They yet scored least among the groups for Item 11 “Feeling additional education/training in the areas identified as beneficial”, despite their higher scores for the above items than the other groups.
Comparisons using a one-way analysis of variance (One-way ANOVA) revealed significant group differences in the level of perceived skills in Items 2, 6, 7 and 10 and in the sum score. As can be seen in Table 5.4, the social workers scored significantly higher for Item 2 “Education/training in counselling and communication skills” (p<0.0001), the nurses scored significantly lower for Item 6 “Education/training in informing” (p<0.05), and the doctors scored significantly higher for Item 7 “Experience in informing” (p<0.01) and Item 10 “Confidence in informing” (p<0.01). There was also a suggestion of a group difference in the data on Item 3 “Education/training in parent-professional relationship” (p<0.1) for which the social workers scored higher than the other groups, although this failed to reach the statistically significant level. Overall lower scores in the nurse group for the items seem to result in a significant group difference in the sum score of this section (p<0.05).
6.1 Introduction

As discussed previously, health care professionals can be an important resource for families of children with a disability. Among a variety of professional disciplines, they are often the first to come into contact with these families, and thus are likely to be responsible for informing parents of their child’s disability. Health care professionals who are involved in the informing interview take an important role in establishing a good relationship with parents to facilitate their positive adaptation to the child’s disability.

The current study investigated health care professionals’ preparedness for informing practice through a questionnaire survey. The literature suggested factors that possibly affect professionals’ practice. These were professionals’ attitudes toward having a child with a disability, knowledge to give sufficient information to parents, and skills necessary in informing parents of their child’s disability. Unfortunately, there were no research instruments available to investigate health care professionals’ preparedness for informing practice in these areas, except for an attitude questionnaire. A questionnaire was consequently developed for the current study with knowledge from the literature. Based on the subjects’ responses to the questionnaire, the current study investigated professionals’ preparedness for informing practice in these areas among different professional groups, including doctors, nurses, and social workers.

A total of 105 health care professionals consisting of 12 doctors, 85 nurses, 6 social workers, 1 medical administrator, and 1 physiotherapist were included in the current
study. In the following section, the findings of each section of the questionnaire are discussed.

6.2 Attitudes toward Having a Child with a Disability

To examine health care professionals' attitudes toward having a child with a disability, 10 out of 49 statements were selected and modified from the scale developed by Nursey et al. (1990, for details of this study, see p.76). They investigated differences in attitude toward individuals with a disability between doctors and parents of children with a disability. The statements were associated with individuals with a disability in relation to four aspects of their lives: the effect on the family, place in society, quality of life and independence and autonomy. The statements selected for the current study related to either the effect on the family (Statement 1-6) or quality of life (Statement 7-10). The remaining statements relating to place in society and independence and autonomy were not included because these seemed to be designed for an older population with a disability than those targeted in the current study, i.e., young children with a disability.

It was found that the subjects in the current study tended to score lower for the statements relating to the effect on the family (mean score of the items was 3.13 points) and score higher for the statements relating to quality of life (mean score of the items was 3.98 points). This indicates that they were likely to be pessimistic about the effect of a child with a disability on his/her family, yet optimistic about quality of life of such a child. A visual representation of the data was given in Figure 5.1 (p.154).

To make a comparison between the current study and Nursey et al.'s study, the researcher also calculated mean scores of the items relating to the effect on the family
and quality of life from the data of Nursey et al.’s study (1990). Similar tendencies were found in their study: doctors scored lower on the items relating to the effect on the family (mean score of the items was 3 points) and scored higher on the items relating to quality of life (mean score of the items was 3.86 points).

With regard to the effect on the family, the subjects in the current study appeared to acknowledge a restricted social life in families of children with a disability (Statement 5), and, except for the social workers, think having a child with a disability is a tragedy for these families (Statement 1). They, though somewhat inconsistently, seemed to believe in parents’ ability to form an attachment to the child (Statement 6).

The finding that professionals tended to be pessimistic about the effect of the child on the family is consistent with other studies. Past researchers reported that professionals overestimated the negative impact of the child on the family (Blackard & Barsh, 1982, for details of this study, see p.74) and underestimated parents’ ability to cope with problems in the family (Urey & Viar, 1990, for details of this study, see p.75).

In relation to quality of life, the subjects in the current study seemed to believe in abilities of the child to achieve a happy life (Statement 7) and form friendships with others (Statement 9), and seem to be hopeful of the child’s potential (Statement 10).

The finding that professionals tended to be optimistic about quality of life of the child was not found in the literature and requires further investigation to assure its reliability.
It should be noted that the scale developed by Nursey et al. (1990) was not validated and questioned its validity by other researchers. Hasnat & Graves (2000a, for details of this study, see p.94) used a modified version of Nursey et al.'s scale to examine the relationship between professionals' attitudes toward individuals with a disability and their informing practice, with no relationship found. The researchers pointed out that “many of the statements expressing a supposed 'negative attitude' towards people with a disability were somewhat subjective and open to interpretation”(p.31). However, the reliability of Nursey et al.'s scale may be, in part, supported by the current finding. Similar to subjects in their study, the subjects in the current study scored lower for the items relating to the effect on the family and scored higher for the items relating to quality of life.

Overall, the subjects in the current study demonstrated positive attitudes (> 3) rather than negative attitudes (< 3) to the statements. This was not expected and may contradict the literature that generally suggests professionals to be pessimistic about abilities of individuals with a disability.

Nursey et al. (1990) assumed that professionals who had personal contact with individuals with a disability were more optimistic about abilities of these individuals than those without such contact. The proportion of subjects who had personal contact with these individuals in the current study seemed to be high (see below). Assuming that this may be a possible explanation for the subjects’ overall positive attitudes to the statements, a further investigation was conducted.
From the demographic data, 80% (n=84/105) of the subjects in the current study indicated personal contact with individuals with a disability. Of these, 37% (n=39) had social contact only (i.e. having either a friend or a neighbour with a disability), 25% (n=26) had family contact only (i.e. having a relative with a disability), and 11% (n=12) had both social and family contacts.

Regrettably, there were no data available in Australia regarding the proportion of professionals who had personal contact with these individuals, and only one U.S. study provided some data on this issue.

Wolraich (1980) reported that 45% of doctors (n=21/47) in his study had personal contact with individuals with a disability. Of these, 30% (n=14) had social contact only, 6% (n=3) had family contact only and 9% (n=4) had both social and family contacts.

As can be seen, the proportion of subjects who had personal contact with individuals with a disability in the current study (80%) is almost twice as much as that of Wolraich’s study (45%). Some possible interpretations for this may be: (1) professionals who returned a questionnaire in the current study tended to be those who had personal contact with these individuals, (2) these individuals have been more integrated into the community since Wolraich’s 1980 study, and (3) a different situation in terms of community integration of these individuals across the countries. However, a large difference in the proportion of subjects who had family contact with these individuals between the studies (36% vs 15%) suggests that the subjects in the current study tended to be those who had family contact with these individuals.
Next, in order to examine Nursey et al.'s assumption of a positive relationship between professionals’ personal contact with individuals with a disability and their attitudes toward these individuals, the sum scores of the attitude section between subjects who had personal contact with these individuals and those without such contact were compared.

The results failed to support Nursey et al.'s assumption. Although subjects who had personal contact with these individuals scored slightly higher (35 points) than those without such contact (33.6 points) it failed to reach the statistically significant level. This suggests that subjects who had personal contact with these individuals did not differ from those without such contact in their attitudes toward these individuals.

From the statistical analysis of the data using a one-way analysis of variance (One-way ANOVA), it emerged that the professional groups did not differ significantly in their attitudes toward having a child with a disability. This may contradict the findings of other studies that found doctors to be more pessimistic about abilities of individuals with a disability than other disciplines (e.g., Wolraich & Siperstein, 1983).

Other indicators, however, seem to suggest somewhat more negative attitudes of the doctors toward having a child with a disability than the other groups. That is, the doctors most frequently demonstrated negative attitudes (> 3) to the attitude statements among the groups. They were also the only group that indicated negative attitudes to Statement 3, 4 and 8. This suggests that they were more likely, than the other groups, to think that having a child with a disability is worse than having a still-born baby, that the negative side of having a child with a disability outweighs the positive side, and that
people with a disability cannot be helped to live virtually normal lives. The small sample size of this group (n=12) might not have had enough power to make this difference to reach the statistically significant level.

Pessimistic attitudes of professionals were found to be a source of parents’ dissatisfaction with informing practice in the literature (Krahn et al., 1993, for details of this study, see p.87). Such attitudes may be conveyed to parents through the information given at the informing interview, which potentially affects parents’ perceptions of the child. Professionals’ pessimistic attitudes may also have adverse effects on their informing practice. For instance, if they have pessimistic attitudes toward having a child with a disability they are less likely to tell parents ‘fully, clearly and at an early stage’ (Nursey et al., 1988).

The current finding may indicate that nurses and social workers can act as a moderator of doctors’ slightly more negative attitudes in informing practice. The involvement of nurses and social workers in informing practice may result in a higher level of parents’ satisfaction with services. Future studies of professionals’ attitudes toward having a child with a disability are required to confirm doctors’ slightly more negative attitudes than other professions.

6.3 Knowledge to Give Sufficient Information to Parents

There were no instruments, the researcher was aware of, to investigate health care professionals’ existing knowledge to give sufficient information to parents at the informing interview. The knowledge section of the questionnaire was, as a result, developed for the current study based on knowledge from the literature. Past researchers
suggested that parents generally require information on causes of their child’s disability (Beavers et al., 1986), treatment and therapy options of the disability (Darling, 1991a), accurate and up-to-date information of the disability (Garwick et al., 1995), educational options for the child (Darling, 1991a), informative materials of the disability (Quine & Pahl, 1989), counselling services (Urey & Viar, 1990), specialty services (Krahn et al., 1993), community services (Kornblatt & Heinrich, 1985), support groups and parent-to-parent referrals (Krahn et al., 1993), and suggestions on how to inform friends and family (Lynch & Staloch, 1988).

The results suggest that more than half the subjects indicated knowledge of all the items, except for educational options for the child (n=38, 36%). The subjects appeared to be most familiar with informative materials for parents (n=79, 75%), followed by counselling services (n=74, 71%), and support groups and parent-to-parent referrals (n=73, 70%). The subjects’ less knowledge of educational options for the child, compared to the other items, was expected prior to the study since this was the only item relating to a non-health care discipline. These findings should, however, be seen cautiously, as the data of the total subjects seem to be influenced by the nurses’ data.

The groups varied in the proportion of subjects who indicated knowledge of the items. The doctors showed overall competency in this section of the questionnaire, exceeding the other groups most frequently (5 items). All but one doctor (n=11, 92%) perceived they were familiar with the cause and history of the disability, treatment and therapy options, and specialty services, while only half the doctors (n=6, 50%) perceived they were familiar with educational options, community services, and support groups and parent-to-parent referrals. Of these, a significantly higher proportion of subjects in this
group indicated knowledge of treatment and therapy options than the other groups (p<0.01).

A relatively modest proportion of subjects in the nurse group indicated knowledge of all the items, except for educational options for the child. Compared to the other groups, a slightly higher proportion of subjects in this group indicating knowledge of community services, while a significantly lower proportion of subjects indicating knowledge of specialty services (p<0.05).

Among the groups, the social workers demonstrated the largest variability in their perceived knowledge of the items. Compared to the other groups, a higher proportion of subjects in this group indicated knowledge of support groups, parent-to-parent referrals, and suggestions on how to inform friends and family, while a lower proportion of subjects indicated knowledge of the cause and history of the disability, treatment and therapy options, and educational options. Of these, a significantly lower proportion of subjects in this group indicated knowledge of the cause and history of the disability than the other groups (p<0.01). There was also a suggestion of a group difference (p<0.1) in that all the social workers perceived they could advise parents how to inform friends and family although this failed to reach the statistically significant level.

Table 6.1 shows the comparative ranking of percentage of subjects in each professional group who indicated knowledge of each item. The data suggest unique clinical competence of the groups in relation to the provision of information.
### Table 6.1 Comparative Ranking of Percentage of Subjects in Each Professional Group Indicating Sufficient Knowledge of Each Item in Knowledge Section

<table>
<thead>
<tr>
<th>DOCTOR Ranking</th>
<th>%</th>
<th>NURSE Ranking</th>
<th>%</th>
<th>SOCIAL WORKER Ranking</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Cause and history of the disability</td>
<td>91.7</td>
<td>1. Informative materials</td>
<td>72.9</td>
<td>1. Suggestions on how to inform friends and family</td>
<td>100</td>
</tr>
<tr>
<td>1. Treatment and therapy options of the disability</td>
<td>91.7</td>
<td>2. Support groups and parent-to-parent referrals</td>
<td>70.6</td>
<td>2. Informative materials</td>
<td>83.3</td>
</tr>
<tr>
<td>1. Specialty services</td>
<td>91.7</td>
<td>3. Counselling services</td>
<td>68.2</td>
<td>2. Counselling services</td>
<td>83.3</td>
</tr>
<tr>
<td>4. Informative materials</td>
<td>83.3</td>
<td>3. Community services</td>
<td>68.2</td>
<td>2. Specialty services</td>
<td>83.3</td>
</tr>
<tr>
<td>4. Counselling services</td>
<td>83.3</td>
<td>5. Cause and history of the disability</td>
<td>64.7</td>
<td>2. Support groups and parent-to-parent referrals</td>
<td>83.3</td>
</tr>
<tr>
<td>6. Accurate and up-to-date information of the disability</td>
<td>75</td>
<td>6. Accurate and up-to-date information of the disability</td>
<td>57.6</td>
<td>6. Accurate and up-to-date information of the disability</td>
<td>66.7</td>
</tr>
<tr>
<td>7. Suggestions on how to inform friends and family</td>
<td>66.7</td>
<td>7. Specialty services</td>
<td>56.5</td>
<td>6. Community services</td>
<td>66.7</td>
</tr>
<tr>
<td>8. Community services</td>
<td>50</td>
<td>9. Treatment and therapy options of the disability</td>
<td>53.6</td>
<td>8. Treatment and therapy options of the disability</td>
<td>16.7</td>
</tr>
</tbody>
</table>

Note that this was derived based on rearrangements of the data that were presented in Chapter 5 (for details, see Table 5.3 on p.157). A visual representation of the data was also given in Figure 5.2 on p.158.

The doctors tended to indicate knowledge of medical aspects of the disability (i.e. cause and history of the disability, and treatment and therapy options of the disability), but tended not to indicate knowledge of community resources (i.e. support groups and...
parent-to-parent referrals, and community services) with an exception of specialty services.

In contrast, the social workers were more likely to indicate knowledge of community resources (i.e. counselling services, specialty services, and support groups and parent-to-parent referrals) and non-medical advice (i.e. suggestions on how to inform friends and family), but less likely to indicate knowledge of medical aspects of the disability (i.e. cause and history of the disability, and treatment and therapy options of the disability).

The nurses appeared to perceive they were somewhat more familiar with community resources (i.e. counselling services, community services, and support groups and parent-to-parent referrals) than medical aspects of the disability (i.e. cause and history of the disability, and treatment and therapy options of the disability).

The finding that the doctors tended to indicate knowledge of medical aspects of the disability while the social workers tended to indicate knowledge of community resources seems to support Jacobs' (1977) claim that professionals tend to be familiar with their own services. What was not expected was, however, the finding that the nurses were slightly more familiar with community resources than medical aspects of the disability. From the demographic data, the subjects in the nurse group were: predominantly female (98%), with a child (77%), had average age of 43 years, had a career of 22 years on average, and were predominantly from an English speaking background (87%). This may shape a picture that they have lived in their residence for a certain period with their family and been involved in the community to some extent, and
as a result, they have become aware of community resources. Another possible explanation for this may be a recent emphasis on community resources in the nursing curriculum, though most subjects in the current study were educated some years ago.

Professionals involved in informing practice not only have to be the informer of diagnosis but also the provider of information. Parents indicate that the major support from professionals at the time of their child’s diagnosis is information (Baxter, 1986). Professionals must have knowledge to give sufficient information to parents at this time, as Baxter stated (1986) that the basic factor underlying parents’ concerns is uncertainty. Parents see uncertainty as a source of additional stress (Quine & Rutter, 1994), and report a high level of dissatisfaction with the provision of information. They often complain about professionals’ lack of knowledge of community resources (Krahn et al., 1993), and express difficulties in obtaining this kind of information on their own.

In this regard, the involvement of nurses and social workers in informing practice is beneficial in providing additional information to parents. The nurses in the current study, compared to the other groups, failed to show any particular expertise regarding their knowledge of the items, nevertheless, the data can be interpreted as one in two nurses being able to provide parents with information on all the items, except for educational options for the child. If parents cannot obtain information on a certain topic from one nurse they can obtain this information from another nurse. Nurses can be an important resource for parents in obtaining information in the aftermath of the informing interview and on an ongoing basis, as they are regarded as more approachable and available than other professionals (Hitch & Murgatroyd, 1983).
The findings in the attitude section might indicate some validity of the questionnaire used in the current study as it generated discriminatory results among the groups, which were expected prior to the study. That is, doctors tend to be familiar with medical aspects of the disability while social workers tend to be familiar with community resources.

6.4 Skills Necessary in Informing Parents of Their Child’s Disability

The literature suggests that health care professionals’ skills necessary in informing practice are closely related to the level of parents’ satisfaction with informing practice. These skills can be developed from education/training that professionals received, and their experience and familiarity with issues pertaining to informing practice. Despite a growing awareness of its importance, past studies did not adequately address this issue except for some training programs on communication skills for medical students. As a result, there were no instruments, the researcher was aware of, to investigate health care professionals’ skills necessary in informing practice. The skill section of the questionnaire was thus developed for the current study based on knowledge from the literature.

The results showed that the subjects in the current study tended to feel their skills in the items as less than adequate (< 3), indicating a less than adequate level of skills in 7 out of 11 items. They tended to perceive their education/training in disability (Item 1) and informing (Item 6) as less than adequate (< 3), and agreed with additional education/training in the areas identified as beneficial (Item 11). Once again the large number of subjects in the nurse group appeared to have an impact on the data of the total subjects.
Although the subjects’ perceived skills in the above areas were less than adequate, they also indicated slightly more than adequate (> 3) education/training in parent-professional relationship (Item 3), experience in observing other professionals’ informing (Item 8), and familiarity with parents’ emotional reactions to the child’s diagnosis (Item 9). All the subjects, except the social workers, appeared to be most confident in their familiarity with parents’ emotional reactions to the child’s diagnosis (Item 9), while the social workers were most confident in their education/training in counselling and communication skills (Item 2).

For the sake of data analysis, the items in the skill section were classified into three categories: informing related items (i.e., Items 6, 7, 8, 10), education/training related items (i.e., Items 1, 2, 3, 6, 11), and parent related items (i.e., Items 4, 5, 9). The categories and items in each category are as follow. Note that Item 6 was thought to be both an informing and education/training related item.

Informing related item

- Item 6. Education/training in informing
- Item 7. Experience in informing
- Item 8. Frequency of observing other professionals’ informing
- Item 10. Confidence in informing

Education/training related item

- Item 1. Education/training in disability
- Item 2. Education/training in counselling and communication skills
- Item 3. Education/training in parent-professional relationship
Item 6. Education/training in informing

Item 11. Feeling additional education/training in the areas identified as beneficial

Parent related item

Item 4. Experience with parents of children with a disability

Item 5. Familiarity with parents’ perspective of having a child with a disability

Item 9. Familiarity with parents’ emotional reactions to the child’s diagnosis

Table 6.2 shows the comparative ranking of mean scores for each skill item for each professional group. The data suggest unique clinical competence of the groups in relation to the skills necessary in informing practice.

INFORMING RELATED ITEMS

With regard to the informing related items, no group indicated more than adequate education/training in informing, while all the groups perceived their experience in observing other professionals’ informing was more than adequate.

The doctors seemed to be most confident in the informing related items among the groups. They tended to perceive they had more than adequate experience in observing other professionals’ informing, and were confident in informing. The doctors were also the only group that indicated their experience in informing as more than adequate. The statistical analysis revealed that the doctors perceived that they had significantly more experience in informing (p<0.01) and were significantly more confident in informing than the other groups (p<0.01).

CHAPTER 6. DISCUSSION
## Table 6.2 Comparative Ranking of Mean Scores for Each Item in Skill Section for Each Professional Group

<table>
<thead>
<tr>
<th>DOCTOR Ranking</th>
<th>Mean</th>
<th>NURSE Ranking</th>
<th>Mean</th>
<th>SOCIAL WORKER Ranking</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. + Familiarity with parents' emotional reactions</td>
<td>3.83</td>
<td>1. + Familiarity with parents' emotional reactions</td>
<td>3.61</td>
<td>1. $ Education/training in counselling and communication skills</td>
<td>4.5</td>
</tr>
<tr>
<td>1. # Confidence in informing</td>
<td>3.83</td>
<td>2. # Frequency of observing other professionals' informing</td>
<td>3.2</td>
<td>2. + Familiarity with parents' emotional reactions</td>
<td>4.33</td>
</tr>
<tr>
<td>3. # Frequency of observing other professionals' informing</td>
<td>3.75</td>
<td>3. $ Education/training in parent-professional relationship</td>
<td>3.01</td>
<td>3. $ Education/training in parent-professional relationship</td>
<td>3.83</td>
</tr>
<tr>
<td>4. $ Education/training in parent-professional relationship</td>
<td>3.17</td>
<td>4. $ Education/training in counselling and communication skills</td>
<td>2.95</td>
<td>4. # Frequency of observing other professionals' informing</td>
<td>3.5</td>
</tr>
<tr>
<td>5. # Experience in informing</td>
<td>3.08</td>
<td>5. # Confidence in informing</td>
<td>2.75</td>
<td>5. + Familiarity with parents' perspective</td>
<td>3.33</td>
</tr>
<tr>
<td>7. $ Education/training in counselling and communication skills</td>
<td>2.92</td>
<td>7. + Familiarity with parents' perspective</td>
<td>2.6</td>
<td>7. # Confidence in informing</td>
<td>3</td>
</tr>
<tr>
<td>7. $# Education/training in informing</td>
<td>2.92</td>
<td>8. $ Education/training in disability</td>
<td>2.32</td>
<td>8. $ Education/training in disability</td>
<td>2.83</td>
</tr>
<tr>
<td>9. + Familiarity with parents' perspective</td>
<td>2.83</td>
<td>9. $# Education/training in informing</td>
<td>2.2</td>
<td>9. $# Education/training in informing</td>
<td>2.67</td>
</tr>
<tr>
<td>10. $ Education/training in disability</td>
<td>2.67</td>
<td>10. # Experience in informing</td>
<td>2.11</td>
<td>10. # Experience in informing</td>
<td>2.5</td>
</tr>
<tr>
<td>11. $ Perceived benefit from additional education/training</td>
<td>2.33</td>
<td>11. $ Perceived benefit from additional education/training</td>
<td>2.01</td>
<td>11. $ Perceived benefit from additional education/training</td>
<td>1.67</td>
</tr>
</tbody>
</table>

# Informing related item: $ Education/training related item: + Parent related item

Note that this was derived based on rearrangements of the data that were presented in Chapter 5 (for details, see Table 5.4 on p.162). A visual representation of the data was also given in Figure 5.3 on p.163.

The line distinguishes items in which subjects in each group indicated a more than adequate (> 3) level of skill from items in which they indicated a less than adequate (< 3) level of skill.
The social workers tended to perceive their experience in informing as \textit{less than adequate}, yet indicated \textit{more than adequate} experience in observing other professionals’ informing, and an \textit{adequate} level (= 3) of confidence in informing. This suggests that they were less likely to be involved in informing themselves, yet frequently observed other professionals’ informing, and were confident in their skill in informing.

The nurses seemed to be least confident in the informing related items among the groups, indicating the lowest level of skills in all the items in this category. Like the social workers, they tended to perceive they had \textit{more than adequate} experience in observing other professionals’ informing, but indicated their experience and confidence in informing as \textit{less than adequate}. This suggests that they frequently observed other professionals’ informing, yet were less likely to be involved in informing themselves and were not confident in their skill in informing.

Along with the discussion, the following section presents detailed data on the subjects’ responses to each skill item. In presenting the data, the professions of the subjects are expressed using abbreviations, DR for doctor, NS for nurse, and SW for social worker.

\textbf{Item 7 Experience in informing (p<0.01)}

<table>
<thead>
<tr>
<th></th>
<th>DR</th>
<th>NS</th>
<th>SW</th>
</tr>
</thead>
<tbody>
<tr>
<td>5 (Excellent)</td>
<td>8%</td>
<td>1%</td>
<td>0%</td>
</tr>
<tr>
<td>4 (More than adequate)</td>
<td>25%</td>
<td>9%</td>
<td>17%</td>
</tr>
<tr>
<td>3 (Adequate)</td>
<td>42%</td>
<td>19%</td>
<td>17%</td>
</tr>
<tr>
<td>2 (Less than adequate)</td>
<td>17%</td>
<td>40%</td>
<td>67%</td>
</tr>
<tr>
<td>1 (Poor)</td>
<td>8%</td>
<td>31%</td>
<td>0%</td>
</tr>
</tbody>
</table>
The level of the doctors' perceived experience in informing was significantly higher than that of the other groups (p<0.01). The subjects’ responses to Item 7 indicate that 75% of the doctors perceived their experience in informing as adequate to excellent (point between 3 and 5), compared to 29% of the nurses and 34% of the social workers.

**Item 10  Confidence in informing (p<0.01)**

<table>
<thead>
<tr>
<th></th>
<th>DR (%)</th>
<th>NS (%)</th>
<th>SW (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly agree</td>
<td>17</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Agree</td>
<td>67</td>
<td>30</td>
<td>33</td>
</tr>
<tr>
<td>Not certain</td>
<td>0</td>
<td>28</td>
<td>50</td>
</tr>
<tr>
<td>Disagree</td>
<td>17</td>
<td>25</td>
<td>17</td>
</tr>
<tr>
<td>Strongly disagree</td>
<td>0</td>
<td>17</td>
<td>0</td>
</tr>
</tbody>
</table>

The doctors also appeared to be significantly more confident in informing than the other groups (p<0.01). The subjects’ responses to Item 10 show that 84% of the doctors were confident in informing, scoring agree to strongly agree (point between 4 and 5), compared to 31% of the nurses and 33% of the social workers.

The statistical analysis using a one-way analysis of variance (One-way ANOVA) revealed a significant group difference in the mean score of the informing related items. The doctors scored significantly higher for these items (the mean score was 3.4 points) than the social workers (2.9 points) and the nurses (2.6 points), suggesting that they were significantly more confident in informing than the other groups (p<0.01). The literature suggests that doctors are primarily responsible for informing practice (Sloper & Turner, 1993). It was thus expected prior to the study that doctors tended to be more experienced and skilled in informing than other professions.

CHAPTER 6. DISCUSSION
The current finding that most doctors (84%) were confident in informing seems to contradict past studies that found a high level of parents’ dissatisfaction with informing practice (e.g., Cunningham et al., 1984; Quine & Pahl, 1987; McKay & Hensey, 1990; Sloper & Turner, 1993; Garwick et al., 1995). However, the relationship between doctors’ confidence in informing and parents’ satisfaction with informing practice is unclear and needs further investigation.

EDUCATION/TRAINING RELATED ITEMS

Despite little evidence in the empirical literature, professionals may receive inadequate education/training in the areas pertaining to informing practice. A minority of paediatricians (n=4/26, 15%) in Hasnat & Graves’s study (2000a, for details of this study, see p.94) perceived lack of experience, training or knowledge as major factors that adversely affected their informing practice. In Turner & Sloper’s study (1992, for details of this study, see p.93), all but one paediatrician (n=23/24, 96%) also expressed the need for some improvements in professional education/training on informing practice.

The data of the current study revealed that the nurses perceived their level of education/training in informing was significantly lower than that of the other groups (p<0.05), though all the groups indicated their education/training in this area as less than adequate.

The subjects’ responses to Item 6 demonstrate that 33% of the doctors perceived their education/training in informing as poor to less than adequate (point between 1 and 2). The same proportion of the social workers and 69% of the nurses indicated their
education/training in informing as this level. Unexpectedly, the same proportions of the
social workers and the doctors (67%) perceived their education/training in informing as
adequate to excellent (point between 3 and 5), while only 30% of the nurses perceived
their education/training in this area as at this level.

**Item 6  Education/training in informing (p<0.05)**

<table>
<thead>
<tr>
<th></th>
<th>DR</th>
<th>NS</th>
<th>SW</th>
</tr>
</thead>
<tbody>
<tr>
<td>5 (Excellent)</td>
<td>8%</td>
<td>2%</td>
<td>0%</td>
</tr>
<tr>
<td>4 (More than adequate)</td>
<td>17%</td>
<td>7%</td>
<td>0%</td>
</tr>
<tr>
<td>3 (Adequate)</td>
<td>42%</td>
<td>21%</td>
<td>67%</td>
</tr>
<tr>
<td>2 (Less than adequate)</td>
<td>25%</td>
<td>47%</td>
<td>33%</td>
</tr>
<tr>
<td>1 (Poor)</td>
<td>8%</td>
<td>22%</td>
<td>0%</td>
</tr>
</tbody>
</table>

The literature suggests that there has been an increasing awareness of the importance of
parent-professional relationship in the service provision for families of children with a
disability. The current findings may reflect this awareness in professional
education/training. All the groups indicated their education/training in parent-
professional relationship as adequate to more than adequate (point between 3 and 4).
The social workers were likely to perceive they had more education/training in this area
than the other groups (p<0.1), though this failed to reach the statistically significant
level

**Item 3  Education/training in parent-professional relationship (p<0.1)**

<table>
<thead>
<tr>
<th></th>
<th>DR</th>
<th>NS</th>
<th>SW</th>
</tr>
</thead>
<tbody>
<tr>
<td>5 (Excellent)</td>
<td>8%</td>
<td>2%</td>
<td>17%</td>
</tr>
<tr>
<td>4 (More than adequate)</td>
<td>25%</td>
<td>28%</td>
<td>50%</td>
</tr>
<tr>
<td>3 (Adequate)</td>
<td>50%</td>
<td>41%</td>
<td>33%</td>
</tr>
<tr>
<td>2 (Less than adequate)</td>
<td>8%</td>
<td>25%</td>
<td>0%</td>
</tr>
<tr>
<td>1 (Poor)</td>
<td>8%</td>
<td>4%</td>
<td>0%</td>
</tr>
</tbody>
</table>
The subjects' responses to Item 3 suggest that all the social workers perceived their education/training in parent-professional relationship as *adequate* to *excellent* (point between 3 and 5), though 16% of the doctors and 29% of the nurses perceived their education/training in this area as *poor* to *less than adequate* (point between 1 and 2).

The literature often reports that professionals receive inadequate education/training in disability since many disabling conditions occur with relatively low frequencies (Wolraich, 1982). For example, in Turner & Slopér's study (1992), a substantial minority of paediatricians (n=9/24, 37%) perceived they had no education/training in disability specifically. Similarly, the current data indicate that all the groups tended to perceive their education/training in disability as *less than adequate*.

### Item 1 Education/training in disability

<table>
<thead>
<tr>
<th></th>
<th>DR</th>
<th>NS</th>
<th>SW</th>
</tr>
</thead>
<tbody>
<tr>
<td>5 (Excellent)</td>
<td>8 %</td>
<td>1 %</td>
<td>0 %</td>
</tr>
<tr>
<td>4 (More than adequate)</td>
<td>17 %</td>
<td>8 %</td>
<td>0 %</td>
</tr>
<tr>
<td>3 (Adequate)</td>
<td>25 %</td>
<td>26 %</td>
<td>83 %</td>
</tr>
<tr>
<td>2 (Less than adequate)</td>
<td>33 %</td>
<td>51 %</td>
<td>17 %</td>
</tr>
<tr>
<td>1 (Poor)</td>
<td>17 %</td>
<td>14 %</td>
<td>0 %</td>
</tr>
</tbody>
</table>

The subjects' responses to Item 1 suggest that half the doctors and 65% of the nurses perceived their education/training in disability as *poor* to *less than adequate* (point between 1 and 2), though surprisingly, 83% of the social workers indicated their education/training in disability as *adequate* (point 3).

The literature reports that professionals often fail to receive adequate education/training in counselling and communication skills. Turner & Slopér (1992) found that 79% of paediatricians (n=19/24) perceived that they had no education/training in counselling.
and communication skills, and a majority (n=13, 54%) indicated a need for additional education/training in this area. As discussed in the previous chapter, the social workers were the only group that scored a more than adequate level (> 3) for Item 2 “education/training in counselling and communication skills”, this reached the statistically significant level (p<0.0001).

**Item 2 Education/training in counselling and communication skills (p<0.0001)**

<table>
<thead>
<tr>
<th>Item</th>
<th>DR</th>
<th>NS</th>
<th>SW</th>
</tr>
</thead>
<tbody>
<tr>
<td>5 (Excellent)</td>
<td>0 %</td>
<td>2 %</td>
<td>50 %</td>
</tr>
<tr>
<td>4 (More than adequate)</td>
<td>17 %</td>
<td>24 %</td>
<td>50 %</td>
</tr>
<tr>
<td>3 (Adequate)</td>
<td>58 %</td>
<td>44 %</td>
<td>0 %</td>
</tr>
<tr>
<td>2 (Less than adequate)</td>
<td>25 %</td>
<td>27 %</td>
<td>0 %</td>
</tr>
<tr>
<td>1 (Poor)</td>
<td>0 %</td>
<td>4 %</td>
<td>0 %</td>
</tr>
</tbody>
</table>

The subjects’ responses to Item 2 reveal that all the social workers perceived their education/training in counselling and communication skills as more than adequate to excellent (point between 4 and 5), while only 17% of the doctors and 26% of the nurses indicated their education/training in this area as this level.

Prior to the study, social workers were expected to have more education/training in psychosocial aspects than other professions. The current findings seem to support this assumption, in that the social workers appeared to be more confident in their education/training in parent-professional relationship and in counselling and communication skills than the other groups.

All but one paediatrician (n=23/24, 96%) in Turner & Sloper’s study (1992) preferred some improvements in professional education/training on informing practice. The current data indicate that all the groups tended to perceive additional education/training
in the areas identified as beneficial. Interestingly, the social workers seemed to more strongly perceive such additional education/training as beneficial than the other groups, despite their significantly higher level of perceived education/training in parent-professional relationship and in counselling and communication skills.

**Item 11 Additional education/training in the areas identified as beneficial**

<table>
<thead>
<tr>
<th>Item</th>
<th>Response</th>
<th>DR</th>
<th>NS</th>
<th>SW</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>(Strongly agree)</td>
<td>8%</td>
<td>26%</td>
<td>33%</td>
</tr>
<tr>
<td>2</td>
<td>(Agree)</td>
<td>67%</td>
<td>59%</td>
<td>67%</td>
</tr>
<tr>
<td>3</td>
<td>(Not certain)</td>
<td>8%</td>
<td>7%</td>
<td>0%</td>
</tr>
<tr>
<td>4</td>
<td>(Disagree)</td>
<td>17%</td>
<td>5%</td>
<td>0%</td>
</tr>
<tr>
<td>5</td>
<td>(Strongly disagree)</td>
<td>0%</td>
<td>4%</td>
<td>0%</td>
</tr>
</tbody>
</table>

The subjects’ responses to Item 11 indicate that all the social workers agreed or strongly agreed (point between 1 and 2) with additional education/training in the areas identified as beneficial, while 25% of the doctors and 16% of the nurses were not certain to strongly disagreed (point between 3 and 5) with this statement. The current finding recalls Morgan & Winter’s claim (1996) that professionals’ awareness of issues relevant to informing practice may affect their practice in informing, and there is likely a positive effect in this area by merely increasing such awareness of professionals.

The statistical analysis using a one-way analysis of variance (One-way ANOVA) revealed a significant group difference in the mean score of the education/training related items. The social workers scored significantly higher for these items (the mean score was 3.1 points) than the doctors (2.8 points) and the nurses (2.5 points), suggesting that they were significantly more confident in their education/training in the areas identified than the other groups (p<0.05).
Professionals' understanding of parents of children with a disability can generate professionals' feelings of confidence and comfort in their abilities to deal with these families, which is, in turn, likely to affect their communication with these families.

The subjects in the current study tended to perceive they were familiar with parents' emotional reactions to their child's diagnosis. For the doctors and the nurses, this is the only item in which they indicated a more than adequate level (> 3) of confidence among the parent related items, and this is also the item in which they indicated the highest confidence among all the skill items.

**Item 9  Familiarity with parents’ emotional reactions to their child’s diagnosis**

<table>
<thead>
<tr>
<th>Level</th>
<th>DR</th>
<th>NS</th>
<th>SW</th>
</tr>
</thead>
<tbody>
<tr>
<td>5 (Strongly agree)</td>
<td>17%</td>
<td>13%</td>
<td>50%</td>
</tr>
<tr>
<td>4 (Agree)</td>
<td>50%</td>
<td>54%</td>
<td>33%</td>
</tr>
<tr>
<td>3 (Not certain)</td>
<td>33%</td>
<td>18%</td>
<td>17%</td>
</tr>
<tr>
<td>2 (Disagree)</td>
<td>0%</td>
<td>12%</td>
<td>0%</td>
</tr>
<tr>
<td>1 (Strongly disagree)</td>
<td>0%</td>
<td>4%</td>
<td>0%</td>
</tr>
</tbody>
</table>

The subjects' responses to Item 9 indicate that the same proportions of the doctors and the nurses (67%) perceived they were familiar with parents' emotional reactions to their child's diagnosis, scoring agree to strongly agree (point between 4 and 5). Incidentally, the social workers indicated their highest confidence in education/training in counselling and communication skills among all the skill items, yet they still remained to be most familiar with parents' emotional reactions to the child's diagnosis among the groups, with 83% scoring at this level.
The social workers seemed to be more confident in the parent related items than the other groups, indicating a more than adequate level of familiarity or experience in all the items in this category. This suggests that they had enough experience with parents of children with a disability, were familiar with parents’ emotional reactions to their child’s diagnosis, and were familiar with parents’ perspective of having a child with a disability.

The doctors seemed to perceive their experience with parents of children with a disability as adequate (= 3), but their familiarity with parents’ perspective of having a child with a disability as less than adequate (< 3). This indicates that they had enough experience with parents of children with a disability, and were familiar with parents’ emotional reactions to their child’s diagnosis, yet were unfamiliar with parents’ perspective of having a child with a disability.

The nurses seemed to be only confident in their familiarity with parents’ emotional reactions to their child’s diagnosis among the parent related items. This suggests that they were familiar with parents’ emotional reactions to their child’s diagnosis, yet did not have enough experience with parents of children with a disability, and were unfamiliar with parents’ perspective of having a child with a disability.

**Item 4  Experience with parents of children with a disability**

<table>
<thead>
<tr>
<th>Item</th>
<th>DR</th>
<th>NS</th>
<th>SW</th>
</tr>
</thead>
<tbody>
<tr>
<td>5 (Excellent)</td>
<td>8%</td>
<td>8%</td>
<td>0%</td>
</tr>
<tr>
<td>4 (More than adequate)</td>
<td>17%</td>
<td>20%</td>
<td>17%</td>
</tr>
<tr>
<td>3 (Adequate)</td>
<td>50%</td>
<td>17%</td>
<td>83%</td>
</tr>
<tr>
<td>2 (Less than adequate)</td>
<td>17%</td>
<td>44%</td>
<td>0%</td>
</tr>
<tr>
<td>1 (Poor)</td>
<td>8%</td>
<td>12%</td>
<td>0%</td>
</tr>
</tbody>
</table>
The subjects' responses to Item 4 show that all the social workers perceived their experience with parents of children with a disability as *adequate to more than adequate* (point between 3 and 4), while 25% of the doctors and 56% of the nurses perceived their experience in this area as *poor to less than adequate* (point between 1 and 2).

**Item 5  Familiarity with parents' perspective of having a child with a disability**

<table>
<thead>
<tr>
<th></th>
<th>DR</th>
<th>NS</th>
<th>SW</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>8 %</td>
<td>5 %</td>
<td>0 %</td>
</tr>
<tr>
<td>4</td>
<td>8 %</td>
<td>15 %</td>
<td>33 %</td>
</tr>
<tr>
<td>3</td>
<td>42 %</td>
<td>31 %</td>
<td>67 %</td>
</tr>
<tr>
<td>2</td>
<td>42 %</td>
<td>34 %</td>
<td>0 %</td>
</tr>
<tr>
<td>1</td>
<td>0 %</td>
<td>15 %</td>
<td>0 %</td>
</tr>
</tbody>
</table>

All the social workers perceived their familiarity with parents’ perspective of having a child with a disability as *adequate to more than adequate* (point between 3 and 4), while 42% of the doctors and 49% of the nurses perceived their familiarity with this area as *poor to less than adequate* (point between 1 and 2). The current findings seem to concur with other studies that found that parents often report doctors’ failures to recognise their perspective of having a child with a disability (Stainton & Besser, 1998).

The statistical analysis using a one-way analysis of variance (One-way ANOVA) indicates no significant group difference in the mean score of the parent related items. The social workers, however, scored higher for the items in this category (the mean score was 3.6 points) than the doctors (3.2 points) and the nurses (3 points), suggesting that the social workers tended to be more confident in their understanding of parents of children with a disability than the other groups.
Prior to the study, it was supposed that social workers were more familiar with psychosocial aspects than other professions. This appears to be supported by the current findings. They tended to indicate more experience with parents of children with a disability, more familiarity with parents’ emotional reactions to their child’s disability, and more familiarity with parents’ perspective of having a child with a disability than the other groups.

The nurses again failed to show any superiority in this area, though their responses to the skill items did suggest the advantage of their involvement in informing practice. For example, approximately 70% of the nurses perceived their education/training in parent-professional relationship and in counselling and communication skills as adequate to excellent (point between 3 and 5), and agreed or strongly agreed (point between 4 and 5) with their familiarity with parents’ emotional reactions to their child’s diagnosis.

Taken all together, the findings of the skill section suggest that the involvement of social workers and nurses in informing practice is of great advantage in establishing a rapport with parents and in providing effective support to them during the informing interview and on an ongoing basis.

The findings may also indicate some validity of the questionnaire developed for the current study as it generated discriminatory results among the groups, which were expected prior to the study. That is, the doctors tend to be experienced and confident in informing, and the social workers tend to be familiar with psychosocial aspects, such as parent-professional relationship, counselling and communication skills, and understanding of parents of children with a disability.
It must be noted, however, that a confounding factor of the questionnaire became apparent during the data analysis. That is, different wordings were used to determine points of the skill items. The point 3 meant "Adequate" for Items 1 to 7 or "Occasionally" for Item 8, while it meant "Not Certain" for Items 9 to 11. If these wordings gave different impressions to the subjects, then this might have had some impacts on their responses to each item.

Whether this was the reason or not, the subjects seemed to score the point 4 "Agree" rather than the point 3 "Not Certain" for the latter items. In addition, the subjects scored highest for Item 9 and lowest for Item 11 (for details, see Appendix 5 and Figure 5.3 on p.163). Note that for Item 11 points were reversed. For reference, these latter items were "Familiarity with parents’ emotional reactions", "Confidence in informing" and "Feeling additional education/training in the areas identified as beneficial", respectively.

Supposing that the different wordings affected the subjects’ responses to the items, this might have had some influences on the comparative ranking of mean scores for the items of the groups, but should not have been an issue in group comparisons of the data. Accordingly, the results of this section need to be seen in this light. It can be supposed that, if the same wording as the former items had been used for the latter items, the subjects’ perceived level of skill might have declined for Items 9 and 10, or increased for Item 11 as points were reversed for this item.

6.5 Relationships Between Variables

In addition to group comparisons, relationships between variables were examined using a one-way analysis of variance and regression plots.
There appeared to be strong positive relationships among scores for all the skill categories (p<0.001). That is, the higher a subject scored for one skill category, the higher he/she scored for other skill categories. This suggests if a subject was confident in informing he/she was also confident in his/her education/training in the areas identified and in his/her understanding of parents of a child with a disability.

Another strong positive relationship was found between the score of the attitude section and the score of the parent related skill items (p<0.05). That is, the higher a subject scored for the attitude section, the higher he/she scored for the parent related skill items. This suggests that subjects who had positive attitudes toward having a child with a disability were significantly more confident in their understanding of parents of such a child, and vice versa. This may concur with Nursey et al.'s (1990) assumption that professionals who have experience with individuals with a disability are more optimistic about abilities of these individuals than those who do not.

There was a significant difference in the sum score of the skill section between subjects who had personal contact with individuals with a disability and those who did not (p<0.005), with a significantly higher score for the former. This suggests that subjects who had personal contact with individuals with a disability were significantly more confident in their skills necessary in informing practice.

Unexpectedly, subjects who had children scored significantly lower for the attitude section than those who did not (p<0.05). This indicates that subjects who had their own child, probably without a disability, were significantly more pessimistic about having a
child with a disability. This has not been discussed in the literature and needs further investigation.

There were also a strong positive relationship between the score of the knowledge section and the score of the skill section (p<0.005). The higher a subject scored for the knowledge section, the higher he/she scored for the skill section. This suggests that the more subjects perceived they had knowledge to give sufficient information to parents, the more they perceived they had skills necessary in informing practice.

The current findings seem to agree with other studies that found a positive relationship between knowledge and communication skills. In a study examining a training program to teach medical students communication skills and content issues, Greenberg et al. (1999, for details of this study, see p.130) found that as students' communication skills improved, their ability to give information increased. The researchers assumed that as students' knowledge to give parents sufficient information increased, they became more comfortable in informing, and thus their communication skills improved.

Age and length of career appeared to have no relations with other variables. This seems to contradict other studies that found that professionals with a longer clinical experience had more accurate understanding of families of children with a disability (Sloper & Turner, 1991a, for details of this study, see p.77).

No relationships were also found between academic background and other variables. The relationships between gender, language background and other variables were not
investigated because most male subjects were doctors, and all subjects whose first language was not English were nurses.
7.1 Introduction

This chapter presents the qualitative results and discussion based on the subjects’ responses to the final section of the questionnaire, an open-ended question asking the subjects their opinions about following guidelines for informing practice (for details, see Appendix 1). These guidelines have been suggested in the literature, and were integrated for the current study. Issues pertaining to these guidelines were discussed in Chapter 3.

Guideline 1. Telling parents as soon as possible
Guideline 2. With both parents together
Guideline 3. With the child present
Guideline 4. In private setting without interruptions
Guideline 5. In person
Guideline 6. In simple and direct language without medical jargon
Guideline 7. With tolerance for parents’ emotional expression
Guideline 8. Giving all the information fully
Guideline 9. In sympathetic and caring manner
Guideline 10. Allowing time for questions
Guideline 11. Giving early opportunities for follow-up interviews

Table 7.1 shows past studies of guidelines for informing practice and guidelines identified in each study.
Table 7.1 Studies of Guidelines for Informing Practice and Guidelines Identified in Each Study

<table>
<thead>
<tr>
<th>Study</th>
<th>The guidelines identified in the study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cunningham et al.</td>
<td>Guideline 1.2.3.4.6.11</td>
</tr>
<tr>
<td>Olson et al.</td>
<td>Guideline 3.4.6.10.11</td>
</tr>
<tr>
<td>Quine &amp; Pahl</td>
<td>Guideline 1.2.6.9.11</td>
</tr>
<tr>
<td>Woolley et al.</td>
<td>Guideline 2.4.7.8.9.10.11</td>
</tr>
<tr>
<td>Krahn et al.</td>
<td>Guideline 1.2.3.4.5.6.10</td>
</tr>
</tbody>
</table>

The question asked the subjects their opinions about the guidelines to investigate their awareness of aspects of informing practice, and their responses to the guidelines in order to examine the relevance of the guidelines in actual practice. Space was provided for comments with anticipation that the issues being raised were likely to arouse some feelings from the subjects’ personal and professional experiences that could not be fully expressed in the format of a questionnaire. Surprisingly, although it was not compulsory to respond to this open-ended question, all but four subjects gave some comments in the space provided, with a majority filling the entire space with their opinions and experience regarding informing practice. Such responses of the subjects may suggest that the topic was a matter of concern for health care professionals who were working in paediatric or obstetric areas.

Subjects whose children had a disability made comments that seemed to verify the relevance of the study from parents’ point of view. These comments called our attention to the importance of an individualised approach to each case.
(NS) "I think it is important to cover the above points. As a parent of a "disabled child", I feel I can relate quite well to parents of disabled children, but a lot has to do with what type of disability it is. I often think parents initially react more upset if the disability is an obvious one e.g. Down’s syndrome rather than a more hidden disability e.g. deafness or blindness. Whatever the disability it is very upsetting to be told your child is not ‘perfect’.”

(NS) "I am very pleased someone is addressing this issue. As a parent of a son [with a disability] (age 18) I have run the whole gamut of emotion and am extremely familiar with the disability field. My son has a severe intellectual disability. In my opinion, Down syndrome is a mild intellectual disability. Please take great care not to generalise. There are many differences between each end of the spectrum. I am writing this in tears, as always.”

7.2 Results and Discussion

Responses from 105 health care professionals, consisting of 12 doctors, 85 nurses, 6 social workers, 1 medical administrator, and 1 physiotherapist, were included in data analysis and were coded into some major themes.

The subjects gave various opinions regarding the guidelines. Table 7.2 illustrates the frequency with which they mentioned each guideline. Numerals in parentheses indicate the number of subjects in each profession who made comments on each guideline. The profession of the subjects is expressed using abbreviations, DR for doctor, NS for nurse, SW for social worker, MA for medical administrator, and PT for physiotherapist.
The most frequently agreed guideline was "(telling) both parents together", commented by 71 subjects (68%), followed by "allowing time for questions" and "giving early opportunities for follow-up interviews", both commented by 70 subjects (67%). On the other hand, the least frequently agreed guidelines were "giving all the information fully" and "with the child present" possibly due to the fact that the subjects had conflicting opinions for these.

Table 7.2 Frequency with Which Each Guideline Was Mentioned

<table>
<thead>
<tr>
<th>Guideline</th>
<th>Number of Subjects Mentioning Each Guideline</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>With both parents together</td>
<td>71 (DR 8, NS 59, SW 3, MA 1)</td>
<td>68</td>
</tr>
<tr>
<td>Allowing time for questions</td>
<td>70 (DR 7, NS 58, SW 4, MA 1)</td>
<td>67</td>
</tr>
<tr>
<td>Giving early opportunities for follow-up interviews</td>
<td>70 (DR 8, NS 57, SW 4, MA 1)</td>
<td>67</td>
</tr>
<tr>
<td>In private setting without interruptions</td>
<td>69 (DR 8, NS 56, SW 4, MA 1)</td>
<td>66</td>
</tr>
<tr>
<td>Telling parents as soon as possible</td>
<td>69 (DR 7, NS 57, SW 4, MA 1)</td>
<td>66</td>
</tr>
<tr>
<td>In sympathetic and caring manner</td>
<td>68 (DR 8, NS 56, SW 3, MA 1)</td>
<td>65</td>
</tr>
<tr>
<td>In simple and direct language without medical jargon</td>
<td>66 (DR 7, NS 54, SW 4, MA 1)</td>
<td>63</td>
</tr>
<tr>
<td>In person</td>
<td>64 (DR 8, NS 51, SW 4, MA 1)</td>
<td>61</td>
</tr>
<tr>
<td>With tolerance for parents’ emotional expression</td>
<td>64 (DR 7, NS 53, SW 3, MA 1)</td>
<td>61</td>
</tr>
<tr>
<td>Giving all the information fully</td>
<td>63 (DR 7, NS 52, SW 3, MA 1)</td>
<td>60</td>
</tr>
<tr>
<td>With the child present</td>
<td>63 (DR 7, NS 52, SW 3, MA 1)</td>
<td>60</td>
</tr>
</tbody>
</table>
In addition to the aspects covered in the guidelines, the subjects mentioned a variety of other aspects of informing practice. Table 7.3 gives the frequency with which the subjects mentioned each aspect of informing practice.

Table 7.3 Frequency with Which Each Aspect of Informing Practice Was Mentioned

<table>
<thead>
<tr>
<th>Aspect</th>
<th>Number of Subjects Mentioning Each Aspect</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information given at the informing interview</td>
<td>82 (DR 11, NS 66, SW 4, MA 1)</td>
<td>78</td>
</tr>
<tr>
<td>Timing of the informing interview</td>
<td>81 (DR 10, NS 65, SW 5, MA 1)</td>
<td>77</td>
</tr>
<tr>
<td>Presence of the child</td>
<td>76 (DR 7, NS 61, SW 6, MA 1, PT 1)</td>
<td>72</td>
</tr>
<tr>
<td>Presence of parents</td>
<td>73 (DR 8, NS 60, SW 4, MA 1)</td>
<td>70</td>
</tr>
<tr>
<td>Affective characteristics of the professional</td>
<td>71 (DR 9, NS 57, SW 4, MA 1)</td>
<td>68</td>
</tr>
<tr>
<td>Language</td>
<td>70 (DR 8, NS 57, SW 4, MA 1)</td>
<td>67</td>
</tr>
<tr>
<td>Allowing time</td>
<td>70 (DR 7, NS 58, SW 4, MA 1)</td>
<td>67</td>
</tr>
<tr>
<td>Follow-up interviews</td>
<td>70 (DR 8, NS 57, SW 4, MA 1)</td>
<td>67</td>
</tr>
<tr>
<td>Private setting without interruptions</td>
<td>69 (DR 8, NS 56, SW 4, MA 1)</td>
<td>66</td>
</tr>
<tr>
<td>Telling parents in person</td>
<td>64 (DR 8, NS 51, SW 4, MA 1)</td>
<td>61</td>
</tr>
<tr>
<td>Who is responsible for informing practice?</td>
<td>16 (NS 12, SW 4)</td>
<td>15</td>
</tr>
<tr>
<td>Support at the time and on an ongoing basis</td>
<td>9 (NS 8, MA 1)</td>
<td>9</td>
</tr>
<tr>
<td>Presence of other professionals and support persons</td>
<td>8 (NS 7, MA 1)</td>
<td>8</td>
</tr>
<tr>
<td>Repetition</td>
<td>5 (DR 1, NS 4)</td>
<td>5</td>
</tr>
<tr>
<td>Written materials</td>
<td>5 (DR 2, NS 3)</td>
<td>5</td>
</tr>
<tr>
<td>Individual differences between professionals</td>
<td>5 (NS 2, SW 2, MA 1)</td>
<td>5</td>
</tr>
</tbody>
</table>
For the sake of discussing the data, the aspects of informing practice that the subjects mentioned were broadly categorised into the following major themes:

Theme 1. Overall agreement to the guidelines
Theme 2. Timing of the Informing Interview
Theme 3. Information given at the Informing Interview
Theme 4. Characteristics of the Professional
Theme 5. Persons Present at the informing interview
Theme 6. Strategies to use at the informing interview
Theme 7. Who is responsible for informing practice?

The first theme is related to the subjects’ “overall agreement to the guidelines”. The following five themes (Theme 2 to 6) are related to their opinions on the aspects of informing practice pertaining to the guidelines. A majority of the subjects devoted space to reason why they agreed or disagreed with particular guidelines. The last theme “who is responsible for informing practice” was not seen in the literature but emerged from the current data. It does not directly pertain to the guidelines, yet was considered significant due to the frequency and consistency with which it appeared.

In the following section, the data are presented and discussed according to the above themes. This is accompanied by examples of the subjects’ comments that were thought to be representative or interesting.
THEME 1. OVERALL AGREEMENT TO THE GUIDELINES

Sixty-two subjects (59%), including 7 doctors, 51 nurses, 3 social workers and 1 medical administrator, showed overall agreement to the guidelines. About half of them (n=28, 27%) indicated their agreement in a couple of sentences without further discussion, e.g. “I agree with all the above”, “All the above appear to be good guidelines”. However, such apparently shallow agreements may, ironically, give impressions that these subjects had little personal opinions to discuss about this issue, probably suggesting that it was a relatively unfamiliar issue for them.

No subject stated that there was a standard procedure for informing practice in their own hospitals, indicating that the subjects in the current study were likely to have developed their practice individually.

THEME 2. TIMING OF THE INFORMING INTERVIEW

Timing of the informing interview was the second most frequently mentioned theme by the subjects. A total of 81 subjects (77%), including 10 doctors, 65 nurses, 5 social workers and 1 medical administrator, made comments on this theme.

Of these, a majority (n=69, 66%), including 7 doctors, 57 nurses, 4 social workers and 1 medical administrator, agreed with Guideline 1 “telling parents as soon as possible”:

(NS) “Openness and honesty is the best policy regarding to any suspicion of disability [sic].”
(NS) “Parents should be told about their child’s disability as soon as possible even if they [professionals] are uncertain, they should still inform the parents before they coming out facts to confirm it [sic]. It isn’t ethical to collect blood from a baby for facts without informing the parents first even if they have doubts about the child’s disability.”

(DR) “I think parents should be informed as soon as possible - in fact on suspicion if it is felt to be likely or reasonable - and with avoidance of misleading information. Parents appreciate honesty and have a right to expect it.”

(NS) “Telling parents as soon as possible is probably important. Parents often have suspicions anyway.”

On the other hand, a minority (n=10, 1%), 3 doctors and 7 nurses, thought that parents should not be told until a suspicion of the child’s disability is confirmed or enough is known to answer parents’ questions:

(DR) “I think that parents should be told as soon as possible but I don’t think that you need to necessarily share your first suspicions with them apart from telling them that there may be something wrong with their child and that you would like to investigate it further. If they were to ask questions, then it is important not to be evasive but to be honest and direct.”
“I don’t agree that parents should be told immediately when disability is first suspected. Results of initial investigation should be available to confirm the suspicion. At times suspicion is just that and not confirmed. We don’t want parents to worry and [be] anxious for suspicions which are not substantiated. If the suspicions is confirmed then both parents should be present with consideration of all the above.”

“Telling parents as soon as possible when enough is known of the condition to answer all or most questions adequately.”

One social worker confessed that informing is often delayed until diagnosis is confirmed:

“In my experience it is often not discussed with parents until diagnosis is confirmed (e.g. by tests). The parents may already have concerns.”

One nurse and 1 social worker indicated that timing of the informing interview would depend on the severity of the disability or the situation of individual families:

“Timing of telling depends on what the disability is being discussed and the seriousness of its consequences.”

Timing of the informing interview was, along with information given at the informing interview, an issue that generated conflicting opinions from the subjects.
The literature reported that a majority of parents preferred to be told as soon as possible if there was something wrong with their child, while a substantial minority did prefer not to be told until a firm diagnosis was made (Krahn et al., 1993, for details of this study, see p.87). Even when parents were told of their child’s disability at an early stage, they were often dissatisfied if there were unnecessary delay, denial and evasion from professionals (Quine & Pahl, 1987, for details of this study, see p.91). On the other hand, parents did not complain about being informed late if there was a reasonable explanation from professionals (Cunningham et al., 1984, for details of this study, see p.85).

The subjects in the current study seemed to acknowledge such parents’ preferences as a majority suggested that they would inform parents as soon as possible, and many regarded honesty and openness as important.

Similar findings were reported by Turner & Sloper (1992, for details of this study, see p.93). Half of paediatricians in their study supported informing parents at an early stage (n=12/24), while, for others, timing of informing appeared to depend on the strength of their suspicions (n=6), the severity of the disability (n=3), or their judgement of parents’ characteristics (n=1). One subject said he would wait until a firm diagnosis was made.

**THEME 3. INFORMATION GIVEN AT THE INFORMING INTERVIEW**

Information given at the informing interview was the theme that was most frequently mentioned by the subjects. A total of 82 subjects (78%), consisting of 11 doctors, 66 nurses, 4 social workers and 1 medical administrator, referred to this theme.
A majority (n=63, 60%), including 7 doctors, 52 nurses, 3 social workers and 1 medical administrator, agreed with Guideline 8 “giving all the information fully”. A substantial minority (n=13, 12%), 4 doctors and 9 nurses, however felt “giving all the information fully” at the initial interview was too much for parents to absorb or to start with, and many recommended spreading out information through several interviews:

(NS) “I feel that covering too much in the initial interview will overload parents who will be in a shocked state anyway. Giving them all the worst possible scenarios and all possible complications would be too much to worry about for them, as it will not all happen. Covering the life long outcomes of the disability is too much to start with.”

(DR) “I heard that telling parents information in ‘stages’ is beneficial.”

(NS) “Fully explaining the situation to some people may be overwhelming so the information needs to be spread out through several interviews.”

(DR) “Short frequent interviews to allow them to take in information, process it and formulate questions.”

(DR) “I usually try to avoid the various diseases associations initially as these, usually lay persons, usually upset new parents of a child with a disability by giving too much information what may alarm and upset the parents who are not prepared to accept this in the early stages [sic].”
Six others, 5 nurses and 1 social worker, said that information they give to parents would depend on parents’ emotional state or understanding, the disability of the child, or physical condition of the mother and the child.

The amount of information was another issue that generated conflicting opinions from the subjects. Jacobs (1977, for details of this study, see p.82) reported decades ago that doctors assumed that parents were unable to take in what they heard due to their emotional state, and accordingly they often did not give sufficient information to parents. Later studies still reported that parents’ dissatisfaction with informing practice was frequently related to lack of information (McKay & Hensey, 1990, for details of this study, see p.100), and that parents were more likely to be satisfied when given a large amount of information (Hasnat & Graves, 2000b, for details of this study, see p.88).

The subjects in the current study seemed aware of such parents’ preference for amount of information. A majority indicated that they would give all the information available to parents at the informing interview.

In relation to parents’ difficulty in taking in all the information at a time due to their emotional state, the use of strategies to help them absorb information is of absolute importance. The subjects in the current study also appeared to recognise this, introducing a variety of strategies to use at the informing interview, which are covered in Theme 6.
THEME 4. CHARACTERISTICS OF THE PROFESSIONAL

A total of 71 subjects (68%), including 9 doctors, 57 nurses, 4 social workers and 1 medical administrator, regarded characteristics of professionals, such as manner and communication skills, as important. Such characteristics of professionals were seemingly analogous to Guidelines 7 “with tolerance for parents’ emotional expression” and 9 “(telling parents) in sympathetic and caring manner”.

The subjects used a variety of adjectives (i.e., open, direct, honest, positive, sensitive, sympathetic, and caring) to delineate characteristics that they thought professionals needed to possess:

(DR) “I agree that being sensitive and aware of their emotions is very important.”

(SW) “Informing parents of such a sensitive issue requires a good communication skill base and the ability of health professional to be able to skilfully and caringly engage with parents/child.”

Five non-doctor subjects (5%), including 2 nurses, 2 social workers and 1 medical administrator, pointed out individual differences among doctors in their skills and abilities that are likely to affect their informing practice:

(SW) “In general the majority of paediatricians would follow above principles but a minority are less skilled and fall down in areas noted above.”
(NS) "...actually being capable to do it [guidelines] is a problem."

(NS) "Not all have expertise to address these situations."

(MA) "Ongoing support will be crucial for the family and not all practitioners are able to provide this."

(SW) "Some other health professionals work differently and issues can arise from this."

**THEME 5. PERSONS PRESENT AT THE INFORMING INTERVIEW**

The fifth theme concerns persons present at the informing interview. The person refers to parents, the child with a disability, professionals apart from doctors, and support persons such as friends or relatives.

**PRESENCE OF PARENTS**

A total of 73 (70%) subjects, including 8 doctors, 60 nurses, 4 social workers and 1 medical administrator, referred to the presence of parents at the informing interview.

A majority (n=71, 68%), including 8 doctors, 59 nurses, 3 social workers, and 1 medical administrator, agreed with Guideline 2 "(telling) both parents together". As mentioned previously, this was the most frequently agreed guideline by the subjects:
(NS) “It is necessary to present any information about the possibility of disability to both parents as soon as possible because if only one parent is present then they may misinterpret information to the other parent.”

(NS) “With both parents together is absolutely [needed to] support each other.”

Although no subject disagreed with this guideline, 1 nurse and 1 social worker said it would depend on the situation of each case:

(SW) “With both parents together depends on setting, parents and the situation.”

(NS) “Sometimes difficult to see both parents together because one parent may not be physically well enough to receive information, e.g. mother after long, difficult labour, language problem.”

PRESENCE OF THE CHILD

Seventy-six subjects (72%), consisting of 7 doctors, 61 nurses, 6 social workers, 1 medical administrator and 1 physiotherapist, commented on the presence of the child at the informing interview. Unexpectedly, there were some conflicting opinions regarding this issue possibly in part because the study failed to clarify the child’s age.
A majority (n=63 60%), including 7 doctors, 52 nurses, 3 social workers and 1 medical administrator, agreed with Guideline 3 “(telling parents) with the child present”, while as mentioned earlier, this was the least frequently agreed guideline by the subjects.

Five others, 4 nurses and 1 social worker, disagreed with this:

(SW) “The presence of the child could impede the process for the parents with the parents unable to freely react to the news and information.”

A further eight, including 5 nurses, 2 social workers and 1 physiotherapist, stated that the presence of the child would depend on his/her age, maturity or cognitive capacity:

(NS) “If the child is at an age of ability to understand then they should be at the meeting because the child may see it as the adults keeping things from him/her.”

(NS) “The child’s presence may be decided by the parents. They may not want him/her present.”

(PT) “Whether the child is present depends on their age, maturity and cognitive capacity.”

PRESENCE OF OTHER PROFESSIONALS AND SUPPORT PERSONS

Eight subjects (8%), 7 nurses and 1 medical administrator, recommended the inclusion of other professionals and/or support persons in the informing interview.
One nurse and 1 medical administrator referred to the inclusion of other professionals:

(MA) “Would suggest presence of social worker/counsellor at initial interview also given that ongoing support will be crucial for the family and not all practitioners are able to provide this.”

Seven nurses mentioned the inclusion of support persons such as friends or relatives:

(NS) “I am concerned about the underlying assumptions of the parent relationship. I believe that support persons should be offered as an option. Parents may want other people present, parents may not be in a stable/safe relationship with each other.”

(NS) “With support person if single parent.”

(NS) “Allow opportunity for all family members to be present.”

Sloper & Turner (1992) found that 38% of mothers in two-parent families were told of their child’s diagnosis without the father present. This may concur with the current finding in which about the same proportion of subjects (32%) appeared to feel the guideline “telling both parents together” was a relatively unimportant issue.

Parents gave an account of their preference for being told together in the literature. That is, when they were told together, they could support each other, while if they were told alone, they felt too distressed to communicate the child’s diagnosis to the spouse or
found it difficult to relay the information to the spouse accurately (Woolley et al., 1989). The comments of the subjects in the current study indicated that some were well aware of such parents’ experience.

Ahmann (1998) recommended giving single parents an opportunity to have a relative or friend as a support person, and also related the advantage of inclusion of other professionals in the informing interview. This included arranging a setting, encouraging communication with parents, and helping parents obtain information they need. Only a few subjects in the current study seemed to recognise the advantage of inclusion of these people in the informing interview, suggesting that this procedure was less likely to be followed in actual practice.

In the case where a child with a disability is a newborn baby, the presence of the child in the informing interview is thought to facilitate parents’ acceptance of the child (Cunningham et al., 1984). Parents reported that the availability of physical contact with their child during the informing interview was important, and appreciated that professionals touched or held the child in a positive and caring manner during this time (Krahn et al., 1993). No subject in the current study, however, seemed aware of such parents’ perspective.

**THEME 6. STRATEGIES TO USE AT THE INFORMING INTERVIEW**

The subjects in the current study showed little disagreement with guidelines regarding strategies to use at the informing interview.
Sixty-nine subjects (66%), consisting of 8 doctors, 56 nurses, 4 social workers and 1 medical administrator, agreed with Guideline 4 "(telling parents) in a private setting without interruptions":

(NS) "Private setting without interruptions is definitely needed, [so that] they can express themselves freely."

(DR) "Private setting without interruptions from visitors, staff, phones and pagers is ideal."

(DR) "In private setting without interruptions is to be emphasised."

The literature reported that parents were often dissatisfied when given their child’s diagnosis in the presence of strangers, such as medical students, unknown staff or other parents (Garwick et al., 1995). A private setting without interruptions is thought to allow parents to release emotions after the initial shock of the diagnosis. The subjects in the current study seemed aware of such parents’ need to release emotions freely during and after the informing interview.

An issue of lack of private settings in hospitals was mentioned by a social worker:

(SW) "In the hospital setting finding a private setting to discuss issues is a problem. Privacy is a big issue in the hospital due to lack of counselling rooms."
This seems to concur with other studies that found lack of private settings in hospitals was a problem. In Turner & Sloper’s study (1992, for details of this study, see p.93), 13% of paediatricians felt that lack of interview or quiet rooms in the hospital was a factor interfering their ideal practice in informing.

**LANGUAGE**

A total of 70 subjects (67%), including 8 doctors, 57 nurses, 4 social workers and 1 medical administrator, referred to the language used at the informing interview.

Sixty-six subjects of these, consisting of 7 doctors, 54 nurses, 4 social workers and 1 medical administrator, agreed with Guideline 6 “(telling parents) in simple and direct language without medical jargon”, with a suggestion of the use of an interpreter if necessary:

(NS) “No point explaining in medical terms. This would only frighten parents.”

(NS) “The easier the language the less likelihood of ambiguity.”

(NS) “Health care professional should speak in plain language, interpreter if necessary.”

One doctor and 1 nurse thought that medical jargon could be used:

(NS) “Some medical jargon is required
(DR) "Medical jargon if used, needs to be fully explained."

One nurse stated that the language would depend on parents’ level of understanding:

(NS) "The language should be directed at the parents/child level as different people have different levels of education, some people may be offended if the language is too simple."

The language used at the informing interview needs to be tailored carefully. Parents in the literature seem to appreciate the use of simple and direct language without medical jargon. In Krahn et al.'s study (1993, for details of this study, see p.87), half of parents preferred the use of simple and direct language at the informing interview, and disliked a communication that included medical jargon.

The use of appropriate language is especially important in a multicultural country like Australia where language difficulty is a common concern in health care services, and can be a major influence on informing practice. Ahmann (1998) stresses that parents need to be informed of their child’s diagnosis in their own language. Surprisingly though only one subject in the current study recommended the use of an interpreter.

IN PERSON

Sixty-four subjects (61%), consisting of 8 doctors, 51 nurses, 4 social workers and 1 medical administrator, agreed with Guideline 5 "(telling parents) in person", but no further comment was made on this issue. Such response may suggest that the subjects take for granted this procedure. However, the literature did reveal that a minority of
parents were informed of their child’s diagnosis by phone or from a message left on an answering machine, and seemed to be hurt their feelings by such insensitive practice (Krahn et al., 1993).

ALLOWING TIME

A total of 70 subjects (67%), including 7 doctors, 58 nurses, 4 social workers and 1 medical administrator, agreed with Guideline 10 “allowing time for questions”. This was the second most frequently agreed guideline by the subjects. They related that allowing parents to have enough time enabled them to ask questions, react emotionally and absorb information:

(NS) “Parents need time to react.”

(NS) “Allowing time for questions is important to gauge what they want to hear/know.”

(NS) “Time for parent’s realisation, grieving, anger etc., [is] very important.”

(NS) “Parents should always be given time to digest information and allowed to ask questions.”

In Hasnat & Graves’s study (2000a, for details of this study, see p.94), the most common constraint on informing practice appeared to be lack of time, which was mentioned by half of paediatricians. This was also a major constraint on informing
practice for 33 % of paediatricians in Turner & Sloper’s study (1992, for details of this study, see p.93).

From parents’ point of view, Krahn et al. (1993, for details of this study, see p.87) reported that parents tended to be dissatisfied with the informing interview when professionals seemed to be distant (e.g., not sitting down, standing near the door) or showed impatience such as a rapid speech. However, the above doctors’ accounts suggest that such professionals’ behaviours are more likely to result from lack of time than insensitiveness.

The diagnosis of the child’s disability is likely to bring about intense feelings and concerns for parents. Allowing enough time at the informing interview is important in order for parents to release such feelings and concerns. The literature suggests that when parents fail to release their feelings and concerns, they are unable to concentrate on the subsequent discussion.

Time also helps parents absorb information. For instance, Woolley et al. (1989) found that when professionals paced information, allowed enough time, and used repetition and clarification, parents seemed to be better able to absorb information. The subjects in the current study appeared well aware of such parents’ need for time to release emotions, absorb information, and ask questions.

FOLLOW-UP INTERVIEWS

Seventy subjects (67%), including 8 doctors, 57 nurses, 4 social workers and 1 medical administrator, agreed with Guideline 11 “giving early opportunities for follow-up
interviews”, with several subjects confessing inadequate practice in this area. This was the second most frequently agreed guideline by the subjects along with Guideline 10 “allowing time for questions”:

(NS) “Follow-up interviews that allow parents to cover the same ground again are also important. People who receive ‘shock’ news often do not remember everything that was explained at the time.”

(DR) “I agree with all these but would more strongly push the last one [giving early opportunities for follow-up interviews]. I would make the appointment before they left.”

(NS) “We, as delivery suite midwives, know little about follow-up. Except for obvious disabilities at birth we have little to do with parents long-term.”

(SW) “For hospital social workers it is hard (due to work guidelines and time constraints) to follow-up with families post discharge, and refer families to other support services.”

Parents’ recollection in the literature revealed that informing practice often consisted of a single interview. Lack of follow-up seemed to be a major source of parents’ dissatisfaction with informing practice.

In Sloper & Turner’s study (1992, for details of this study, see p.101), 43% of parents reported that they were not provided with appropriate follow-up after the informing
interview. Similarly, in Hasnat & Graves’s study (2000b, for details of this study, see p.88), lack of follow up, which was identified by half of parents, was the most common source of parents’ dissatisfaction with informing practice.

Parents in the literature often indicated difficulty in absorbing the information given at the informing interview due to their emotional state. Immediate follow-up after the initial interview may give them opportunities to cover the same information again, obtain further information and ask questions that may arise after the initial interview (Firth, 1983).

Follow-up is also beneficial for professionals to check parents’ understanding of the information, correct any misunderstandings, and check parents’ use of resources after the initial interview (Olson et al., 1987). Comments of the subjects in the current study suggested that they were aware of parents’ difficulty in absorbing information through a single interview and their need for follow-up immediate after the initial interview.

From professionals’ point of view, a majority of paediatricians in Turner & Sloper’s study (1992, for details of this study, see p.93) indicated insufficient follow-up after the informing interview in actual practice. Main factors that hindered them from following this procedure were inadequate resources and lack of time. As discussed previously, professionals in the literature commonly perceived that lack of time was a major constraint on their informing practice. This also appeared to be a factor that interfered in providing follow-up for some subjects in the current study.
ADDITIONAL STRATEGIES

Apart from the strategies covered in the guidelines, additional strategies emerged from the subjects' comments.

Five subjects (5%), 1 doctor and 4 nurses, recommended the use of repetition to facilitate parents' understanding of information:

(NS) “Parents should be fully informed although the information may need to be repeated to them as they may be in shock.”

(NS) “There is a lot of parents can’t fully absorb, so I have found repetition important.”

(NS) “Parents frequently ‘don’t hear’ what is said and need information repeated.”

Five others (5%), 2 doctors and 3 nurses, stated that written materials for parents to take home were also beneficial to facilitate parents’ understanding:

(DR) “Written information which parents can take home and read is very useful and important.”

(NS) “Perhaps some written handout information can be given to parents to take home. So that when the initial ‘shock’ of confirmation of suspicions is
over, they can then sit down and read the information and further questions that arise may be answered either in the handout and at a later interview.”

Nine subjects (9%), 8 nurses and 1 medical administrator, emphasised the importance of support at the time and on an ongoing basis:

(NS) “Encourage parents to handle and call for baby as normal and giving them the extra support and understanding they need.”

(NS) “It is important for health professionals to make themselves available because the parents will come back and will want answers in their own time.”

(MA) “Ongoing support will be crucial for the family.”

THEME 7. WHO IS RESPONSIBLE FOR INFORMING PRACTICE?

The theme “who is responsible for informing practice” was not seen in the literature but emerged from the subjects’ comments in the current study. It does not directly pertain to the guidelines, yet was considered significant due to the frequency and consistency with which it appeared. A total of 16 subjects (15%), 12 nurses and 4 social workers, made comments on this theme. Some emphasised doctors’ primary responsibility in informing practice, and others stressed their role to support parents after the informing interview:
(NS) “I feel the above guidelines are all important but I feel as a registered nurse the diagnosis of a disability and informing the parents/child of the disability are not part of my role. My role is to offer support and ensure referral to social work and other appropriate professionals (e.g. physiotherapists, genetic counsellors).”

(NS) “[I am] usually not involved in the process of initial interview with parents. Would be the role of the medical team. Agree with above points though.”

(NS) “I have never been involved in informing parents of child’s disability. Paediatrician informs parents I have only reassured. Social worker has given information to parents. Devastating information is given by doctor.”

(NS) “Unfortunately in my limited experience with children or neonates it would be the obstetrician that would be delivering the news and the nursing staff that act as the emotional backstop afterwards, and for questions after.”

(NS) “Nurses support the parents after they are informed and begin the process of involving other professionals in the other support fields.”

Traditionally, doctors are exclusively responsible in providing medical information to clients and their families, and other professionals are trained to assist doctors in this responsibility (Quine & Pahl, 1986). Medical information includes diagnoses of clients, as a result, doctors inevitably assume a primary responsibility for informing practice.
For example, 89% of parents in Sloper & Turner's study (1993, for details of this study, see p.66) were informed of their child's disability by doctors, with the remainder being told by other professionals.

Other professionals are traditionally not allowed to give medical information to parents, and are only required to explain or reinforce the information given by doctors. One nurse in the current study stated:

(NS) "In Australia the culture of health professionals is that the role of informing parents of a diagnosis is the doctors, thus they need education in these issues. Nurses are often with the family at this time and continue the supportive and sympathetic role."

Consequences of this may be other professionals' indifference to informing practice, or their inability in this professional practice. The current data revealed the nurses' relative inability in most aspects of informing practice compared to the other groups. One nurse said:

(NS) "This is a very sensitive issue. We all need to know more."

Three nurses in the current study appeared to believe that informing was not their responsibility, and seemed to remain indifference to this issue. They commented on the front page of the questionnaire as follows:

(NS) "Feel this is not relevant to our field of nursing."
Two of these nurses returned the remainder of the questionnaire entirely unanswered. One nurse even appeared almost resentful to the researcher's asking their role in informing practice:

(NS) "It is not a nursing role to inform parents of any disability. It is the role of the paediatrician or registrar. If we told parents the baby was disabled and it turned out it was not - how would they feel. Nurses merely support the parents after they are informed and begin the process of involving other professionals in the other support fields. WE DO NOT DIAGNOSE!!"

Such attitudes, however, seemed to be somewhat overreacting, and unnecessarily negate their potential contribution in this area.

Interestingly, no doctor related to this theme. In contrast to the belief of doctors' exclusive responsibility in informing practice among several nurses and social workers, none of the doctors said that informing practice was their exclusive responsibility or other professionals were not responsible for this. This suggests that the doctors in the current study overlooked that other professionals became involved in this issue.

The literature suggested that the belief of doctors' exclusive responsibility in informing practice among other professionals could generate parents' dissatisfaction with services. A small number of parents in Quine & Pahl's study (1987, for details of this study, see p.91) reported that they had to face unnecessary delay, denial and evasion from nurses before the diagnosis of their child's disability. Such nurses' attitudes can cause a feeling
of uncertainty in parents and have an adverse effect on their future relationships with professionals. One mother said:

“I suspected as soon as she was born. She had feeding difficulties and she was all floppy. I kept asking the nurses but they wouldn’t say anything until the doctor came. He didn’t come until the next day. I don’t see why they had to wait for the doctor to tell me.” (Quine & Pahl, 1986, p.56)

The current findings suggested that the social workers tended to be more positive about having a child with a disability, more knowledgeable about community resources, more confident in counselling and communication skills and in parent-professional relationship, and have more understanding of parents of children with a disability than the other groups. Despite this expertise, they were less likely to be involved in informing practice. In fact, in the researcher’s professional experience as a registered nurse, social workers were only involved in the informing interview at a request of ward staff. Their comments also suggested that the system in hospitals interfered with their active involvement in this issue:

(SW) “Please note that social workers in hospitals are not permitted to inform parents of diagnosis of disability. This is done by paediatricians.”

(SW) “For hospital social workers it is hard (due to work guidelines and time constraints) to follow-up with families post discharge, and refer families to other support services.”
Admitting doctors’ primary responsibility in informing practice and the provision of medical information, the involvement of other professionals in informing practice is thought to be extremely beneficial for families of children with a disability. This does not mean that nurses and social workers must take the doctor’s place, but means they must be more involved and show a greater expertise in this professional practice.

The literature and the current findings suggested that doctors tended to perceive lack of resources, such as time and setting, as major constraints on their informing practice. On the other hand, comments from non-doctor subjects in the current study indicated individual differences between doctors in their skills and abilities in performing this task:

(SW) “In general the majority of paediatricians would follow above principles but a minority are less skilled and fall down in areas noted above.”

(NS) “Not all having expertise to address these situations.”

(MA) “Ongoing support will be crucial for the family and not all practitioners are able to provide this.”

From the current findings and the literature, it appears that in the majority of cases doctors are, regardless of their skills and abilities, solely responsible for informing practice and likely benefit from more cooperation from other professionals. Nurses and social workers can play an important role in arranging an appropriate setting and timing.
and in establishing effective communication between all parties. They can also help parents obtain information from doctors, evaluate and facilitate parents’ understanding of information, and provide non-medical information and emotional support to parents throughout the process.
CHAPTER 8 CONCLUSION

8.1 Limitations of the Study

Before discussing implications of the findings, a number of limitations of the current study must be acknowledged.

Firstly, the use of a convenience sample may reduce the ability to generalise the findings, though it was felt that this was a practical way to obtain a sample of appropriate subjects. The participating hospitals were chosen from a variety of localities, including rural, regional and city areas. The subjects from these hospitals, therefore, tended to be fairly representative of a broader Australian community of health care professionals. The unequal sample size across the professional groups was another issue, introducing unequal variance of the sample in each group being tested.

A possible sampling bias may limit the applicability of the findings. The demographic data revealed that the subjects in the current study tended to be those who had personal contact with individuals with a disability, with 80% of the subjects indicating contact with these individuals.

The relatively low response rate may also reduce the ability to generalise the findings. Of the total of 281 questionnaires sent to the directors of nursing, or distributed to the attendants of the conference and the private practitioners, 108 were returned to the researcher. This was likely to bear a possible response rate of 38.4%, which seemed to be relatively low. It should be noted, however, there was a difficulty in estimating an actual response rate, since accurate information about the number of the questionnaires...
that reached professionals from the Directors of Nursing was not available due to the nature of the sampling procedures. In addition, according to May (1997), it is not uncommon that response rates of a survey will be low with an average rate of 40%. The rate of 38.4% of the current study seems to be fairly comparable to this average figure.

The subjects’ responses could be affected by social desirability bias. The effect of social desirability on responses to self-report measures has been debated by a number of writers (Foddy, 1993; May, 1997). These writers, for example, related that the relationship between attitudes and behaviours is not always very strong, and what people report on them is often biased toward what they think socially desirable. A possible effect of this bias on the current findings is that the subjects might have felt being positive, knowledgeable or skilled as socially desirable, and thus scored higher than they actually were.

The failures to establish validity and reliability of the questionnaire used in the current study were other issues that may reduce the applicability of the findings. To some extent, this limitation appeared to be negated due to the findings that indicated some validity of the questionnaire. The study generated some discriminatory results between the groups, which were expected prior to the study. That is, doctors tend to be familiar with medical aspects of the disability and have experience and confidence in informing, and that social workers tend to be familiar with community resources and psychosocial aspects.

As discussed earlier, the different wordings used in the skill section might have confounded the current findings, and future studies are required to clarify these findings.
Not specifying the nature or severity of disability seemed to cause a difficulty in answering some items in the questionnaire, with a minority of the subjects (n=10, 10%) commenting, “it depends on the disability”. However, as explained previously, the researcher did not specify these aspects of disability intentionally so as to attract flexible responses from the subjects based on their personal or professional experiences in disability.

8.2 Conclusion

The current findings gave an insight into health care professionals’ preparedness for informing practice among different professional groups, including doctors, nurses and social workers. The study uncovered the doctors’ primary responsibility in actual informing practice, yet proved that there is likely the advantage of involvement of other professionals in this area.

The professional groups did not significantly differ in their attitudes toward having a child with a disability. The doctors, however, somewhat more frequently demonstrated negative attitudes to the attitude statements than the other groups. Parents in literature complained of professionals’ negative stereotypes for their child’s future and appreciated the information that included positive characteristics of the child (Krahn et al., 1993). The current finding may indicate that nurses and social workers can act as a moderator of doctors’ slightly more negative attitudes in informing practice. The involvement of nurses and social workers in informing practice may result in a higher level of parents’ satisfaction with services.
Statistically significant differences were found between the groups in their knowledge to give sufficient information to parents. The results indicated that the doctors were significantly more familiar with treatment and therapy options of the disability than the other groups (p<0.01). The social workers more strongly perceived they could advise parents how to inform friends and family of their child’s disability than the other groups (p<0.1), though this failed to reach the statistically significant level.

The groups, except the nurses, had an area in which they showed particular clinical competence in relation to the provision of information. That is, the doctors tended to be familiar with medical aspects of the disability, and the social workers tended to be familiar with community resources and non-medical advice.

Parents in literature often expressed dissatisfaction with the provision of information and criticised professionals’ lack of knowledge of community resources (Krahn et al., 1993). The current findings support an assumption that the involvement of other professionals in informing practice is likely advantageous in providing additional information to parents. The social workers seemed to be more familiar with community resources and non-medical advice than the other groups. Although the nurses, as a group, failed to show any particular expertise in this area, the data suggested that one in two nurses could provide information on all the knowledge items, except educational options for children with a disability.

Statistically significant differences were also found between the groups in their skills necessary in informing practice. The doctors indicated significantly more experience in informing (p<0.01) and significantly more confidence in informing (p<0.01) than the
other groups. The nurses seemed to be significantly less confident in their education/training in informing than the other groups (p<0.05). The social workers seemed to be significantly more confident in their education/training in counselling and communication skills than the other groups (p<0.0001). They also appeared to be somewhat more confident in their education/training in parent-professional relationship than the other groups (p<0.1), though this failed to reach the statistically significant level.

When the skill items were categorised into the “informing related”, “education/training related” and “parent related” items, the groups showed particular clinical competence in relation to the skills necessary in informing practice. The doctors seemed to be significantly more confident in informing than the other groups (p<0.01). The social workers appeared to be significantly more confident in their education/training in the areas identified than the other groups (p<0.05). They also indicated somewhat more confidence in their understanding of parents of children with a disability than the other groups, though this failed to reach the statistically significant level. Again, the nurses, as a group, failed to show any particular expertise in this area, however, about 70% of subjects in this group appeared to be confident in their education/training in parent-professional relationship and in counselling and communication skills, and familiar with parents’ emotional reactions to their child’s diagnosis.

The current study also found the following significant relationships between certain factors and professionals’ preparedness for informing practice.
• Professionals’ understanding of parents of a child with a disability is positively related to their attitudes toward having a child with a disability;

• Professionals’ knowledge to give parents sufficient information is positively related to their skills in informing practice;

• Professionals who have personal contact with individuals with a disability tend to be more skilled in the areas identified than those who do not; and,

• Professionals who have their own child tend to be more negative toward having a child with a disability than those who do not.

The subjects' responses to the open-ended question also provided invaluable information about their preparedness for informing practice. The subjects varied in their level of awareness of aspects of informing practice. Some appeared to be unfamiliar with this issue, yet the others seemed well aware of this, sharing opinions or their own procedures developed based on their professional experience.

From non-doctor subjects’ views, there appeared to be individual differences among doctors in their skills and abilities in informing practice. The doctors, on the other hand, seemed to perceive lack of resources, such as time and settings, as major constraints on their ideal practice.
The results suggest that the involvement of other professionals in informing practice is beneficial for families of children with a disability. The social workers appeared to be more positive about having a child with a disability, more knowledgeable about community resources, more confident in counselling and communication skills and in parent-professional relationship, and have more understanding of parents of children with a disability than the other groups. Despite such expertise, the social workers commented that the system in hospitals interfered with their active involvement in informing practice.

The nurses, as a group, failed to show any particular expertise in the provision of information and the skills necessary in informing practice. Nevertheless, they can be an important resource for families of children with a disability, as they are regarded as more approachable and available than other professions (Hitch & Murgatroyd, 1983). The current data suggested that one in two nurses could provide information on all the knowledge items, except for educational options for children with a disability. Moreover, a high proportion of the nurses appeared to be confident in their education/training in parent-professional relationship and in counselling and communication skills, and seemed to be familiar with parents’ emotional reactions to their child’s diagnosis. Despite their possible contribution in this area, there appeared to be a belief regarding doctors’ exclusive responsibility in informing among the nurses. Such belief seemed to act as an obstacle to their active involvement in informing practice.

8.3 Recommendations

There are several recommendations emerging from the current findings.
• **Routine involvement of nurses and social workers in informing practice**

The different skill and knowledge focus of the social workers as compared to the doctors indicates that the routine involvement of social workers in informing practice would be extremely beneficial to improve the service provision for families of children with a disability. Nurses can also play an important role in arranging an appropriate setting and timing, and in establishing effective communication between all parties.

• **Enlightenment of nurses**

The nurses’ failure to show any distinct expertise in informing practice and their belief regarding doctors’ exclusive responsibility in informing practice suggest that nurses need to be made aware of their potential contribution in this professional practice.

• **Evaluation of informing practice by nurses**

One area where nurses can make a greater contribution would be ensuring follow-up after the initial interview. Lack of follow-up seemed to be a major source of parents’ dissatisfaction with informing practice in the literature. As Ahmann (1998) argues, nurses are in an ideal position to conduct an evaluation regarding parents’ needs after the informing interview and on an ongoing basis. After the initial interview, nurses can assess parents’ understanding of the information they received, and correct any misunderstanding. In an ongoing evaluation, they can also assess parents’ additional needs for information and support. This will allow nurses to find out whether parents are in need for formal support from professionals or informal support from family and friends, or are in need for parent-to-parent or support group referrals.
• **Establishment of standard procedures and continuing educational programs to prepare staff for informing practice in hospitals**

Hospitals must establish standard procedures for informing practice similar to the one discussed in the current study, and secure sufficient counselling rooms and appropriate time management for informing practice. Hospitals can also provide continuing educational programs to staff in this area.

• **Additional professional education/training in this area**

The findings may help educators consider what should be additionally included in education/training for health care professionals in relation to informing practice. Professionals need to spend more time with individuals with a disability and their families, and need to be sensitive to families’ perspective of having a member with a disability in the family in order to provide services appropriate to their needs.

• **Future studies in this area**

Future studies of health care professionals’ preparedness for informing practice are required to confirm the current findings by using validated instruments. An enlarged sample with equal numbers of subjects in each professional group would permit a greater ability to generalise findings. Employing face-to-face interviews with health care professionals as a method of data collection would generate more in-depth information about health care professionals’ preparedness for informing practice.
APPENDIX 1 QUESTIONNAIRE

Please tick boxes, or put numbers or words as appropriate.
Please use a black or blue pen.

A. Are you?
   - Male
   - Female

B. What is your age?
   - years old

C. What is education related to your profession?
   - Certificate or diploma
   - Bachelor's degree
   - Postgraduate qualification

D. Is your first language?
   - English
   - Non-English

E. Do you have any children?
   - Yes
   - No

F. How many years have you worked as a health care professional?
   - years

G. What is your profession?
   - Paediatrician
   - Obstetrician
   - Midwife
   - Registered Nurse
   - Social worker
   - Psychologist
   - Other (please specify)

H. Do you know anyone with a disability?
   - None
   - Yourself
   - Relative
   - Friend
   - Neighbour
   - Other (please specify)
I. Please circle the appropriate initials that show how you feel about it.

SA: strongly agree; A: agree; NC: not certain; D: disagree; SD: strongly disagree
*Numbers are arranged for calculations.

1. I feel that having a child with a disability is a terrible thing for most families.

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2. I believe that having a child with a disability gives parents a special sense of purpose in their lives.

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3. I feel that having a child with a disability is worse for most parents than having a stillborn baby.

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4. I think that the positive side of having a child with a disability outweighs the negative side for most parents.

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5. I think that having a child with a disability restricts most families socially.

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6. It is possible for most parents to love their child with a disability as much as non-disabled child.

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7. I believe that most people with a disability are usually unhappy.

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8. I believe that most people with a disability can be helped to live virtually normal lives.

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9. I think that most people with a disability cannot make close independent friendships with other people.

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10. I believe that encouragement and care can help most children with a disability to do more than is initially expected of them.

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APPENDICES
J. This question is related to the initial interview in informing parents of their child’s disability. Please tick boxes as many as appropriate, that is topic on that you believe you can provide some adequate information to parents.

- Causes and natural history of the disability
- Accurate and up-to-date information of the disability
- Treatment/therapy options for the disability
- Educational options for the disability
- Informative materials for parents
- Counselling services
- Specialty services
- Community services (local organizations, intervention service and programs)
- Support groups and parent-to-parent referral
- Suggestions on how to inform friends and family

The following statements are related to the experience and education/training you have ever had. Please circle the number corresponding to words that show how you feel about it.

K. Your education/training in disability.

L. Your education/training in counseling and/or communication skill.

M. Your education/training about parent-professional relationship.
N. Your experience with parents of children with disabilities.

5  4  3  2  1
Excellent  More than adequate  Adequate  Less than adequate  Poor

O. Your familiarity with parents’ perspective of having a child with a disability.

5  4  3  2  1
Excellent  More than adequate  Adequate  Less than adequate  Poor

P. Your education/training in informing parents of their child’s disability.

5  4  3  2  1
Excellent  More than adequate  Adequate  Less than adequate  Poor

Q. Your experience in informing parents of their child’s disability.

5  4  3  2  1
Excellent  More than adequate  Adequate  Less than adequate  Poor

R. You have observed other professionals informing parents of their child’s disability.

5  4  3  2  1
Often  Sometimes  Occasionally  Rare  Never

S. You are familiar with emotional process that parents would experience after the initial diagnosis of their child’s disability.

5  4  3  2  1
Strongly Agree  Agree  Not Certain  Disagree  Strongly Disagree

T. You feel confident in your skills to inform parents of their child’s disability.

5  4  3  2  1
Strongly Agree  Agree  Not Certain  Disagree  Strongly Disagree

U. You feel you would benefit from additional education/training in any of the above areas.

1  2  3  4  5
Strongly Agree  Agree  Not Certain  Disagree  Strongly Disagree
V. The following guidelines have been recommended by a numbers of studies for good practice at the initial interview. Please describe your opinion about these in the space provided.

- Telling parents as soon as possible (sharing first suspicions with parents)
- With both parents together
- With the child present
- In private setting without interruptions
- In person
- In a simple and direct language without medical jargon
- With tolerance for parents' emotional expression
- Giving all the information fully
- In sympathetic and caring manner
- Allowing time for questions
- Giving early opportunities for follow-up interviews

Thank you very much for taking the time to complete the questionnaire.
Please check that no answer has been inadvertently missed out, and please return the questionnaire in the addressed envelope attached as soon as possible.
A short abstract of the major findings of the study is going to be sent the hospital when the analysis is completed.

Fumiko Tachibana
APPENDIX 2 PARTICIPANT’S CONSENT FORM

Research title - Informing parents of their child’s disability: A survey of health care professionals’ preparedness in informing practice

Researcher - Fumiko Tachibana

This research project is being conducted as part of degree of Master of Science supervised by Isla Bowen in the Department of Nursing at the University of Wollongong.

Your participation in this research is voluntary, you are free to refuse to participate and you are free to withdraw from the research at any time. Your refusal to participate or withdrawal of consent will not affect your relationship with the University of Wollongong.

If you would like to discuss this research further please contact Fumiko Tachibana on Ph (02) 4227 6068 or E-mail: ft09@hotmail.com or my supervisor, Isla Bowen on Ph (02) 4221 3470 or E-mail: Isla_Bowen@uow.edu.au. And if you have any enquiries regarding the conduct of the research please contact the Secretary of the University of Wollongong Human Research Ethics Committee on Ph (02) 4221 4457.

I, _______________________ (Participant’s name) consent to participate in the research conducted by Fumiko Tachibana as it has been described to me in the information sheet. I understand that the information I provide will be treated as confidential, and use solely for research purposes. When reporting the research findings, only processing data will be used and my name and hospital will not be identifiable. I consent for the information to be used in that manner.

Signed Date
/ / /
APPENDIX 3 PARTICIPANT’S INFORMATION SHEET

Research title - Informing parents of their child’s disability: A survey of health care professionals’ preparedness in informing practice

Dear Health Care Professional,

My name is Fumiko Tachibana. I am a student and I am going to conduct research as part of my degree at Master of Science (Developmental Disability) supervised by Isla Bowen in the Department of Nursing at the University of Wollongong.

I am interested in support for parents of children with disabilities, especially after their child’s initial diagnosis. The way in which parents are first informed of their child having a disability often has a profound effect on their ability to cope with the event and on the long-term parent-professional relationship. The majority of parents are told the news by hospital health care professionals from a variety of fields. Giving this news to parents is a challenging yet important task for these professionals. Their attitude toward children with disabilities, and their knowledge, experience and skills are identified as crucial factors in determining how well they will be able to communicate the news to parents. I have therefore decided to conduct a survey of health care professionals’ preparedness in informing practice.

Your assistance will help me better understand health care provision for families of children with disabilities and may result in the future improvement in the field.

Information you provide will be treated as confidential, and used solely for research purposes. When reporting the research findings, only processing data will be used and your name and hospital name will not be identifiable.

If you would like to discuss this research further please contact Fumiko Tachibana on Ph (02) 4227 6068 or E-mail: ft09@hotmail.com or my supervisor, Isla Bowen on Ph (02) 4221 3470 or E-mail: Isla_Bowen@uow.edu.au. And if you have any enquiries regarding the conduct of the research please contact the Secretary of the University of Wollongong Human Research Ethics Committee on Ph (02) 4221 4457.

When you have finished, please keep the information sheet and return the questionnaire and the consent form in the addressed envelope provided as soon as possible.

With thanks in anticipation of your prompt return of the completed questionnaire.

Yours sincerely

Fumiko Tachibana

橘 史子
### APPENDIX 4 SUBJECTS’ RESPONSES TO THE SKILL ITEMS

#### Item 1 Education/training in disability

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#### Item 2 Education/training in counselling and communication skills

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#### Item 3 Education/training in parent-professional relationship

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#### Item 4 Experiences with parents of children with a disability

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### Item 5  Familiarity with parents’ perspective of having a child with a disability

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### Item 6  Education/training in informing

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### Item 7  Experiences in informing parents of their child’s disability

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### Item 8  Frequency of observing other professionals’ informing

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### Item 9  Familiarity with parents’ emotional reactions to the child’s diagnosis

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### Item 10  Confidence in informing parents of their child’s disability

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### Item 11  Feeling additional education/training in areas identified as beneficial

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REFERENCE LIST


**REFERENCES**


McKay, M. & Hensey, O. 1990, ‘From the other side: Parents’ views of their early contacts with health professionals’, *Child: Care, Health & Development*, vol. 16, no. 6, pp. 373-381.


REFERENCES 259


*REFERENCES*


REFERENCES


