CHILDREN'S AND PARENTS'/CARERS’
PERCEPTIONS OF MENTAL HEALTH AND STIGMA

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Abstract

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Children’s and parents’/carers’ perceptions of mental health and stigma

The severe and pervasive effects of the stigma of mental health are known to impact on individuals and their families, and can result in intense feelings of shame, social exclusion and a reluctance to seek help. However, there has been little research on the perceptions of stigma in young children with mental health needs, or those of their parents.

This study examined the perceptions of mental health and stigma in young children with emerging mental health problems, and those of their parents or carers. The study’s objective was to gain some understanding of the context and impact of stigma on children and their parents/carers, and to determine factors which could contribute to service improvement and policies to tackle stigma.

A qualitative design, using Interpretative Phenomenological Analysis, was undertaken to explore children’s and their parents’/carers’ perceptions of mental health, children’s mental health services and the stigma attached. Semi-structured interviews, using a specifically designed storybook technique, were conducted with 20 children, aged 5 to 11 years, who had been referred to Child and Adolescent Mental Health Services for the first time. In addition, semi-structured interviews were undertaken with their parents or carers (n=23).

The study found that young children and their parents/carers have sophisticated and complex perceptions of mental health and the stigma attached. However, the findings show that understanding of the definition of mental health is not salient, and that participants experience the discriminatory effects of the stigmatisation process. The effects of stigma are communicated within the parent/carer-child dyad, which serves to contribute to perceptions of shame, blame and being different held by children and parents/carers. Participants also have preconceived ideas about mental health and children’s mental health services, which contribute to the stigmatisation process. In turn, this affects help-seeking and can contribute to the severity of children’s mental health problems.

The study highlights that collaborative approaches with young children and their parents/carers in education about mental health and stigma, development of non-stigmatising mental health services, and tackling stigma should be mainstreamed at a local and policy level, in order to effect positive change.
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I dedicate this thesis to Sam, Jasmine and Matthew. Three very special children. Children are the key to the future.
Abbreviations

ADHD  Attention Deficit-Hyperactivity Disorder
ASD    Autistic Spectrum Disorder
CAMHS  Child and Adolescent Mental Health Services
DDA    Disability Discrimination Act
DfES   Department for Education and Skills
ECM    Every Child Matters
GP     General Practitioner
HAS    Health Advisory Service
IPA    Interpretative Phenomenological Analysis
LREC   Local Research Ethics Committee
NIMHE  National Institute of Mental Health in England
NSF    National Service Framework
PCT    Primary Care Trust
PMHW   Primary Mental Health Worker
PPF    Priorities and Planning Framework
SDQ    Strengths and Difficulties Questionnaire
SPSS   Statistical Package for the Social Sciences
UK     United Kingdom
USA    United States of America
WHO    World Health Organisation
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Chapter One

The Context of Reform and Policy Frameworks in relation to Child Mental Health and Stigma

1.0 Introduction and background

This chapter will present an introduction to the current context of reform within child and adolescent mental health, which underpins this research study. It will consider the definitions of child mental health, and the policy frameworks around children and the improvement of Child and Adolescent Mental Health Services (CAMHS). It will also present plans to combat mental health stigma and discrimination across the lifespan.

Over the last ten years there have been some radical developments in child and adolescent mental health, which have focused on definition, provision of comprehensive services, strategic direction, and health and social care policy (Health Advisory Service, 1995; Department of Health, 2004a). The context of this reform has centred on the many specific aspects which should assist the child and their family to participate in and benefit from the outcomes of change. The developing reform frameworks have sought to assimilate the principle of shaping services which are based on the needs, perceptions and wishes of children, young people and their families (Williams and Kerfoot, 2005).

The findings from the thematic review of CAMHS, in England - 'Together We Stand' (Health Advisory Service, 1995), and the requirements of the National Service
Framework (NSF) for Children, Young People and Maternity Services (Department of Health, 2004a) emphasised the need to create a strong relationship between the development of child mental health strategy and service provision, and those who use, or potentially use the services. In addition, programmes have been developed by central government which emphasise the need to consider consultation with key stakeholders (including children and their families) on health care provision in relation to stigma, discrimination and mental health (NIMHE, 2004b). As a way of promoting a positive change in attitudes about mental health, current government health policies and their implementation plans have focused on mental health promotion. A principal aim of these policy developments has been to empower people to gain greater understanding and control of their health (Dowie et al, 1990).

When considering the implications for health care redesign and improvement, it is vital to gain a profound understanding of the experience, knowledge and perception of users who can contribute to such fundamental changes (Kurtz, 2005). Within the field of child and adolescent mental health, examining such perspectives has been developing slowly. Most research and consultation has been undertaken with young people who are above the age of eleven years, both within the community, and with those who use mental health services. Research studies examining younger children’s perceptions of mental health have tended to focus on the general community (Weiss 1986 and 1994; Spitzer and Cameron, 1995; Adler and Wahl, 1998). However, a huge gap exists in relation to the understanding of the perceptions of children who use CAMHS. Future research should focus on this to ensure the development of services which are non-stigmatising, accessible and responsive to the needs of the children who use them (Department of Health, 2004b).

In addition, a combined approach to understanding perceptions of mental health held by children and their parents or carers, appears to be deficient in literature. Recent
policy proposes that services should intervene early (Department of Health, 2004a). However, in order to develop responsive services, it is important to understand the issues, not only from the perspective of children with mental health needs, but also from the perspective of those who parent them. Parents are likely to make decisions about initiating access to help, and may consider possible implications for the future of their children. In addition, understanding the influence they might have on their children’s attitudes toward mental health could assist with planning for mental health promotion, ill health prevention and the development of anti-stigma campaigns.

1.1 Defining child and adolescent mental health and illness

In order to enable the exploration the views of child mental health held by children and parents, it is necessary to consider the current thinking around theoretical and operational definitions of mental health, which are commonly used within CAMHS.

Children’s mental health has been described as being on a continuum. The continuum, which starts with the concept of an ideal state of mental health, or ‘mental well-being’, moves through early and emerging mental health problems to conclude with mental ill health or mental disorder. It acknowledges that mental health is not static, but rather depends on several interrelated factors across the child’s psychological, social, environmental, cultural and spiritual life. Changes in these factors can, therefore, result in changes to mental health status (Dogra et al, 2002). The main task is to maintain mental health, which can be assisted or hindered by external circumstances and is dependant on personal potential and life experiences.

In recent years, there has been much work on defining ‘mental health’ in children. The use of the terms ‘mental health’ and ‘mental illness’ can cause certain concerns due to the implications of what they signify, their aetiology and the resultant
consequences. The Health Advisory Service (HAS) report (1995) suggested that, because of these perceived implications, the terms themselves can be stigmatising and discriminatory, therefore identifying the child as being 'different' by default. As a response to such concerns, two commonly used definitions of mental health, from a positive perspective, have been developed. The provision of valid definitions around children’s mental health seems to be necessary to ensure terminological clarity and to assist commissioners, strategic planners and practitioners to develop some certainty around the objectives to which they aspire. A summary of two frequently used definitions is presented in Boxes 1.0 and 1.1:

Box 1.0: A definition of child mental health, adapted from the Health Advisory Service (1995: 15)

- The capacity to enter into, develop and sustain mutually satisfying personal relationships
- The continuing progression of psychological, emotional, intellectual and spiritual development
- An ability to play and learn, with attainments that are appropriate to age and intellectual ability
- A developing moral sense of right and wrong
- The degree of psychological distress and maladaptive behaviour being within the normal limits for the child’s age and context
Box 1.1: A definition of child mental health adapted from the Mental Health Foundation (1999: 6)

- The ability to develop psychologically, emotionally, creatively, intellectually and spiritually
- The capacity to initiate, develop and sustain mutually satisfying personal relationships
- The ability to use and enjoy solitude
- To be aware of others and empathise with them
- The ability to play and learn
- The capacity to develop a sense of right and wrong
- To be able to face and resolve problems and setbacks, and learn from them

However, definitions of mental health cannot exist in isolation. Therefore, it seems reasonable to suggest that both definitions should be considered in relation to the variety of human responses, choices, culture, individuality and ability. Such an approach may be required in order to gain a true representation of what the achievement of ‘mental health’ would mean across social groups, and in particular to children and families.

When considering the definition of the rest of the continuum, it is crucial to recognise mental health problems, difficulties or disorders as issues which may arise as a result of any number of interrelated congenital, constitutional, environmental, family or illness factors. They should also be considered, not only for the presence of certain features or symptoms, but in relation to the impact on a child’s quality of life (Spender et al, 2001). Services which are developed to be responsive to these multi-factorial needs should be designed on the basis of these dimensions. The recent NSF has a tendency to define ‘mental health’ as problems or disorders (Department of Health,
2004b). It uses a definition of mental health that has been adapted from the Health Advisory Service (1995) and the Office of National Statistics (Meltzer et al, 2000) reports, which emphasises the notion of mental health being associated exclusively with problems:

"Mental health problems may be reflected in difficulties and/or disabilities in the realm of personal relationships, psychological development, the capacity for play and learning, and in distress and maladaptive behaviours. They are relatively common, and may or may not be persistent"

(Department of Health, 2004b: 44)

As can be seen from the variation and fragmentation of definitions available, there is a potential to reduce the significance of the definition which pertains to mental wellbeing, and to exchange it for or to prioritise a problem and illness oriented model. Such ambiguities only serve to add to the rhetoric which surrounds the mental health of children, not only in the continuation of confusion amongst children and families, but also amongst professionals. However, although the guidance issued within the NSF (Department of Health, 2004b), has a tendency to focus on problems, it does offer an expanded definition of a comprehensive child and adolescent mental health service. This includes all children, and suggests mental health promotion, preventative strategies and early intervention should be available as part of an equitable service. It also endorses the four-tiered model of CAMHS provision, first presented by the Health Advisory Service (1995) (Appendix 1). This reform of CAMHS suggests that the achievement of an optimum state of 'mental health' is a desired outcome for children, although plans to ensure that both professionals and families understand this new approach still need to be defined, and would be integral to any approach to reducing stigma.
1.2 Child mental health problems: prevalence

In recent years, many studies have been undertaken on the prevalence of mental health problems in children (Kurtz, 1996; Audit Commission, 1999; Meltzer et al, 2000; Green et al, 2005). Recent studies have indicated that around 20% of children and young people experience mental health problems (Mental Health Foundation, 1999; Meltzer et al, 2000; World Federation of Mental Health, 2003). In addition, these studies found that around 10% of five to fifteen year olds had a diagnosable mental health disorder; 5% had clinically significant conduct disorders; 4% were assessed as having emotional disorders (such as anxiety and depression), and 1% were rated as being hyperactive (Meltzer et al, 2000). When considering these results against the population of children in England, it would suggest that around 1.1 million children and young people under the age of eighteen may require the use of specialist mental health services (Department of Health, 2004b). The Office of National Statistics reports (Meltzer, et al, 2000; Green, et al, 2005) estimated that around 40% of children and young people with a mental health disorder are not receiving any service. The reasons for this are unknown, but could be attributed to a range of issues, including the fear of accessing services, stigma and inequality of provision.

The number of children with less serious problems, who could require some intervention, has been cited as being around the same level (Department of Health, 2004b). In most cases, this intervention will be provided by professionals who work with children in primary care, e.g. Health Visitors or School Nurses, or on an everyday basis, such as teachers (Hill, 2005). In addition to developing knowledge about prevalence, there is a call for recognising that all children and families should have access to education about mental health, to enable them to identify emerging mental health needs early (Department of Health, 2004a; 2004b; 2004c). Such an
approach would assist them in developing their knowledge and attitudes, would give them choices about their healthcare, and would help them to recognise when they might need support. Thus, when considering the extent of the population to which we have responsibility, in relation to mental health, there would be a need to include all children, young people and their families (Mental Health Foundation, 1999; DfES, 2004b).

1.3 National policy frameworks

In recent years there has been a strong policy direction towards consulting and involving service users, particularly children, in the active development of their health care and education. In parallel, many policies and campaigns have emerged which promote the tackling and reduction of stigma across the mental health arena and in the general population.

The following section sets out the policy context, in relation to children, mental health, and stigma reduction.

1.3.1 Children’s policy frameworks

Across the realm of children’s agencies, there has been an emphasis on working together to improve the lives and well-being of children, young people and their families. Since the beginning of the new millennium there have been many policy drivers for children’s services to examine the shape of services and to identify their strategic development. Emerging policy has suggested radical changes are required in quality, accessibility and coherence of services. Many of these policies and legislative frameworks include a push to ensure the involvement of children in all aspects of their care. The Health and Social Care Act (HM Government, 2001), the Education Act (HM Government, 2002) and the UN Convention on the Rights of the
Child (Article 12) (Office of the High Commissioner for Human Rights, 1989), all
advocate the requirement to help children express their views.

In 2004, the Government passed the Children Act (HM Government, 2004), which is
a legislative framework by which children's services reform will be steered. The
overall aim of the Act is to encourage integrated planning, commissioning and
delivery of services, as well as to improve multi-disciplinary working, remove
duplication, increase accountability and improve the coordination of individual and
joint inspections of services.

In tandem with the Children Act are two pieces of guidance which will shape the
future of services for children, across a range of issues. Firstly, the Every Child
Matters: Change for Children programme (DfES, 2004b) sets out a national
framework, on which to base local change plans. This will enable the building of
better services around the needs of children and young people, in order to maximise
opportunity and minimise risk. Every Child Matters (ECM) highlights five key outcome
areas for children and young people, which have legal obligation, as components for
well-being and which will define the purpose of co-operation between agencies. The
five key outcomes will require inclusion of the principles of positive mental health to
enable their successful achievement (presented in Box 1.2).

Box 1.2: Every Child Matters: five key outcomes for children (DfES, 2004b: 9)

- Be healthy
- Stay safe
- Enjoy and achieve
- Make a positive contribution
- Achieve economic well-being
A common thread that runs throughout the ECM programme is the requirement for children, young people and their families to be involved, consulted and enabled to make a positive contribution in every aspect of their lives, and to the services that wrap around them. The programme places the child, family and community at the centre of all development and change. The guidance emphasises the requirement of listening and being responsive to the diverse needs of children, and the need to offer services which are accessible, responsive, targeted and less stigmatising. Such directives underpin the necessity of considering perceptions of mental health and stigma in the improvement of children's mental health services.

The second piece of guidance issued in 2004, was the National Service Framework (NSF) for children, young people and maternity services (Department of Health, 2004a), which is a ten year programme intended to stimulate long-term improvement in children’s health. It aims to ensure equitable, high quality and integrated health and social care, which begins from pregnancy and extends to adulthood. The central premise of the NSF is to be a catalyst for massive cultural change, which will ensure that services are designed and delivered to meet the needs of children and families. It proposes a set of ten standards, which include a standard for the mental health and psychological well-being of children and young people (Standard 9) (Department of Health, 2004b). The first five standards are core (Department of Health, 2004d) and include health promotion and early intervention (Standard 1), parenting (Standard 2), and child and family centred services (Standard 3). A key outcome throughout the NSF is the requirement to give children and their families increased information, power and choice over the support they receive, and to involve them in the planning of their care and services. More specifically, Standard Three of the NSF states that children and families should receive high quality services, which are co-ordinated around their needs and take their views into account.
1.3.2 Child and adolescent mental health policy frameworks in England

Child mental health has been set as a priority for service improvement and strategic development in recent years. The changes in child mental health provision were initiated by the publication of the recommendations of the HAS review of CAMHS (Health Advisory Service, 1995). The radical recommendations suggested by the HAS have been followed by a number of reports, guidance and policies which propose fundamental changes in the way services are delivered (Department of Health, 1998; Audit Commission, 2000). In 2003, the Department of Health issued a Circular (HSC 2003/003: LAC(2003)2) related to CAMHS, which proposed, for the first time, an initial definition of a 'Comprehensive CAMHS across all levels of need and complexity', and included the need for development of early intervention and prevention services. The Priorities and Planning Framework (PPF) (Department of Health, 2002) then followed by identifying the expectation that a comprehensive CAMHS would be available in all areas in England, by 2006. The definition of a comprehensive CAMHS stipulated that, in any locality, there will be clarity about how the full range of users needs is to be met. This would include a range of provision from services that give advice regarding minor problems to arrangements for admitting a young person to hospital with serious mental illness.

In 2004, Standard 9 of the NSF (Department of Health, 2004b), which relates specifically to the mental health of children and young people, outlined the requirement for an improvement in the mental health of all children and young people. The Standard suggested that such improvements can only be achieved through working in partnership, promotion of mental health, provision of early intervention and consideration of models of service provision for children and young people with established or complex mental health needs. To support such developments, the principle that services should be based on best evidence and
provided by staff with appropriate skills and competencies should be embedded within strategic thinking.

Standard 9 of the NSF proposes that it is necessary to consider the effects of stigma, in order to develop services which are more responsive, more accessible and less stigmatising for children and families. The Standard also suggests that children and families have a role to play in the evaluation of services, and that they should be thoroughly consulted when commissioners are formulating a needs assessment, on which to plan the strategic direction of the CAMHS provision.

1.3.3 Mental health, anti-stigma and social exclusion guidance

The roots of stigmatisation against people with mental illness go back a long way. In the UK, the Royal College of Psychiatrists, launched a campaign called Changing Minds (Crisp, 2004), in 1998. The vision of the campaign was to tackle the problem of stigmatisation related to people with mental health problems. The aims of the campaign were to increase public and professional understanding of mental health problems, and to reduce stigma and discrimination. This campaign includes a section which emphasises the importance of tackling stigma in children and young people.

Following this, the National Institute of Mental Health in England (NIMHE), introduced a five-year plan to tackle the effects of stigma and discrimination related to mental health (SHIFT - NIMHE, 2004a). This plan includes several activities which should be pro-active in changing attitudes towards mental health, one of which focuses on the education of young people.

In 2004, the Social Exclusion Unit (England) published a report commissioned by the Government, which considers what can be done to reduce social exclusion amongst adults with mental health problems (Social Exclusion Unit, 2004). The report raises a number of important issues that are also pertinent to children and young people.
These include: highlighting the serious barriers to accessing services; the severe impact of discrimination in social and educational settings; and the pervasiveness of stigma throughout society. The report highlights the concern that, although there have been a number of campaigns to reduce stigma, there has been little impact on attitudes (Taylor Nelson Sofres, 2003). Within the suggested actions, the report identified that young people are one of the key target groups for the reduction of stigma, and that integration of mental health awareness into the school curriculum should be essential in changing attitudes. In parallel to the drivers within the report, two programmes emerged to support the challenging of stigma, which included children as a target audience – From Here to Equality (NIMHE, 2004b) and the National Healthy Schools Standard (Health Development Agency, 2004).

This chapter has considered the frameworks that provide the context which underpins this thesis. Previous evidence indicates the need to develop a more detailed understanding of the meaning of stigma and mental health for children and their families. The next chapter will thus examine and review the literature which relates to issues of stigma and mental health, in both adults and children. There is limited literature available which relates young children and mental health. The following chapter will also draw upon studies that have been undertaken in relation to adolescents’ perceptions of mental health, children’s views of other stigmatised groups, and families’ perceptions of mental health and stigma in order to provide a comprehensive overview of the existence, process and effects of stigma.
Chapter Two

Literature Review: Mental Health and Stigma in Children and Adults

2.0 Introduction: Stigma, discrimination and mental health

This chapter will explore the literature that underpins thinking around mental health and stigma across children, adolescents and adults. Most literature focuses on the adult population, although recently there has been increasing attention on adolescents and young people. Although there is some literature on young children’s knowledge of mental health and illness, there is little published research on their views of mental health and stigma, especially from the perspective of children who have experienced mental health problems themselves. In order to develop a greater understanding of children’s perceptions of mental health, this chapter will also explore studies which examine theories developed from research on children’s perceptions of other stigmatised groups. Although there has been little research on the perceptions of parents in relation to their children’s mental health, much of the work in the adult field is relevant. This chapter will, therefore, discuss related evidence on the effects of stigma on the family, as well as on parents’ and carers’ perceptions of mental illness.

2.1 Definitions and concepts of stigma

Compounding the complexity of mental health problems and mental illness and the impact they have on the individual, is the stigma that surrounds them. Stigma operates at a number of levels within individuals, families, education systems, the community, healthcare provision, the media and within social policy (Hinshaw, 2005).
There is a growing body of knowledge related to the field of stigma and its relationship with mental health. There has also been much work around the theoretical perspectives of stigma from a sociological, psychological and evolutionary perspective (Crocker et al, 1998; Kurzban and Leary, 2001). Some research suggests that people who are labelled as being mentally ill, regardless of diagnosis, are stigmatised to a greater degree than those with other health conditions (Weiner et al, 1988; Corrigan et al, 2000). In order to challenge the effects of stigma, it is necessary to understand its definitions, concepts, extent, and impact on the individual and within society. The majority of studies in the adult field raise issues that are likely to also apply to children. These are discussed next and the specific evidence that relates to children will be discussed at the end of this section (2.2).

2.1.1 Defining stigma and discrimination, and their relationship to mental illness

The origin of the term stigma is reported to stem from ancient Greek. The term was used to signify a visible mark or brand placed on members of tainted groups, such as slaves or traitors (Goffman, 1963). Recently, stigma has been defined as a mark of discredit, disfavour or disgrace that sets a person, or a group of people, apart from others. It would appear that the term ‘stigma’ is often referred to as the negative effects of a label placed on any group (Hinshaw, 2005). This label can cover a wide range of experiences including mental illness, physical disability, race, culture or sexual identity. ‘Stigmatisation’ has been determined as the process whereby one aspect of a person is linked by strong attribution to a wide and pervasive dimension of their identity; it is therefore, the establishment of deviant identities, based on negative stereotyping (Alexander and Link, 2003).
With regard to mental illness, Hayward and Bright (1997) highlight the concerning fact that there are 33 synonyms in Roget's *Thesaurus*, for the term 'insane', most of which sound discriminatory or prejudicial, and many of which are still in use in general vocabulary. A great deal of work on defining stigma and its relationship to mental illness was undertaken over 40 years ago, however, the discriminatory aspects still seem prominent when considering contemporary studies on mental health and stigma. The relevance of exploring the impact of stigma relates to the fact that the most disabling context of mental health can be the effect of stigma itself (Page, 1995). This effect has been reported to have a severe impact on the individual and the way that they perceive themselves, in relation to the rest of the community (Link, 1987; Wahl, 1999). Some of the early studies around stigma found that the general public tended to define people with mental illness as 'needing treatment', and they generalised about mental illness to the point of considering them to be dirty, unintelligent and worthless (Star, 1957; Nunnally, 1961).

Goffman (1963) stated in his classic work *Stigma: Notes on a Spoiled Identity*, that stigma was socially discrediting, permanent and affected the perceptions of the person as a whole. He defined *stigma* as the situation of the individual who is disqualified from full social acceptance. He suggested that cues which signal stigma are not always readily evident. With this in mind, it seems reasonable to suggest that people with mental illness or mental health needs can 'hide' the tarnish, to some extent, which identifies them with a stigmatised group. Therefore, this effect can be seen to continue and contribute to the fear of being discredited by their condition.

In order to understand the associated stigma of mental health and mental illness, it is necessary to develop a specific definition of stigma. Developing a finite description is not without problem, as there seems to have been much deliberation of the definition itself. Miles (1981) suggests what appears to be a clear definition of the stigma related to mental illness. She states:
'Stigma is a societal reaction which singles out certain attributes, evaluates them as undesirable and devalues the persons who possess them'

(Miles, 1981: 70)

In contrast, Huxley (1993) put forward the idea that stigma equals discrimination and suggested that the discrimination is negative and uninformed. Miles (1994), however, goes on further to say that the stigmatised attribute is seen as so important and distinguishing by the person who possesses it, that they become identified in terms of that one attribute. Penn et al (1994) state that mentally ill people are frequently labelled as being 'different'. The recent report on mental health and stigma, from the Social Exclusion Unit (2004), suggests that stigma arises from negative stereotypes associated with the symptoms or diagnosis of mental health problems.

Although a number of different definitions of stigma exist and it is important to recognise key themes that inhabit them. These key themes relate to the feelings of discrimination and suffering experienced by the stigmatised individual; the stereotypes that are imposed upon stigmatised groups; and the impact stigma can have on the individual's quality of life. In addition, it has been suggested that the extent of the effects of stigma make integration into the community increasingly difficult for individuals labelled as having mental illness, resulting in their marginalisation and exclusion (Social Exclusion Unit, 2004).

2.1.2 The extent of stigma and discrimination

Research exploring people's perceptions of mental health has mostly focused on adult views (Philo et al, 1993; Penn et al, 1994; Brunton, 1997). Studies undertaken with the general public, service users and professionals seem to show little consensus on the meaning of 'mental health' (Macdonald, 1993). Two qualitative
studies carried out by the Health Education Authority and the Health Education Board for Scotland on adults' perceptions of mental health, provide a helpful illustration of the importance of understanding lay perspectives, as they challenge professional wisdom on mental health and the issues contributing to the continuation of stigma (Parvis et al, 1996; Rogers et al, 1996). Understanding of lay perspectives can precipitate a reduction in the obscurity which surrounds mental health and illness, and a subsequent improvement of services that are available to help. In addition, developing an understanding of the meanings that mental health and stigma have for potential service users will prompt the development of approaches to changing attitudes. This should influence the creation of responsive and accessible services for children and their families, and people in general.

An early study (Cumming and Cumming, 1957), which examined the attitudes of the general public in relation to mental illness, concluded that most people feared and disliked the mentally ill, and would avoid them at all costs. Such early research is particularly striking when compared to the results of the Social Exclusion Unit consultation (2004), which highlighted that 83% of people with mental health problems reported that stigma was a still serious issue, and 52% had experienced negative attitudes towards mental health in the community.

Some discrimination surrounding the stigma of mental illness is reported to result from a genuine misunderstanding of the nature of mental illness. However, the stereotype of severe mental illness appears to have been so absorbed in beliefs and thinking, and so frequently portrayed in the media, that it seems impossible to dispel the negative beliefs of the general public. Stigma has now become widespread, and a number of studies show that socially stigmatising attitudes toward people with mental health problems are profuse (Byrne, 1997 and 2000). Green et al (2003), in their qualitative study of 27 mental health service users in the United Kingdom (UK),
reported that 14 out of the 27 had experienced overt discrimination in relation to their mental health, from a range of people, including friends, family and the general public. These findings suggest that the effects of stigma can be pervasive within support networks, and could contribute to the further maintenance of its disabling outcomes.

Studies of the general population’s attitudes toward the mentally ill, which have taken place over the last three decades, show that there has been little improvement in beliefs about stigma. A MORI poll was undertaken in 1979, which surveyed public attitudes toward mental illness on a nation-wide basis. This survey found that 89% of the sample agreed that most people were embarrassed by mental illness, however, only 21% admitted to being personally embarrassed. Huxley (1993) repeated some of this work in 1993, and found the results to be similar. Hall et al (1993) carried out a survey of over 2000 people, using four vignettes ranging from depression to paranoid schizophrenia. The results showed a clear discrimination against mentally ill people; however, one of the limitations of this study is that discrimination was measured against a response to a list of symptoms, rather than people with actual mental illness. Murphy et al (1993) also found similar levels of discrimination amongst the general population.

Corrigan (2000) states that stigmatising views about mental illness do not seem to be limited to the general population. Some research studies which examined attitudes of well-trained professionals, including those from mental health disciplines, showed that they subscribe to prejudicial stereotypes about mental illness (Keane, 1990; Lyons and Ziviani, 1995). Wahl and Harman (1989) undertook a systematic survey in the United States which revealed that the primary source of stigmatisation reported to be experienced by people with mental illness and their families, was from the demeaning attitudes of the professionals providing their care.
Mental illness appears to be given a high profile in the media. The common stereotype of the mentally ill patient can be seen as a subject in a wide range of media products, from horror films like *Silence of the Lambs* and *Nightmare on Elm Street* to children's comic books and soap operas (Wahl, 1995 and 2003). Sieff (2003), in a study examining the potential of media representations or 'frames', stated that the media does have a strong impact on perceptions. In the USA, many adults reported that most of their knowledge about mental health and illness came from mass media coverage (Wahl, 1995). Philo et al (1993) surveyed the reporting of mental illness in the UK during April 1993. The comments were divided in five categories – comedy; violence/harm to others; violence to self/suicide; sympathetic; and critical representation. Five hundred and sixty references to mental illness were found. The highest proportion was in the category for 'violence/harm to others' with over 350 references. This suggested that media images lay a heavy emphasis on people with mental health being dangerous, and the potential for the general public to be at risk. A survey of Canadian newspapers showed that portrayals of people with mental illness where often associated with violence and crime, and that people were often described as dangerous, unpredictable, unemployed and transient (Day and Page, 1986). Other research in relation to children's exposure to mass media confirms such findings (Wahl, 2003). Although mass media can be a useful source of learning and information, it is important to recognise that the impact of negative attributions associated with mental health and illness can begin at a very early stage in development and can be sustained throughout the lifespan. Therefore, the focus of campaigns to combat stigma using media as a conduit must target children, as well as adults, if they are to elicit any change.

2.1.3 The process of stigmatisation and mental health

Goffman (1963) determined stigma as containing a two-way process between 'normal' society and the stigmatised, and conceptualised it as drawing a line between
the 'self' and 'others'. Stigma incorporates a number of processes, and some terms are often used in conjunction with stigma and the process of stigmatisation. Corrigan and Watson (2002) conceptualise stigma in two social-cognitive models. They determine the two processes that take place within society, as public stigma and self-stigma. Public stigma relates to the reaction that the general population has towards people with mental illness, whilst self-stigma relates to the experiences of those people with mental illness, as a response to the stigma process. Both forms of stigma contain three specific terms which are commonly used to describe the processes; these are Stereotyping, Prejudice and Discrimination (presented in Box 2.0).

**Box 2.0: Common terms in the stigmatisation process**

- **Stereotyping** is a process by which members of a group are perceived to have a set of common characteristics or traits (Crocker et al, 1998).
- **Prejudice** relates to negative, emotive pre-judgements about members of visible groups (Crocker et al, 1998).
- **Discrimination** can be defined as the less favourable treatment of persons, including a reduction in access to both opportunities and resources, which can arise as a result of stigma (Welsh Assembly Government, 2002). Discrimination can be applied to persons or groups on the basis of belief, perception and alleged or other attributed characteristics, rather than actual ones.

Within the process of stigmatisation, stigma is said to emanate from these potential sources, but in particular from the experience of discrimination. The process of discrimination can have an impact through three potential avenues: overt
discrimination, perceptions, and fear of discrimination (Green et al, 2003). People with mental illness will experience all of the key features of the stigma process; they will be officially labelled, shunned, connected to undesirable characteristics and broadly discriminated against, in all aspects of their lives (Alexander and Link, 2003).

In relation to Corrigan's (2000) definitions of self-stigma, the person with mental illness assigns the process to himself, i.e. he will apply a negative stereotype to himself and agree with the prejudicial effects, resulting in low self-esteem. He will then behave in a way responds to the prejudice, i.e. avoiding specific social settings, therefore experiencing discrimination.

In addition, to public stigma and self-stigma, is the notion of courtesy stigma, which was invoked by Goffman (1963). Courtesy stigma is defined as a social disapproval for persons associated with a stigmatised individual. Families, friends and even neighbours are possible recipients of the effects of courtesy stigma. In this respect, people who experience courtesy stigma as a result of their affiliation with an individual can experience varying levels of stigma, which they can regulate through their ability to distance themselves from the person with mental illness (Gray, 1993).

Although the terms described in Box 2.0 are most commonly applied to stigma, Corrigan (2004) adds a fourth dimension to the beginning of the sequence. In his research looking at the effects of stigma and its interface with mental health care, he describes the process of stigmatisation commencing with cues. The cues relevant to the process are those inferred by the general public, in relation to their view of mental illness. They have four main attributes with which the general public identify (presented in Box 2.1.).
**Box 2.1: The attributions of cues for stigmatisation**

- The presence of psychiatric symptoms
- Social skills deficits
- Physical appearance
- Labels

(Adapted from Corrigan, 2004)

Studies of the general public show that the process of stigmatisation or cues from stigma can be developed as a direct result of an individual being labelled with a psychiatric diagnosis (i.e. such as giving an individual a diagnosis of psychosis) (Socall and Holtgraves, 1992; Link et al., 2001). Similarly, beliefs about people with poor social skills and appearance, e.g. a dishevelled person in a doorway has a mental illness (Penn et al., 1997; Corrigan, 2004) can also have a stigmatising effect. Although overtly detectable in the adult population, such opinions have not yet been elicited in relation to children, who are seen as having mental health problems. In this respect, it is probable that such preconceptions were more likely to relate to labels of delinquency or neglect, rather than mental illness.

In his classic work *Being Mentally Ill*, Scheff (1966) outlines that stereotyped imagery of mental disorder is learnt in early childhood. He states that patterns of social differentiation affect the individual’s concept and learning about mental illness. Similar learning patterns have been found in studies undertaken on the acquisition of children’s beliefs about race (Goodman, 1970), suggesting that stigmatising attitudes need to be tackled early, if there is to be lasting change. Penn and Wykes (2003) state that there is little evidence to confirm the effects of stigma on young children,
and that negative attitudes do not appear to be fully formed until adulthood. However, despite the lack of evidence, such statements suggest that it is vital to consider that approaches to tackling the development of negative attitudes should commence at an early age, and should continue throughout the lifespan.

When examining ‘Labelling Theory’ in relation to mental illness (Szasz, 1961; Sarlin, 1967; Horwitz, 1982), it is claimed that the acquisition of stigma is an ongoing process and is related to the responses of others including family, the community and professionals. Individuals can obtain labels from others (i.e. from diagnoses), or by association. The causes of stigmatisation are said to be complex and deeply rooted in cultural attitudes, as a result of entrenched historical ideas or myths about ‘madness’, and from assumptions about the nature of mental illness. Labelling theory grew out of sociological theories of deviance and suggested that many presentations of mental illness were in fact, deviant behaviour (Scheff, 1974). A consequential effect of being labelled ‘mentally ill’ is for the individual to modify their actions toward that stereotypical label, thus creating further and more entrenched deviant behaviour or a self-fulfilling prophecy (Rosenthal, 1995). In addition, labelling has been found to be an efficient way of categorising social groups and behaviours. They enable those in lay groups to rapidly formulate impressions of individuals (Corrigan, 2000), and allow the general population to make sense of an incongruent individual or set of behaviours.

Corrigan and Watson (2002) extend these views of labelling and stereotyping to include a distinction, which is made in the course of stigmatisation that occurs between the process of being stigmatised by the public and the effects of self-stigma by the individual. The difference between the two processes seems to be that public stigma results in the individual avoiding the label, whereas self-stigma can result in the individual avoiding treatment. Such processes can also be seen in the behaviour
of carers, when seeking help for their relative. Thus, the situation of the individual can escalate, which then contributes to the cycle within the stigmatising process and the excluding effects of stigma.

2.1.4 Consequences of stigma and discrimination

Discrimination of all kinds has been shown to have a detrimental effect on mental health, not only after problems have developed, but possibly at the onset of the problems, or illness itself (Penn and Wykes, 2003). A damaging aspect of stigma, highlighted in a study by Green et al (2003), was the effect of internalising stigma on those with mental health problems, including a belief that they were 'spoiled' and of less value than 'normal' people. Associated feelings of stigma include guilt and shame, self-protective denial and a serious reluctance to access help (Kendell, 2004).

Stigma can have a disabling impact on the individual's sense of self, including a significantly diminished self-esteem, self-value and confidence. Being subjected to the process of stigmatisation can cause the individual to internalise the ideas conveyed within society and believe that they are of lesser value because of their mental health problems (Link et al, 2001). The effects of stigmatisation become so pervasive that the person with mental illness can become secretive about the illness itself, and selectively avoid those who know about it. Similar responses to stigma have been found to be true of families, or carers of people with mental health problems, who often portray their experience of stigma in the form of shame and self-blame (Link et al, 2001). Avoidance of help-seeking has also been reported to be a common consequence amongst people with mental health problems, and by their families. This is often manifested as a feeling that they would be disgraced or would disgrace others within the family unit (Leaf et al, 1986; Corrigan, 2004). Sirey et al (2001) conducted longitudinal studies in the USA, which showed a link between the
effects of stigma and the diminished likelihood of adherence to pharmacological treatments for depression. Stigma has also been shown to have an impact on adherence to ongoing contact with help providers (Corrigan, 2004).

When considering the influences of stigma and discrimination, it seems necessary to illustrate the pathway of discrimination over the life span. The discriminatory effects can influence the experience of being stigmatised, from the first emergence of mental health problems, and throughout the course of the problem. Discrimination against mental health problems comes from many quarters, including the immediate family circle and peers, and from all levels in society. The results of experiencing stigma to this extent can be cyclical and can impact on the individual in a number of ways. They are presented in Box 2.2.

Box 2.2: Effects of stigma on the individual (adapted from Penn and Wykes, 2003)

- Contribution to increased severity of mental health problems and associated experiences, i.e. coping with traumatic experiences
- Prevention of help-seeking, due to internalisation of stigma
- Reduction of participation in work and social life

2.2 Children, young people's and family perceptions of stigma, mental health and illness

A report by the Mental Health Foundation (1999) - 'Bright Futures', which aimed to promote children's and young peoples' mental health, highlighted the need for professionals to understand the perceptions of mental health held by young people and their families, and to increase the knowledge of families and professionals in relation to mental health and mental illness. Despite the acknowledgement that
beliefs and perceptions surrounding mental health are formed in early childhood and are influenced by the peer group, the family and the media, there has been little contemporary research to assist in the understanding children’s perceptions of their own mental health.

The difficulty in exploring the definition and impact of stigma in relation to children and adolescents appears to stem from the low status that children have proffered throughout history, as well as the devaluing of mental illness within society (Hinshaw, 2005). This reluctance could also bear relation to the knowledge that from an early age and during the child’s development, children begin to hold negative beliefs about disordered behaviour in others (Wahl, 2002), therefore suggesting that adult definitions could also apply to children.

This section will explore the development and acquisition of beliefs about mental health in children, examine the concepts and causes of stigmatisation, and present a critical review of studies in relation to children’s and young peoples’ perceptions of mental health, mental illness and stigma in others. It will also include a section on stigma and mental health in families.

2.2.1 The development and acquisition of beliefs about mental health and illness

Research in social cognition has suggested that the development of mature attributional styles and personality traits is still in progress between the ages of six to twelve years (Flavell et al, 1993). The Health Education Authority completed a national survey of mental health awareness in young people in Scotland, and concluded that young people of all ages could provide a description for the terms ‘mental health’ and ‘mental illness’. Within this research it was found that mental
health tended to be described as something positive, whereas mental illness perceptions were largely negative (RAMH Education, 1996).

A study undertaken in 1972 by Cook explored children's stereotypes of mental illness. The findings highlighted that children aged six years have an understanding of everyday language and terms related to mental illness (Cook, 1972). These beliefs were found to be comparable with those of their parents and professionals they came into contact with.

Some of the following studies which look at attitudes toward mental illness can be difficult to appraise or compare, due to the variability of methodologies used. Although as a group they tend to elicit similar trends in relation to the developmental effect on acquisition of beliefs, it is still difficult to draw a finite conclusion.

In two studies looking at attitudes toward mental illness, Weiss (1986 and 1994) outlines that a developmental consequence occurs in the acquisition of beliefs. In his 1986 study, he measured the attitudes of 577 children in elementary school toward people with mental illness. The results indicated that a developmental effect takes place. Between grades two and four, children's attitudes changed positively, and by grade six to eight became more stable. Overall, children's perceptions of mental health became more positive with maturation. The results of these studies relate closely to theories developed by Scheff in the 1960s, which suggest that attitudes are learned at an early age, and that perceptions about stereotypes are continually reinforced by ordinary social interaction (Scheff, 1966).

In an eight-year follow-up study, Weiss (1994) evaluated the attitudes of 35 of the kindergarten students from the previous cohort. He comments that attitudes toward the mentally ill have developed and become clear by kindergarten. The results in the
follow-up study were similar to those found in the 1986 study, with attitudes toward the mentally ill becoming more positive over time. However, people regarded as 'crazy', a term which was defined as being different to mental illness, remained a perceived threat to children and adults alike. The significant difference in this study was that children were more accepting of people defined as 'mentally retarded' (mental retardation was defined as a biological entity, i.e. something occurring from birth, therefore more predictable). However, there was no change in the positioning of mental illness in the social acceptability ranking. An explanation for this could be associated with the greater acceptance of Special Education at the time, during the study. Weiss (1994) concluded that with maturation children became more psychologically sophisticated and were able to differentiate between the attributes of a range of presentations. Acceptance was more positive if the child had experience of or contact with someone with a mental health problem. The study suggests that with increasing age, children display attitudes and perceptions that progress from a general nature to those resembling adult specificity and differentiation.

Other recent studies on children's perceptions of mental illness, also in the USA, examined the developmental aspects of children's knowledge of mental illness using both qualitative and quantitative methods (Spitzer and Cameron, 1995; Adler and Wahl, 1998). Spitzer and Cameron's (1995) study examined how children (aged six to thirteen years) perceived mental illness, paying attention to the impact of age and gender on the ability to conceptualise and characterise those with mental illness, and their understanding of causality and treatment. The findings of this study indicate that age was not a significant factor in children's ability to classify 'deviant' behaviour. Almost all children correctly identified the 'normal' child from vignettes. This study also found that gender had an influence on the ability to identify behaviour. Boys were more able to identify deviant behaviours than girls. The developmental trend occurred in children's awareness of mental health, their understanding of
characteristics of mental illness and the ability to differentiate between mental illness and mental disability. Again, as in previous studies, children in vignettes who displayed overt behaviours like aggression were viewed more negatively.

Wahl (2000) argues that a combination of community, parental and peer beliefs and media representation is responsible for the development of perceptions in children. A review of research on help-seeking in children and young people, showed that there was a great reluctance to actually access the help available (Wahl, 2000). Wahl identified that the public's perception of mental illness and the stigma attached was the main reason for this. He reiterated that children learn from an early age that people with psychiatric problems are often perceived as failures.

2.2.2 Concepts and causes of stigmatisation in children

Many studies on the process of stigmatisation in children have focused on physical disability, race, ethnicity and religious groups. In studies that examined racial attitudes, very young children were found to have developed some negative attitudes, and that as they grew older, they were more likely to possess a negative attitude over a positive one (Goodman, 1970). Indicators which relate to the negative acquisition of beliefs and the beginning of the process of stigmatisation at an early age, suggest that children first display reactions to those who are physically or visually different (Katz, 1982). Preference has also been found in young children, for able-bodied, rather than physically disabled people (Sigleman et al, 1986).

Wilkins and Velicer (1980) examined the process of stigmatisation in children and their attitudes towards three stigmatised groups: those with physical disability, learning disability and mental illness. Their study highlighted the distinct attitudes towards all three groups held by children as early as in the third grade. An important
finding was that with age children’s reactions toward the mentally ill group seemed to receive the most negative association. Although there was no evidence in the study to suggest why this might be, there appears to be an implication that the more negative attitudes toward mentally ill people were learned within the family and established before entry into the school system. Evidence from studies in this field unite the premise which suggests that the process of stigmatisation can begin in preschool years, and that children display a preference for those who are similar to themselves, as opposed to those who they identify as being dissimilar. Even infants, when attempting to make sense of their world and their identity, will categorise others in “like me” and “not like me”, preferring the former (Lewis and Brooks, 1974). Wahl (2003) supports these theories around acquisition of beliefs, suggesting that children acquire understanding about mental health in three ways: through socialisation, by contribution from significant others, and through the mass media.

In relation to mental illness, the concept of stigmatisation in children has been suggested to evolve from fear and associated personal safety issues. Roberts et al (1981) explored children’s perceptions of medical and psychological disorders in their peers, and found that negative responses to those with mental illness were related to the fear of irrational or aggressive behaviours. Reducing such perceptions of mental illness would require significant investment in developing professionals’ and parents’ understanding of mental illness, for this to be conveyed to children.

A recent qualitative study of ten and eleven-year-olds (Roose and John, 2003), suggested that children’s concepts of mental health were sophisticated and that they considered many different behaviours to be an indication of a serious mental health problem. Children were clear about the difference between mental health and physical health problems, and were able to articulate them. There was also evidence of empathy and help-seeking knowledge in relation to those with mental health
problems. Children’s level of understanding enabled them to contribute to discussions about service development, and to make suggestions about how their needs should be met. These findings are significantly different from earlier studies, as they indicate an increase in children’s positive perceptions about mental health. Although there are few recent studies about younger children’s ability to develop positive concepts, some earlier studies indicate that this is more likely in those approaching adolescence. Wahl (2002) suggests that as children reach their teenage years, they begin to understand that behaviours expressed externally could be a result of inner distress. This enables them to form more positive opinions about behaviours related to mental illness, which they had previously deemed to be irrational.

Stereotypes and negative attitudes in children have been reported to stem from messages in the media available to children, from television and film to internet and video games. As discussed earlier, media influence has had a great impact on adults’ attitudes. Wahl (2003) explored this further with children. He cites the evidence that young children in the USA spend nearly three years of their life watching television before they enter the first grade of school. The majority of depictions of mental illness in the media are of a negative ilk, with most people with mental illness being portrayed as villains, or as cartoon characters with unpredictable behaviours. Images of mental illness and madness appear frequently in the media, with every one in four Parental Guidance (PG) rated films depicting mental illness in some form (Wahl, 2003). From such depictions one could speculate that children receive verification of negative ideation on a regular basis through one of their most significant forms of leisure activity.
2.2.3 The process of mental health and stigmatisation in children

The process of stigmatisation in adults, as discussed in Section 2.1.3, relates similarly to children. However, studies in the child population are far less prevalent. There is some evidence that the process regarding children and stigma is less direct. Hinshaw (2005) suggests four main elements which relate to the process of stigmatisation in children (presented in Box 2.3).

**Box 2.3: Stigmatisation in children and adolescents (Hinshaw, 2005)**

- **Courtesy stigma**: social disapproval of people associated with a stigmatised individual
- **Labelling effects**: the negative effects of a label on the individual and their outcomes
- **Effect of parental mental illness**: parents having a mental illness can be a key issue in relation to impairment of and perceptions in offspring
- **Children's perceptions of mental illness**: the way that children perceive mental illness and their understanding

Hinshaw (2005) suggests that, as a result of *Courtesy stigma*, children associated with people with a mental disorder (e.g. a parent with mental illness) can be shunned by peers, the community and society. Courtesy stigma can extend in either direction, i.e. children can think the same of others in the same situation, or parents may struggle disassociate themselves from the blame for their child's mental health problem.

Labelling can also have effects on the child. Adams *et al* (2003) suggested that labelling a young person with anti-social behaviour can have negative effects on their
future, and can emphasise the development of delinquent behaviour. There is also a body of knowledge to suggest that labelling can influence peer response towards children with mental health problems. Harris et al. (1992), in their study of children in the third through to the sixth grades, found that in pairs of children, a negative expectation of behaviour emanated from a non-labelled child about a child with a label or diagnosis. The effects of labelling were also reported to begin in infancy. Young children, whose parents had been labelled (for example, parents who had participated in the use of narcotics), were found to experience negative responses from other adults, in relation to their behaviours or mental health problems, as opposed to infants who were not labelled in this way (Woods et al., 1998).

Conversely, some studies have been undertaken which showed that having a diagnosis can be empowering. This is especially evident in relation to children with Attention Deficit-Hyperactivity Disorder (ADHD), and the emphasis of diagnosis within the school environment. Some parents reported that once their children had been given a diagnosis, they received greater access to more support, and professionals were more empathetic and helpful (Klasen, 2000).

Hinshaw's (2005) third domain of stigmatisation in children relates to the effect of parental mental illness. Research on risk and resilience factors highlights that parental mental illness can be a causative factor for mental health problems in children; not just from a biological point of view, but in relation to attachment and in the child's experience within society (Kurtz, 1996). On this point, both of the previous factors discussed would have an impact in relation to the effects of parental mental illness. The fourth area of Hinshaw's model relates to children's perceptions of mental health and illness. This will be discussed in the following section (2.2.4).
2.2.4 Children's perceptions of mental health and illness in others

In comparison to adult studies on perceptions of mental health and illness, which focus on the general public and those with a mental health problems, all of the research that has been undertaken with children, looks solely at their perceptions of others. In children aged up to eleven there are few recent studies, and most relate to research undertaken in the USA. The paucity of studies with younger children can be mainly attributed to the complexity of gaining perceptions from younger subjects. Many of the studies undertaken in the UK relate to young people over the age of eleven. As aspects of these studies could apply to younger children, they will be discussed in the next section (2.2.5).

Most studies which have looked at children's conceptions of mental illness, have focused on children's knowledge of mental illness, with respect to its identification, classification, cause and treatment. Early studies carried out in the USA during the 1970s, examined children's understanding of their emotionally disturbed peers (Novak, 1974; Kalter and Marsden, 1976 and 1977). Kalter and Marsden (1976) undertook interviews with 31 children from the forth and sixth grades, to ascertain their understanding of the behaviour of one 'normal' and four 'emotionally disturbed' boys, described in case vignettes. The vignettes of the 'emotionally disturbed' boys included such descriptions as an aggressive disorder, a passive-aggressive disorder, a child with school phobia and a boy with borderline psychosis. Analysis of the findings looked at the degree of liking and disliking felt by subjects about the figures in the vignettes. Results showed that the 'normal' figure was liked significantly more than the passive-aggressive and the aggressive figures. The figures with school phobia and borderline psychosis were disliked less than the passive-aggressive and the aggressive figures. The findings also suggested that children were sensitive to the clinical severity, however, their liking and disliking scores were not related to
severity, but to those cases where the management of aggression seemed to be the
problem.

Although this study does not directly examine children's understanding of mental
illness per se, it starts to identify the concept that children's social judgements are
sophisticated at an early age and that they can begin to understand the severity of an
individual's disturbance. However, judgement about one domain does not necessarily
predict another, and some judgements seem related to observable threat rather than
perceived disturbance.

In a second study, Kalter and Marsden (1977) examined how children might account
for the development of such childhood disorders. Using a similar approach to the first
study, children were asked the question "How might (the child) get to be the way he is
in the story?", of each of the vignettes. Whilst children did hold specific views about
the aetiology of disorders, they were related to factors other than severity. In general,
there was a lack of consensus across all grades, with no evidence of widely shared
theories. Conclusions that can be drawn from such findings would suggest that it
could be expected that aetiological theories held by children would become more
consistent as they mature. Also there is evidence of developmental trends found in
similar studies (presented in Section 2.2.1). However, it is evident that views held by
children in these age groups tended to be egocentric and based on personal blends
of experiences and concerns.

Weiss (1980 and 1986) studied children's attitudes toward socially stigmatised
groups, including people with mental illness. He looked at the attitudes amongst
elementary school children, from kindergarten (five years) up to year eight (twelve
years). The study used a combination of qualitative and quantitative measures and
focused on the following issues:
1) Existence of social distance hierarchies, including preference for those labelled 'mentally ill'
2) Children's ability to verbalise knowledge and information about stigmatised groups
3) Acquaintance with stigmatised groups and mental health professionals
4) Willingness to work with mentally ill
5) Reported viewing of media images of mental illness
6) Developmental trends exhibited through the Opinions about Mental Illness Scale

Four distinct clusters emerged from the research findings in relation to social distance measures. These ranged from 'normal', physically handicapped, mentally ill/mentally retarded/ emotionally disturbed to convict/ 'crazy'. Within the age groups the only change in rank order was the reversal of the position of convict and crazy in year six and eight students. This indicates that the opinions formed in kindergarten show little positive change with maturation. Weiss also found these results to be comparable to studies of attitudes carried out with adults. When examining developmental trends, Weiss found that with increasing age, children were more likely to verbalise a response, regardless of its accuracy. Children in kindergarten were unexpectedly able to make highly discriminated judgements about their preference of stigmatised groups. 'Crazy' people were regarded with fear, disgust, distrust and aversion by children and adults alike.

Focusing on the theme of children's attitudes toward mental illness, Weiss (1985) conducted a further study on children's attitudes using the 'Opinions about Mental Illness' questionnaire and concluded that, with increasing age, children adopted a less authoritarian attitude towards people with mental illness and viewed them as
more like themselves. However, they took an increasingly parent-like view of those with mental illness and seemed consider that they may be able do something to help them. They also gradually became more able to define mental illness as different to other illness and saw people as less of a threat to society.

Poster et al (1986) investigated children's attitudes toward the mentally ill using case vignettes in grades three through to six. Mediums used to elicit their conceptions included Kinetic Figure drawings and story writing. The children were given six case vignettes describing problematic behaviours of children and adults with anxiety disorder, schizophrenia, and depression. Each vignette was followed by a series of questions to prompt children's thinking about the behaviour exhibited. They were then asked to draw a picture of a 'crazy' person doing something and write a short story about what their character was doing. The findings identified that children attribute a variety of specific types of behaviours to the mentally ill, which range from inappropriate behaviour to suicide. There did not appear to be any particular developmental trends, which is contrary to some of the findings in other studies mentioned earlier. One hypothesis was whether the increase in media portrayal of mental illness, and violence has increased children's awareness of such issues.

Adler and Wahl (1998) asked 104 third grade students (eight year olds) to tell stories in response to pictures of adults labelled mentally ill. The aim of the study was to determine whether children of elementary school age attributed clear and consistent definitions to people labelled mentally ill, and if so, whether these attributions had negative characteristics similar to those in adults. The results suggested that young children lacked consistent conceptions of mental illness, with an inability to articulate examples of mental illness. On the whole, those labelled mentally ill were described in more negative terms than those with physical illness, showing agreement with findings in most studies to date. The findings indicated that, even without a clear
definition of mental illness, children have generally developed a negative way of responding to mental illness by the age of around eight years old.

More recently, Wahl (2002) looked at the understanding displayed by young children and found that they were more accurate about mental illness as they approach adolescence. Children's understanding of the treatment of mental illness was also more apparent, showing that they considered internal problems, related to thoughts and feelings, were more appropriate for treatment than overt or disruptive behaviours (Dolinger et al, 2002).

2.2.5 Young people's perceptions of mental health and illness

This section explores recent research with adolescents in relation to perceptions of mental health and illness. Research on children and young people's perceptions of mental health in the UK has tended to focus on the views of older children, usually over the age of eleven years. However, the findings from studies with this age group may be relevant to future research with younger children. In order to achieve the development of responsive and targeted services, there has been an increase in approaches to gain understanding of the target population's views on addressing their own health needs (WHO, 1986; Ashton and Seymour, 1988). Also with the emergence of important legislation in relation to children and young people, such as the Human Rights Act (HM Government, 1998), and the Children Act (HM Government, 2004) there has been increasing progress in recognising that the value of views of the child, in the UK.

In 1996, a Christmas lecture for young people was delivered to 200 children in the UK aged between eleven and seventeen. The focus of the lecture was "Is it dangerous to be different?". Following the lecture, 106 children completed a questionnaire which asked questions about attitudes and understanding of mental illness, concerns
children that may have and their views of appropriate treatment interventions (Bailey, 1999). The conclusions of the study indicated that the participants had a wide range of understanding and acceptance of people with mental illness. Overall, it was found that young people felt that adults could give them constructive solutions for dealing with mental illness, but they also wanted to be part of the process. These results are similar to the findings from Roose and John's study (2003) with younger children. These recent studies seem to suggest that children and young people are becoming more understanding and accepting of mental health and illness, which would indicate a drive to educate children earlier and to consider how professionals communicate about mental health, across all organisations.

The Mental Health Foundation developed a programme called “Hear Me!” to promote consultation with children and young people on mental health services (Laws, 1998). The programme evaluated five different models which enabled young people using mental health services around the UK, to have a view on their care. These models utilised a range of means which enabled young people to have a voice. These included training young people as researchers, group and art work, and in-depth qualitative interviews. The most striking finding was that young people expressed a strong desire to be involved in decision making about their lives and their care, and that they needed more information about mental health. They also suggested that developing knowledge about mental health within children's services was vital. These findings show that such interventions could potentially decrease the sense of stigma, and that the development of positive attitudes toward mental health needs to be integral to their education.

A similar study, which looked at young people's experiences of mental health services – “Time to Listen” (Laws et al, 1999), concluded that young people sometimes felt that the way they were treated in mental health services made them
feel worse and was impersonal. They articulated that they felt they were not listened to, and that accessing help for the first time was particularly difficult. They also recalled experiences of being stigmatised, which included feelings of shame, embarrassment, and that their problems were not understood by family and friends.

A follow-on study - ‘Listening to children’ (Armstrong et al, 1999) examined young people’s (aged 12 to 14) perceptions of mental health. They employed a qualitative approach to exploring the attitudes and perceptions of 45 young people. The sample included young people from a variety of social and minority ethnic groups, attending mainstream schools in rural, suburban and inner-city areas. Using a combination of focus groups and individual interviews, the research focused on understanding of mental health and its promotion, the importance of mental health to them, how young people cope with difficult feelings, and the perceived differences between young people and adults. The study also gave young people an arena to set their own agenda. The findings show that understanding about the term ‘mental health’ was not always clear and consistent. Young people had definitive views about the issues which affected their mental health, wished be listened to and believed that professionals should have a clear understanding of mental health and how information is imparted to them. They suggested that through an improved understanding amongst professionals and families, there could be better communication with young people about mental health and a more appropriate response to emerging problems. This reiterates findings from studies discussed earlier, undertaken with younger children and also with adults.

In addition to the main sample, the study also recruited two sub-sample groups; one group of 16 young people with an identified psychological, emotional or psychiatric problem, and a group of 8 young people living with a mentally ill adult. There were many similarities in the findings; however, some distinct differences also emerged.
These differences were portrayed in the reactive way in which young people dealt with negative feelings, their limited knowledge of how to promote mental health, and the feeling that they were responsible for their behaviour. They also engaged in an enhanced discussion of socially unacceptable behaviour and its identification with mental illness. Young people seemed to display more punitive attitudes towards those with mental illness, possibly as a result of their own mental health needs, and the interventions they suggested were based on their own experience. Some of these perceptions were related to stigma, and were replicated by a study of young offenders (Anderson et al, 2002). Young people in this group related their perceptions of mental illness, in particular depression and psychosis, to their inability to cope and their previous experiences.

Durham (2000) looked specifically at Gujarati girls' attitudes towards mental health and contrasted them with those of white British girls. Both groups reported being generally happy with their lives, with little evidence of mental health needs. Many of their concerns fell into the area of emotional health, and they showed little experience of what they considered to be 'real' mental health issues. They came across as being very similar in their perception of mental health, with the most distinct difference occurring in the Asian girls' experience of family life, which they appeared to find more acutely distressing. Both groups showed a good empathy for people with mental health issues. However, they considered there to be some stigma attached to both having and needing help for mental health problems. Such findings are echoed in the Armstrong et al (1999) study, which included a representative sample from black and minority ethnic groups, suggesting that the differences in attitudes across ethnic groups are minimal.

Gale and Holling (2000) developed a project called "HEADstuff", which is a mental health resource for 14 to 17 year-olds from social disadvantaged backgrounds. The
messages about mental health were distributed through a two-minute cinema trailer entitled “1 in 4”. In order to produce something that was relevant in style and language, Gale and Holling undertook focus groups with young people. The key findings were that young people’s knowledge and understanding of mental health was extremely low, they did not always possess the language to express their emotional needs effectively, and they did not have much experience of being close to someone with a mental illness. Some of these findings contrast with the findings from the studies discussed earlier. In the Armstrong et al study (1999), young people appeared to be particularly articulate about their mental health needs, and in Durham’s (2000) study, young people were able to explain and understand their emotional needs. Such contrasts would perhaps indicate that young people from socially disadvantaged backgrounds have less access to information, support and help regarding mental health.

A recent study in Germany (Schulze et al, 2003) explored the impact of an awareness raising programme, undertaken with 90 school students (aged 14 to 18 years), regarding their attitudes and intentions towards people with schizophrenia. In the initial baseline assessment, only a few students subscribed to negative stereotypes about people with schizophrenia or rejected entering into a relationship with them. However, rather than subscribing to negative views, students tended to identify that they were unsure about definitions and descriptions. When students were re-assessed they showed significant reductions in subscribing to negative stereotypes. This study too, supports findings outlined in other studies which report that in recent years there has been a gradual shift towards more positive understanding and acceptance.

Sessa (2005) explored the experiences of stigma in 200 young people from local schools. 100 of the young people completed questionnaires on their attitudes towards
physical illness, and the other half on mental illness. The most striking finding, which contrasts with similar studies in the USA (Wilkins and Velcier, 1980; Sigleman et al, 1986), is that both groups displayed severely stigmatising views and attitudes towards both mental and physical illness, but with a greater emphasis towards mental illness. The attitudes which attracted the highest rates of stigma were; having a relationship with someone with a mental illness; that mentally ill people were unreliable; and that people with mental illness were far less attractive than those without. Such attitudes would have an implicit impact on adolescents who have suffered from mental illness, in terms of reintegration in the community and peers, and living a ‘normal’ life.

2.2.6 Stigma, mental health and the family

It must be recognised that stigma not only has a severe and enduring effect on the individual, but can also have an effect on the family. Some research in the adult field has emerged in recent years; however, there is little identified work on the experience of stigma in parents or carers in relation to young children’s mental health.

As a response to stigmatising mental health attributions, the family can have a negative impact on the process of stigmatisation. A number of studies have examined the responses of parents and siblings towards their family members with a mental illness (Leff and Vaughan, 1985; Kavanagh, 1992), and have found that their feelings can often include hostility, shame, intensive criticism and anger.

Gilbert (2004) explored shame within the family as a result of mental illness, and established a variety of experiences. These experiences related to stigma, external shame, internal shame, and humiliation. Shame is a common experience in relation to stigma. Humiliation is a result of devaluation or power abuse by others, and is seen
as unjustified and unfair. Shame and humiliation are regular experiences described by families of people with mental illness. Gilbert reiterates the concerning fact that families and individuals will go a long way to conceal their stigmas from others. The concealment of stigma can have detrimental effects in the long run, as it can prevent the family from accessing services, increase fear of detection, and maintains negative self-perceptions and evaluations.

Many families have demonstrated good caring for offspring with mental illness. However, Gilbert (2004) highlighted that in low-resource environments, children are less likely to be invested in and are treated less favourably. When examining cycles of shame and stigma within families, Lansky (1992) indicated that unresolved emotional conflicts in families are likely to impact on parenting. Sometimes the parent with the emotional conflict can withdraw, resulting in the child being the target of negative projection.

Some of the stigma related to parents and carers of children with mental health problems can give rise to the belief that the illness has been perpetuated by poor parenting skills and dysfunctional families (Mohr et al, 2000). In addition, mental health services often perpetuate this belief by using non-collaborative interventions which result in parents and carers feeling disempowered in the process. Central to all family experiences of mental health and stigma are the key features of suffering, sacrifice, and burden. Some of these issues can relate to the environment, i.e. time, financial cost and negotiations to do with care logistics (for example, supporting a child who has been excluded from school, when parents have to work; or getting to appointments), whilst others are related to psychological pain, suffering and shame. The latter group of issues have been found to have stronger impact on families (Hinshaw, 2005).
Parents and carers often express their exasperation in relation to difficulties in accessing services, waiting lists and the lack of knowledge of certain professionals about their child. Window et al (2004) outlined parents' desire for a responsive service, which could also give more direct involvement to children. Farnfield (1995), in a study of parents' and carers' experiences of professionals, highlighted that they were critical of the knowledge and understanding of staff in mainstream schools.

2.3 Rationale for the study

This chapter highlights the severe and pervasive impact that stigma can have on those with mental health needs and mental illness. The studies within the adult population emphasise the extent of the problem and the complexity of the process of stigma: a process that can be hard to tackle and that requires intervention on many dimensions. The studies related to the child population indicate there is a developmental establishment of beliefs about mental health, which usually begins at an early age. The adolescent research shows the possibility of creating a more positive perception, through education and collaboration with young people. In combination, these findings indicate the necessity to develop an understanding about perceptions of mental health and stigma held by those who have identified mental health needs, and who may potentially use services. The most effective period to focus this understanding would be during early childhood, in order to help establish children's understanding of mental health at an age when beliefs are acquired. In addition, it would seem vital to consider the associated impact of stigma on those who care for children and make decisions about their mental health needs. This study will aim to consider the relevance of these highlighted issues.

The next chapter will focus on the methodological framework of the research study undertaken as part of this thesis, which examines the perceptions of mental health,
services and stigma in primary school aged children, who have been referred to a Child and Adolescent Mental Health Service for the first time, and those of their parents/carers.
Chapter Three

Methodology

3.0 Introduction

This chapter will present the research questions, aims and anticipated benefits of this study and will describe the methodology used to establish children's and parents'/carers' perceptions of mental health, children's mental health services and stigma amongst children (aged five to eleven), who have been referred to specialist CAMHS for the first time. The epistemological and methodological rationale will be presented and discussed. Finally, the specific methodology of Interpretative Phenomenological Analysis (IPA) employed as a framework for conducting the study will be presented.

3.1 Research questions

The overarching research question, within this study is:

*What are the perceptions of children (aged five to eleven), who have been referred to a specialist CAMHS for the first time, and their parents/carers, of mental health and illness, Child and Adolescent Mental Health Services, and stigma?*

This research question is sub-divided into the following questions:

1. What are the perceptions of children (aged five to eleven) and their parents/carers, of mental health, mental illness and stigma?
2. What are children’s and parents'/carers' perceptions and experiences of seeking help, in relation to the child’s mental health needs?

3. What are children’s and parents'/carers' perceptions of child mental health services and interventions they may receive in relation to the child’s mental health needs?

3.2 Aims of the research

The aim of this study is to develop an understanding of the perceptions held amongst children of primary school age, who have been referred to CAMHS, and those of their parents/carers, in relation to mental health and mental illness, children’s mental health services and the stigma attached. The research aim is to establish these perceptions, as well as their understanding and meanings associated with mental health, before assessment and intervention at a specialist child mental health service. The intention is to elicit children’s and parents'/carers’ views before they attend the service, therefore minimising the likely influence of first-hand experience of the mental health services on preconceived notions and perceptions.

The aim of the study is also to develop a picture of children’s and parents'/carers’ perceptions and experiences of the pathway to seeking help, in relation to the child’s mental health need. The study will examine the participants’ views and their expectations of child mental health services, and the impact of their perceptions on the process of seeking help for their child’s mental health problems. In addition, the study will examine the interplay between parents'/carers' and children's perceptions through exploration of the emerging themes for both sets of participants.
3.3 The anticipated benefits of the study

The anticipated benefits of this research are to develop a greater understanding of
the perceptions of mental health and stigma held by parents/carers and their children.
This will enable policymakers, strategic planners and service providers to obtain
knowledge and understanding from the service users' perspective. This is likely to
inform strategic planning of mental health services for children, encouraging good
practice in service delivery and increased accessibility. These improvements could be
better achieved through the development of evidence-based partnership between
professionals, the child and their family. Such evidence, underpinning service
developments could embrace the principles outlined in recent UK policy on the
improvement of children’s services, and tackling the stigma of mental health
(presented in Chapter One).

In addition, the findings are likely to contribute to the limited body of knowledge
related to views about mental health and stigma, in young children and their
parents/carers. More specifically, the findings are likely to provide new knowledge
and understanding on the views of young children and their parents, where there has
been an identified mental health need. To date there has been dearth of research in
this area.

The findings will be disseminated across a range of organisations and key
stakeholders, relevant to children's mental health, including children and parents
where possible. An anticipated benefit of such dissemination could be to provide a
catalyst for more research in this field and to assist stakeholders in recognising the
benefit of planning needs led and responsive services.
In the long term, the findings of this study are likely to contribute to an increase in positive outcomes for and the empowerment of children and their parents/carers in relation to mental health and mental health services. They are also likely to assist in the reduction of the stigma that continues to surround them.

3.4 Methodological framework

The methodological basis for this study is from a qualitative stance. Qualitative research can be defined as “multi-method in focus, involving an interpretive, naturalist approach to its subject matter” (Denzin and Lincoln, 1994: 2). It is a method of naturalistic inquiry that enables the study of people within their social settings (Hockley, 2000). The focus of the qualitative approach is on the meanings that participants attach to their own world and is concerned with the in-depth study of phenomena or individual situations, therefore of particular relevance to the focus of this study. The following section will discuss the context of qualitative research and the rationale for its use in this study. Phenomenology and the Hermeneutic tradition of inquiry, which form the philosophical and theoretical underpinnings of this study will then be presented, followed by a description of Interpretative Phenomenological Analysis (IPA) (Smith and Osborn, 2003), which offers a context and framework within which this research was undertaken. This section will explore the approaches chosen, and the rationale for the framework used to explore of children’s and parents'/carers’ views.

3.4.1 Qualitative versus quantitative approaches

Qualitative inquiry can be less obtrusive than quantitative investigation, as it aims to make use of naturalistic settings and to collect data occurring in conversations (Bowling, 2002). Although qualitative inquiry does not always rely on theory or seek to involve statistics, it is often compared to quantitative research using this dichotomy
Qualitative research encompasses many distinct approaches, methodologies and philosophies, therefore, based on this premise it is difficult to make such generalisations. In addition, qualitative research presents a different approach to the way participants see the world. Also, it is difficult to differentiate the point at which research becomes scientific or objective, and this is a strongly debated issue (Potter, 1998). Where quantitative research has been reported to fail to elicit the contradictions and misconceptions in its analysis, qualitative research can allow the researcher to explore these areas in-depth, thus enabling more complete understanding and representation of the participants' world (Ritchie, 2003).

A benefit of utilising qualitative over quantitative methods is that they can capture new viewpoints, particularly in areas with little pre-existing research. They are also beneficial in the exploration of sensitive or complex issues, allowing opportunity for detailed exploration and the generation of hypotheses (Bowling, 2002). Qualitative design can be particularly effective in eliciting views from vulnerable groups or children, especially where issues require more probing and greater interpretation. All of these issues are particularly pertinent in relation to this study, due to the sensitive nature of the subject area, the young age of the children, and the potential of eliciting emotive information from parents and children alike (Eiser and Twamley, 1999). The approach enables the researcher to be 'reflexive', i.e. to consciously consider their own assumptions, beliefs, judgements and interpretations, in relation to those of the participants and to reflect those in the discussion (King, 1996). Using a qualitative approach within which reflexivity is integral enables the researcher to make sense of the participants' responses, in tandem with the dialogue of the researcher, and for the researcher to explore their own beliefs and the impact they may have on the study.

The ability to be reflexive in this study allows the researcher to respond to and to
interpret the participants responses, therefore enabling a more detailed and crucial representation of the participants' world in relation to mental health. Reflexivity and its implications within this study will be discussed in more detail in Chapter Seven.

Abramson and Abramson (1999) suggest that qualitative inquiry allows the researcher to develop culture specific maps about beliefs and behaviours; this in turn allows development and improvement of programmes that are suited to the individuals that use them. However, they go on to comment that such an approach allows a goodness of fit to specific needs, although the nature of the inquiry does not enable the research to account for the prevalence in the population. This allows strategic planners to understand the best way of meeting people's needs, but not to identify the quantity of resources required to achieve this efficiently. Within this study, the former assertion is more relevant rather than the latter. The focus of the study is not to establish the quantity of perceptions related to mental health and stigma, as such work has already been undertaken (presented Chapter Two, Sections 2.2.2 through to 2.2.6), but rather to understand the experiences, perceptions and processes that occur for the individuals. The importance of both approaches enables the development of services and programmes to tackle stigma. This study therefore aims to contribute to knowledge of the extent of the issues, through the development of an understanding that is based on the real experiences of those who could be subjected to stigma, or those who have suffered the consequences.

3.4.2 Qualitative research

Historically research, particularly within health and social care, has tended to be based on the tradition of experimental design and statistical analysis; however, the interest in exploration from a qualitative perspective has emerged over the last three decades (Murphy and Dingwall, 1998). This move to qualitative inquiry has been
driven by the wish to elicit views from the perspective of the service user and to plan care that is responsive to their needs. Jupp (1989) proposes that qualitative methodologies have been associated with enabling professionals to gain a greater understanding of their patients' mental health needs, in order to meet them effectively. Under this edict, qualitative research will seek to understand actions of children and their parents/carers, and to develop an explanation of their meaning, thus influencing the way provision is conceptualised.

The remit of qualitative methodology in research is diverse; therefore conceding a precise definition can be difficult. The terms tend to be used as an overarching category, which includes a wide range of methods and approaches (Snape and Spencer, 2003). Denzin and Lincoln (2000) suggest that qualitative research consists of interpretative practices that make the world visible. The observer or researcher is located in that world. The researcher is able to gain understanding about the world of the individuals in it, by using qualitative practices to make sense of it. Qualitative research seeks to answer questions about social reality from the perspective of the individuals being studied. It, therefore, seeks to describe events, experiences and meanings that phenomena have for the individuals concerned. Qualitative assumptions are based on many views of the 'world' and are generated from humanistic inquiry (Hunt, 1994). This opposes the quantitative approach, commonly described as a method of investigation based on measurable data.

The qualitative approach has been developed as a response to the assumption that human beings not only react, but also act upon and create meanings from experiences. Based on such an assumption, the external and internal realities of experiences cannot be separated. It, therefore, seeks to provide us with an accurate description of an experience, a situation, or a social world and the contextual
meanings and perspectives of those that inhabit it. The process employed relates to the description and interpretation of what is actually happening for the participant, with the aim of gaining a holistic view of the nature of reality and what is happening within it (Duffy, 1987). Key aspects of qualitative research include those which enable the flexibility of research design; ability to represent the richness of the data; and approaches to analysis and interpretation which facilitate the unique representation of the perspective of those being studied (Snape and Spencer, 2003). Such an approach would embrace the principles underpinning this study, in that it will enable the researcher to produce an in-depth understanding of the participating children's and parents'/carers' world. It will also enable a flexible and reciprocal framework that assists the researcher in making sense of the participants' experiences and perspectives, in relation to mental health and stigma.

The strength of qualitative research is the ability to study people and their experiences, within their field. The approach allows for a range of methodologies, which can be selected to be responsive to the particular angle and subject of inquiry. Within qualitative methodology, the researcher is concerned with establishing the complexity, context and authenticity of the field being researched (Buston et al., 1998). The researcher, therefore, seeks to clarify the phenomena and the subjectivity of the participants, by getting as close to their life-world as possible with the minimum of illusion (Fryer, 1991). The choice of the method in qualitative inquiry can be inextricably linked to a combination of the philosophical viewpoint, the questions to be considered and the characteristics of the participants.

As the main methodology used by anthropologists, psychologists and social scientists, qualitative methodology is deeply rooted in both ethnography, i.e. studying participants within their cultural perspective, and in the phenomenological perspective. When considering the influence of these paradigms within this study, the
nature of methodologies based on structured measurement, are not suitable to elicit
the perspectives of the participants. Such restrictive approaches would not allow the
researcher to capture the breadth of domains represented within the participant's
world (Bowling, 2002). Therefore, they would also not allow for the capture of the
subjectivity of human beings. In contrast, qualitative methodology includes data
collection methods that range from observation, to in-depth interviewing, group
discussions, narratives and documentary analysis. Utilising such approaches enable
the researcher to become immersed in data that is closer to those being studied, and
to explore the nuances of the material. Such ability within qualitative methodology is
likely to precipitate the exploration of mental health and stigma with children and their
parents/carers. Eiser and Twamley (1996) emphasise this point in relation to
research with children who are suffering ill health, suggesting that children who are ill
or in sensitive situations, merit the demand for more insightful approaches to
understanding their experiences. Therefore, it is vital to ensure that the approach
selected can be mindful of the nature of difficult areas that may be discussed, and
that it can enable participants to talk about issues that they may find hard to
elucidate.

Qualitative methodology allows the development of a process of investigation that
enables the participants to engage in interaction, which is based on their own terms
and in language that they use to describe their perceptions. The social world is
considered to be dynamic, enabling interpretation in a number of ways. Enabling
people to use their own language to describe their views facilitates the
communication of perceptions, which can only be understood from the context in
which they are experienced (Silverman, 2001). The research process is thus
conceptualised as a social process, enabling the researcher to use skill and
judgement to enable people to express their views (Cassell and Symon, 1994). The
researcher is required to approach the research from a position of empathic neutrality
(Snape and Spencer, 2003), ensuring the use of personal insight from a non-judgemental position. Using this approach is particularly valid in this study, as it is important to engage with both children and parents/carers, so that they can consider subject areas they had possibly not articulated before. The partnership with the researcher enables a responsiveness and interplay that may not have been as accessible through quantitative approaches.

Guba and Lincoln (1985), in their work *Naturalistic Inquiry*, were a major influence in the recognition of qualitative research methodology as a legitimate approach. They presented a 'new' paradigm within the world of qualitative inquiry, which proposes a set of approaches based on the postulate of how the world works. They suggested that there are multiple realities and socio-psychological constructions, which form an interrelated whole. These are subjective rather than potentially objective. Based on these assumptions, the method of inquiry must embrace these posits. This paradigm is seen to influence the approach used in this study, showing a perspective that seeks to understand and determine children's and parents'/carers' experiences. Using such an approach should allow the participants to explore their life-world in relation to the meanings and their understanding of social reality, thus enabling demonstration of the views that shape their beliefs and actions (Guba, 1990). This should enable the researcher to make sense of their world, provide clarifications and demystification of the 'whole' picture. The paradigm is particularly relevant to the exploration of mental health and stigma in children and parents, as it remains an area which has not been investigated in-depth from a qualitative position. Therefore employing a method of inquiry, which enables the participant to present the nuances of their views, should elicit greater detail than previously available.
3.4.3 Qualitative research with children

Early research in the 1970s, on the emergent sociological perspectives of childhood (James and Prout, 1977), outlined that children are active social agents who can shape the structures and processes that happen around them, and whose interactions with society are worthy of study in their own right. Further work looking at the child's function within health and welfare research suggests that, in order to produce a clearer picture around the influences of theories and models that professionals impose on children, there is a need to move to participatory research, i.e. research where the child takes part, rather than being the object of study (Williams et al, 1999).

Taking a qualitative approach with children should increase the awareness of the gaps between theories and models and their experiences of them in practice, and will create understanding of the influence of cultural and social factors on outcomes. Shifting the emphasis from the perspective of the researcher, to include the perspective of the researched, will enable knowledge of children's lives to influence the development of responsive policy and provision. Morrow (2001), in her qualitative study on young people's perspectives of their environment, advocated that the employment of qualitative methodology with children enables the explanation of processes and experiences, which cannot be elicited through empirical research. Whilst quantitative methods have been historically undertaken with children, and are beneficial in the identification of trends, they do not appear to have the capacity to draw out meaning, perspective and contexts. It is on such a premise that recent research with children suggests that it should include an appreciation of the world and context in which the child sees it (Backett-Milburn and McKie, 1999).
Kellett and Ding (2004) suggest that children and young people are the best source of information around issues that concern them. In their work on researching middle childhood, they address some of the methodological issues, pointing out that collecting data directly from children is preferable. Although such information can be collected through both qualitative and quantitative methods, using qualitative methods enables a direct exploration with children. Developing a rapport with children through qualitative methods can encourage more detailed responses and aid in the understanding of meanings. In comparison, using quantitative or closed methods will possibly elicit misunderstanding or even reduce confidence in the answers given by children.

Undertaking qualitative research with children, therefore, produces a framework that enables subjectivity. This notion evokes the view that children’s subjective perceptions, emerge through interaction with others. This is particularly pertinent within this study, as the field being researched is principally enigmatic, therefore the ability to explore perspectives with children is likely to produce a rich picture of their perspectives. The ability to make sense of how children understand their experiences and how this affects the way they feel, should enable researchers to understand their social world.

When choosing the most appropriate methodological approach, the same rules should apply to research with children as they do with adults. Methodology, data collection and analysis should reflect the principle assumptions of the study (Grieg and Taylor, 1999). Such rationales are outlined throughout this chapter and in Sections 3.4.1 and 3.4.2. A qualitative approach in this study is implicated with children, as it enables children to be active participants, so that they can provide a view of their own world as they construct it. The researcher, therefore, becomes a partner who can guide the child, seeking and clarifying their perspectives.
However, research with children and the utilisation of any methodology, is not without its complications. Particular consideration needs to be applied to ethics, consent and competence, confidentiality, validity and reliability, and the practicalities of undertaking the research. All of these issues will be discussed later in Chapter Four. Consideration should also be made when selecting the method of data collection (Dockrell et al, 2000). Instruments may require adaptation for particular age-groups, paying attention to engagement of the child, use of age-appropriate language, making allowances for shorter concentration spans, the sensitive nature of the research, and the vulnerability of the group.

3.5 The epistemological groundings of qualitative research

The epistemological groundings of qualitative research have been an area of great debate. This debate has centred on the intricacies of the origin of qualitative research and its place within social research (Becker, 1996). Most of the rhetoric has surrounded the epistemological questions in social science, related to the employment and comparison of qualitative and quantitative methods. Becker (1996) argues that the two approaches, based on different epistemological foundations, can lead to the exploration of the same questions, as such similar arguments from each epistemological view point can provide a warrant for both approaches. He suggests that epistemology, methodology and the emergent theories are intrinsically linked. Therefore, the fundamental necessity for understanding the epistemological premise for qualitative research, is to steer the researcher to make decisions about the philosophical framework from which they will execute the study, and in turn, to assist in the pragmatic selection of a method of data collection. Oka and Shaw (2000) argue that, without an understanding of the influence of philosophy on research strategies, researchers can be confused about the analysis and understanding of data. The sections (3.4.1 and 3.4.2) above outline the rationale for undertaking a qualitative
approach in this study. This section will explore the decisions made around the epistemological and philosophical basis for the methods chosen.

Epistemology is a branch of philosophy that is concerned with the nature of knowledge, its presuppositions and foundations and its extent and validity. Within qualitative research, the epistemological basis enables the answering of questions by reasoning of first principles, rather than by empirical investigation. The nature of knowledge is usually approached from four main paradigms: Positivism, Post-positivism, Critical Theory and Constructivism (sometimes referred to as ‘Constructionism’). The definitions of each paradigm are presented in Table 3.0.

Within contemporary social research, Positivism is rarely evident as a fully developed philosophical basis; it is most commonly associated with quantitative studies. Polit and Hungler (1991) comment that the orientation of positivism is rooted in empiricism and in a process whereby evidence located in objective reality gathered indirectly or directly, is used as a basis as generating knowledge. The activity of investigating is to ensure that there is no influence on what is being investigated (Shepard et al, 1993). It would prove impossible and unrealistic to develop a study aiming to gain a real understanding of the participants' life-world, on the basis of this paradigm. A study based on the positivistic paradigm would merely set out to test pre-conceived notions or hypotheses. Although many of the studies discussed in Chapter Two used quantitative methodology, they were limited by not being able to formulate a holistic picture of the participants' beliefs and perceptions of mental health and stigma. Therefore, they are not able explore the entirety of the meanings individuals hold around stigma, within the situational context.
| **Positivism** | The system of philosophy based on experience and empirical knowledge of phenomena. The objective world exists independently of the perspective of the researcher. The central tenet is that only events within the real world, which can be observed, and propositions which are testable, have a claim to truth.  
(Ashworth, 2003) |
| **Post-positivism** | A modified form of positivism, which admits that human beings cannot have a finite understanding of reality, however, with rigorous data collection and analysis, the researcher can approach the truth. Post-positivists concur that although there is an interaction between the researcher and the researched, objectivity must remain the regulatory ideal.  
(Guba, 1990) |
| **Critical Theory** | The broad definition of Critical Theory is to include the basic paradigms of research that generate emancipation or empower social change, through research. Through rejection of realism, critical theorists argue that values mediate inquiry. The object of inquiry is to raise people to 'true consciousness', wherein they can act to transform the world.  
(Guba, 1990) |
| **Constructivism** | Constructivism advocates multiple socially constructed realities, which when known more widely will produce more diverging inquiry. The reality of a study cannot be achieved in segments, i.e. through variables, and must be understood holistically. The person is thought of as a conceiver, and their perception always has meaning within their life-world and how they make sense of it or construct it.  
(Guba, 1990; Ashworth, 2003) |
The nature of what becomes known through the positivistic process is not from the point of reality, but of what has created the result. As the principle concern of this research study is to facilitate the participants to explore the meanings phenomena have for them in relation to mental health, an integral relationship is formed between the researcher, the children and their parents/carers. The focus of this study is to understand, explore and develop the participants’ perceptions; therefore, such notions would be difficult to test through empirical data, indicating that the positivist paradigm would not be suited to this research.

A number of the studies discussed in Chapter Two would fall into the post-positivistic paradigm, because whilst they acknowledge that they are attempting to control variables across a range of issues, the interactions with the researcher and interpretation of the findings must have an influence. The post-positivistic paradigm, whilst starting to acknowledge the interaction between the researcher and the researched, continues to expend some regulatory governance on data collection. A key feature of post-positivistic research is the ability to generalise about the population and then to predict future behaviour (Guba, 1990). Based on this premise, this paradigm was also considered not to be fit for the purposes of this study, and was rejected for similar reasons to the positivist paradigm.

The most suited paradigms for this study are Critical Theory and Constructivism. An exploration of Critical Theory raises a number of considerations. Whilst the central tenets are more suited to the exploration of participants’ perceptions about stigma and mental health, the intended outcome of this study was not to produce social change within the group, at this point. The severe and enduring nature of stigma and its effects on the individuals and society as a whole, would suggest that a real understanding of stigma and mental health, especially in relation to children and their families, is yet unknown. Whilst critical theory enables a degree of person-centred
approach, the philosophy of this paradigm pays particular attention to the social values held by the participants (Harvey, 1990). In relation to this aspect, the role of the research in this study is not to explore social values and make transformations based on the interpretation of these, but rather to understand the realities existing for the participants in the form of multiple conceptions and constructions.

The constructivist paradigm allows the role of interpretation and interaction between the researcher and the researched. Both the inquirer and the participant become fused, and the findings are likely to be created by a process of interaction between the two (Guba, 1990). Papadopolus and Schraube (2004) interviewed Ian Parker, who argued that constructivism should not be adopted as an 'alternative' to other paradigms, because of its concern with sensitivity. He described it as radical stance that enables deconstruction and representation of the lived experience, and based on this premise it, therefore, offers a way of challenging the axiomatic truths of the individual. It also enables the exploration of perceptions or conceptions and how these are developed or constructed. The constructivists argue that knowledge can only be gained through the media of human minds and bodies, therefore, the knowledge of self and the world is mediated and constructed through thoughts and activities (Yardley and Marks, 2004). Taking a subjectivist view, the paradigm enables the unleashing of constructions held by individuals. Within this construct it should be recognised that the researcher is also involved in the process, and would consider that research itself is a social construction (Bines, 1995). This would require the researcher acknowledging and being subject to their own beliefs and demands, as a participant within it. Such an interaction seemed most suited to this study as it would enable the participants to identify the way they perceive, understand and experience stigma and mental health, through an interactive relationship with the researcher. In relation to these philosophies, the constructivist paradigm will form the philosophical basis for this research study.
The constructivist paradigm defined the methodology chosen for this study. This is driven from the principles of ensuring subjectivity, which should facilitate an open dialogue between researcher and researched, and enable the exploration of the sophistication of constructions and communication. The methodology chosen within this paradigm is Phenomenology, i.e. an individualistic approach focusing of the person's unique experience of phenomena. In addition, Interpretive Phenomenological Analysis (IPA) (Smith and Osborn, 2003) was chosen as a framework within which to conduct the study. IPA is a research method and analytic tool which combines phenomenology and hermeneutics, thus allowing interpretation within the method chosen. Phenomenology and Interpretive Phenomenological Analysis are discussed in Sections 3.6 and 3.7 of this chapter, in relation to this study.

3.6 Phenomenology and the Hermeneutic tradition

The philosophical basis for this study stems from the phenomenological perspective. Phenomenology is described as the study of human experience (Field and Morse, 1996), and is concerned with interpreting the meanings that phenomena have for the individual, within their world. It is based on the premise that there is no single reality, and that each individual has their own reality (Mills, 1994). The philosophy of phenomenology, and the associated methodology used within this study is based largely on the Hermeneutic tradition. The tradition of Hermeneutics relates to the branch of phenomenology which focuses on the interpretive approach to understanding the individuals' life world (Heidegger, 1962; Diekelmann, 1992).

This section will present and explore the phenomenological approach and the hermeneutic tradition, in relation to this study.
3.6.1 Phenomenology: a philosophy and research methodology

Phenomenology concentrates on the study of phenomena and the essence of ‘things’. It is concerned with the understanding of life from the perspective of the participant. It, therefore, studies human consciousness by focusing on the world that the participants subjectively experience. In undertaking investigation from this angle, it is suggested that deeper insights into human nature and beliefs can be achieved (Maggs-Rapport, 2000).

Phenomenology was introduced in the 1900s by Husserl, a European philosopher (Husserl, 1913: 2002). One of the key aims of the introduction of phenomenology was to ground knowledge. Husserl commenced with examining the structures of experiences and events as they present themselves in the consciousness, without recourse to the theory and assumptions located in positivistic inquiry. Husserl initially claimed that the task of phenomenology was to study the ‘essence’, for example the essence of emotion. However, as he developed his thinking further, he went on to advocate that it is the essences of particularly conscious structures that form the basis of phenomenology. He, therefore, postulated that phenomenology is the study of the structures of consciousness, which enable the consciousness to refer to objects outside of itself. This form of reflection was termed ‘phenomenological reduction’. Husserl noted that the mind can be directed toward non-existent, as well as real objects. Reflection does not presuppose that anything exists, but sets aside the question of the real existence of the contemplated object. What emerged from such thinking was that the mind considered such acts through a process of remembering, desiring and perceiving, and to such acts the individual assigned ‘meaning’. ‘Meaning’ enables directed intentionality towards acts or objects, and can be constructed or evolve through the course of the experience. The question that relates to the philosophical basis of this study is the need to consider whether stigma
exists before meaning is applied to mental health, therefore using such an approach enables the exploration and interplay of the fundamentals for the participants.

It is on such a philosophical basis that phenomenology has been adopted for frequent use in health and social care research. The primary position of this approach is that human truths can only be accessed through the exploration of inner subjectivity (Burch, 1989). Phenomenology has been used to explore many realms of the human experience of health and illness, looking at quality of life, health perspectives (Anderson, 1985), the experiences of those suffering from AIDS (MacLachlan, 1992), post-natal depression (Beck, 1992), mental health and stigma (Mullen et al, 1996), and in children within the education system (Jenks, 2000). It is with this regard that phenomenology formed the philosophical basis for this study. In order to provide a comprehensive understanding of mental health and stigma for children and their parents/carers, it is necessary to investigate the totality of experience for them through the approach that phenomenology facilitates. This can be achieved through a process which assists the participants to not only consider what they experience on the surface, but to think about what meanings their experience may have, and how these are constructed.

The predominant features of phenomenological methodology are identified as focusing on the clarification of nature of lived experience; holding in abeyance one's scientific predisposition about a phenomenon, and reflecting deeply on the meaning of the experience (Ray, 1987). Phenomenology does not attempt to analyse the compartments of human experience, but rather it attempts to investigate the extent of human experience, within a given cultural and contextual situation. Therefore remaining faithful to the phenomena under study and the context within which they arise. The aim of adopting phenomenology in this research is to seek participants who have immediate experiences of phenomena, so that they can describe the
events and meanings attached to them. When approaching the experience from this perspective, it is envisaged that the essence of the phenomena can be discovered.

Giorgi and Giorgi (2003) point out, that whilst awareness is parallel to the lived experience, participants are rarely totally synchronized with the event and respond in different ways, with different levels of perception. As a result of employing a phenomenological approach to the study of a lived experience, perspectives elicited can be extremely enlightening. Based on the possibility of such outcomes, the phenomenological approach should enable the researcher to portray an in-depth picture of perception from the findings of this study.

3.6.2 The Hermeneutic tradition

A tradition to emerge within phenomenology is that of ‘Hermeneutics’. Hermeneutics is an interpretative human science approach, which enables the investigator to draw on how the participants become conversant with their lived experience. Originally introduced by Heidegger (1962), hermeneutics gives the ability to describe how the individual interprets the ‘script’ of life (Walters, 1995). More specifically it asks what experiences are like, enabling interpretation and understanding of the meaning of everyday occurrences. The hermeneutic approach allows the examination of the human-world interrelationship, creating a unified phenomenon. Such an approach enables the participant to convey their own experiences within their life context; two phenomena that are difficult to separate. Heidegger explained these integrated phenomena as ‘being-in-the-world’. He used the hyphens within this phrase to denote the meanings of the inseparable relationship and interplay between the words, for the individual. The relationship between the words presents a symbolism which means ‘care’ or ‘caring’, i.e. the individual cannot exist in the world without determining that some things matter, and some are not quite so significant (Benner and Wrubel,
1989). This approach is particularly relevant to this study, as it enables the exploration of the meanings mental health and stigma have for participants, and enables the researcher to determine if these participants are assigning such importance to the phenomena they are experiencing.

Interpretation of meaning for the participants, using the hermeneutic approach, involves an in-depth consideration of all three aspects of 'being-in-the-world', and entails the utilisation and interpretation of the phrase “What does it mean to be a person in the world?”. The researcher should ensure that such a premise is integral to the whole study; including data collection and analysis. In focusing both on the individual and their 'world', the researcher can develop an understanding of a meaningful set of relationships and practices, and can embed this context throughout the conversation and interaction with the participant. Consideration of the participant and the data evoked using this approach can further enable reflection on the emphasis that any one of the three concepts can have on the others (Walters, 1995). Thus, utilising this approach in this study should enable the findings to demonstrate a view derived from the participants, and based on the fundamental concern of what it means to them to exist within the world they inhabit. The process can enable the individual to undertake a self-exploration of the meanings an event or issue has for them, where ordinarily they may not have reflected on such matters.

Reed (1994), who studied the use of phenomenology and hermeneutics when examining expertise required by staff working in long-term care, commented that people tend to engage with their worlds in an unconscious way, without paying much attention to the subject-object relationship. In relation to this, it seems that much of human context is unconscious. The individual can be so immersed in their world that they often do not consider an issue to require further exploration. In relation to such
an assertion, the benefit of using hermeneutics is that it allows further revelation of
significance in the nature of the world.

As the self is not a radically free arbitrator of meaning, utilising a hermeneutic
approach in research enables a deep understanding of events and the significance
accredited as taking place within them (Hamill, 1994). Any interpretation in this
manner must involve the researcher's consideration of their own value base, if they
are to understand the dialogue, culture and history that the experience holds for the
participants. When considering the hermeneutic approach in relation to this study, it
seems that the combination of enabling the participant to get in touch with the
meaning experience holds for them, and the interpretation that is free of judgements
and values held by the researcher, can facilitate the discovery of original meaning.
The employment of the hermeneutic approach in this way, allows the researcher to
grasp the inner meanings of the participants (Hughes, 1990), thus leading to the
understanding of the processes and beliefs that lead to the production of the
meaning, and the resultant actions and perceptions.

As discussed in Chapter Two, little is known about the meanings that mental health
and stigma have for parents/carers and children. The purpose of employing such a
methodology is to permit them to explore a possibly concealed area of their life
experience, therefore adding to the body of knowledge that informs providers and
strategists when developing a valid response to meeting the mental health needs of
children. Bowling (2002) acknowledges that 'health-related quality of life is dependant
on the interpretation of and the perceptions of the individual' (Bowling, 2002: 40).
Using a hermeneutic approach enables the capturing of the subjectivity of the
participants and allows the process of interpretation. Embedding such principles
within this research study should facilitate interplay between the researcher and the
researched, developing an accurate picture of the perceptions of mental health and stigma for both parents/carers and children.

Bjerrum Nielsen and Rudberg (1996) sum up the interaction between the researcher and participant, suggesting that using interpretative methods is like a dance, with both being actively involved and responding to each other's movements. Such a reciprocal interchange enables the story of the participant to be developed. The task of the researcher is to challenge both themselves and the participant in order to develop a rich interpretation outlining the entirety of the experience.

Following consideration of the philosophy underpinning the research, and the requirement to evoke and construct the meanings of mental health and stigma for the participants in this study, a particular method was chosen, for the collection and interpretation of such data. Interpretative Phenomenological Analysis (IPA) (Smith, and Osborn, 2003) is both an interpretative method, seated in phenomenology, and an analysis tool. The next section will outline the fundamentals of IPA, its application and relevance to this study.

3.7 Interpretative Phenomenological Analysis (IPA)

Interpretative Phenomenological Analysis (IPA) was developed in the 1990s by Jonathon Smith (1996). IPA was introduced as a response to an increased move towards the use of qualitative methodologies in health psychology and social care research. Due to a number of relevant epistemological, methodological and theoretical frameworks with overlapping approaches being available, the need for an approach to integrate some of them was prompted.
IPA has three main elements; it represents a constructivist epistemological position, a framework for conducting research and a data analysis protocol. This section will consider the epistemological and methodological elements of the approach, in relation to this study. The framework for conducting the research and analysis will be discussed later in Chapter Four.

Smith and Osborn (2003) suggest that IPA is particularly suitable when trying to explore how individuals are perceiving situations they are faced with. It aims to explore in detail participants’ perspective of their lived experience and how they make sense of that experience. It is phenomenological in origin and incorporates the hermeneutic tradition of interpretation. The approach is a dynamic process, with its main concerns being not only to understand individuals' perceptions of events or objects, but to also place the researcher in a central role of making sense of the participant's personal experience. This enables the researcher to get close to the participant’s world and to gain an inside perspective (Conrad, 1987). Smith and Osborn (2003) suggest that, whilst most phenomenological methodologies enable this process to happen, it can never be achieved entirely. Accessing participants’ perspectives can often be complicated by the researcher’s views and conceptions. IPA acknowledges that such conceptions are a necessary part of the process and can facilitate the understanding of the participant’s world, through the practice of interpretation. Within the methodology, IPA contains what is termed a ‘double hermeneutic’ process. Smith (2004) describes this process as the participant trying to make sense of their world and the researcher trying to make sense of the participant trying to make sense of their world.

In order to gain a greater depth of understanding, this methodology also allows the researcher to challenge and ask critical questions of both the participant and the data that emerges. Different interpretative stances are possible and combine empathic
hermeneutics with questioning hermeneutics, i.e. understanding the life-world of the participant and then considering their responses to a more advanced level. This would involve trying to make connections, and to gain a sense of what the experience is like from the point of view of the participant. Within this process of understanding, IPA also recognises the premises of Symbolic Interactionism. Symbolic Interactionism is a major theoretical perspective in Sociology, which emphasises the subjective meaning of human behaviour, social process, and pragmatism, and is concerned with how meanings are constructed by individuals within their world, on both a social and personal basis (Blumer, 1969; Denzin, 1995). IPA is also influenced by social and cognitive paradigms, therefore creating the possibility of mapping the underlying thoughts and processes taking place within participants’ identified conceptions about an experience.

Consequently, it seems that IPA has a theoretical commitment to the person across several dimensions. It enables the establishment of the chain of connections between their talk, thoughts and emotional state. When considering the employment of IPA, it seems reasonable to acknowledge that such a chain of connections is complex. Utilising the approach within this study should enable the researcher to gain insight into the mental processes, as well as the constructs surrounding perceptions of mental health and stigma.

IPA can be particularly relevant in the exploration of health and illness, as it is concerned with the notion that participants have many thoughts and perceptions about real personal entities, such as illness or problems. It, therefore, enables the uncovering of the chain of perceptions connected with personal conditions. IPA has been used within many fields of health research within the mental health field. It has focused on topics such as psychological distress and self-harm (Alexander and Clare, 2004), the experience of delusions and hallucinations (Rhodes and Jakes,
2000; Knudson and Coyle, 2002), and more recently in the exploration of stigma with people diagnosed with schizophrenia (Knight et al, 2003). Knight et al (2003) point out that research using IPA within the mental health field has enabled the development of insight into the experience of the participants, has informed the improvement of clinical interventions and service provision, and has highlighted the benefit of using IPA in exploring life experiences related to social exclusion.

There are limited examples of the use of IPA with children. One study examined the development of children with Attention Deficit-Hyperactivity Disorder (ADHD) (Smith and Dunworth, 2003). Smith and Dunworth (2003) suggest that certain consideration has to be made when using IPA with children, in relation to the engagement of the child in the process, and the use of gentle probing questions in interviews. Smith (2004) suggests that the researcher may benefit from the use of professional experience and expertise when modifying existing IPA research protocols that have been used with the adult population. Such considerations formed the basis for the design in this study. This design and related research methods, tools and research procedures will be discussed in Chapter Four.

The rationale for using IPA in this study is to provide a comprehensive perspective of children and their parents/carers related to their experience of mental health, accessing mental health services and the associated stigma on the child and family’s life.

This chapter has presented the epistemological and methodological frameworks which underpin this qualitative research study. The following chapter will set out the methods and procedure for conducting the research and the process for data analysis.
Chapter Four

Research Methods and Procedures

4.0 Introduction: Research design

This chapter will present the research design employed within this study. It will outline the data collection framework developed through the Interpretative Phenomenological Analysis (IPA) method, and the rationale for the use of semi-structured interviews, as a data collection method with parents/carers and children. The procedures for conducting the study will be described, including the justification and development of data collection tools. It will describe the sample population and setting of the study. It will also illustrate the characteristics of the participants, and the procedure for the research. A discussion of ethical issues will follow, and the chapter will conclude with a presentation of the data analysis framework utilised in this study.

4.1 Data collection methods and research instruments

The following sections will outline the use of Interpretative Phenomenological Analysis as a data collection method, and will discuss the employment of semi-structured interviews with parents/carers and children, and their use within this study. They will also present the process of developing a semi-structured interview tool for use with the five to eleven year olds taking part in the study, and the involvement of early years child care professionals in the design and development of this instrument.
4.1.1 Interpretative Phenomenological Analysis as a methodological framework

As discussed in Section 3.7 of Chapter Three, Interpretative Phenomenological Analysis (IPA) has a philosophical basis, but also presents a methodological framework within which to conduct research, and is a template for data analysis. This section will discuss the characteristics and process of implementing IPA as the methodological framework for this study.

4.1.2 The characteristics of Interpretative Phenomenological Analysis as a data collection method

Within IPA, the quality of the outcome is reliant on the personal analytic work undertaken at each stage of the procedure. IPA contains three characteristic features, which relate to the acquisition, presentation, analysis and quality of outcomes. These features include the consideration of the study from an idiographic, inductive and interrogative stance. Consideration of the study on this basis means that analysis and interpretation occur at three levels within the framework. Firstly, on an individual case basis during data collection, and during the case by case analysis that follows. Secondly, across the emerging themes for the whole data set, and thirdly, during interpretation and integration of the data alongside what is already known in the field. The roles of the key characteristics of IPA in this process are outlined below.

Within the IPA framework, the 'idiographic' stance involves the examination of one case through detailed analysis until closure or 'gestalt' is achieved. 'Closure' in this case refers to the achievement of unity, wherein the 'whole' cannot be separated from or described through the summation of its parts (Smith, 2004). Once this has been achieved, the researcher moves on to the next case and continues in this vein
through the corpus of cases. Taking such a stance can enable further probing and exploration of emerging issues during the data collection phase. To enable this process, the researcher needs to be skilled in enabling the participants to explore issues in more depth, and be conversant with their own beliefs to ensure that the approach remains subjective. Following this, a process of detailed analysis should take place, which will be discussed later in this chapter (Section 4.16). During the analysis there can then be an interrogation of themes on an individual and cross-case basis, which allows for comprehensive consideration of convergence and divergence between the cases and themes (Smith, 2004).

The term 'idiographic' refers to a reflection on the concerns and issues emerging for the individual. The process used in IPA allows for representation on both an idiographic and nomothetic (across groups) basis, allowing the researcher to speak about the groups under investigation, as well as the individuals within them. Smith and Osborn (2003) suggest that IPA is especially appropriate for use with small sample sizes. This allows the researcher to 'parse', or breakdown, narrative in two ways: firstly, to identify shared themes across participants and secondly, to represent the individual's own accounts.

Using such an approach could facilitate learning derived from emerging generic themes, but also from the position of the individual's life-world and stories related to it. This approach is particularly pertinent in this study, as it allows in-depth explanation of the children's and parents'/carers' experiences. Accessing such detail should move the researcher closer to the significant aspects of a shared humanity and to bring forth the 'essence' of meanings, linking back to the philosophical underpinnings advocated in Husserl's view of phenomenology (Smith, 2004). This should enable an establishment of the intricacies of the participants' stories about their 'life-world' within the context of the study.
The 'inductive' stance in IPA suggests that research techniques should be flexible and allow for the emergence of unanticipated topics or themes, both during the data collection phase and during analysis. As IPA does not attempt to corroborate or negate hypotheses, the process should prompt the emergence of broader research questions, which in turn can lead to the collection of more expansive data. Many qualitative methodologies contain interplay between inductive and deductive approaches, but within IPA induction is in the foreground (Smith and Osborn, 2003). This should allow for a more responsive interaction with the participants during the data collection phase. The relevance of using this approach in this study is that it will enable exploration of views to a greater extent, especially where the participating children may have some difficulties describing their views without intervention from the researcher.

The third feature relates to 'interrogation'. The interrogative aspect enables the outcomes of the research to not only stand alone, but also to open up the interrogation against existing research, therefore aiming to illuminate contemporary theories (Grigoriou, 2004). This phase should occur during the analysis and the discussion stage, and will be presented in Section 4.16 and in Chapter 7.

4.1.3 The process of data collection within Interpretative Phenomenological Analysis

The gathering of data within IPA requires the employment of a flexible data collection method and instrument (Willig, 2001). Smith (2003) suggests that the most responsive way of collecting data is through a semi-structured interview. Utilising semi-structured interview methods should enable the researcher and the participants to engage in talk, whereby questions can be modified in response to participants, and where ideas and concepts can be probed and prompted as they arise (Smith, 1995).
However, it is suggested that it could be possible to use other data collection methods within IPA (Smith, 2003), such as structured interviewing, where there are a set of defined questions and the interviewer has control over the way in which they are delivered and structured (Robson, 1993). Such a rigid approach would not be appropriate to this research, especially given the age of the children and the sensitivity required when talking about mental health and stigma. When exploring sensitive subject areas and working with vulnerable participants, a gentler, more empathetic and shared approach is required, to enable exploration at a deeper level (Smith and Dunworth, 2003; Kellet and Ding, 2004).

Using the semi-structured approach should enable the interview to be guided by a schedule related to the research question, rather than it being dictated by pre-determined structure and questions. The aim would be to establish a rapport with the participants and to connect at a deeper level with their inner world. With this in mind, it seems that this approach would also enable flexibility during interviews and would develop the ability to produce richer data, thus embracing the doctrine of the phenomenological stance and objectives of interpretation (Smith, 1995 and 2004).

When considering the central tenets of IPA and the principal aims of this study, it would seem that the use of semi-structured interviews is most suited to elicit the participants’ perceptions of mental health and stigma. This approach will be discussed within the following two sections of this chapter (Sections 4.3 and 4.4)

### 4.3 Semi-structured interviews with adults

Literature outlines studies that have been undertaken within the field of qualitative research, on the use of semi-structured interviewing as medium for collecting data
(Smith, 1995; Mathieson, 1999; Grigoriou, 2004). Semi-structured interviews can be indicated when the focus of the study is to gain a detailed picture of the participants’ beliefs or perceptions about a particular topic. They should allow a greater amount of flexibility and reflexivity than other more structured approaches, and enable the researcher to follow up emerging areas of interest, in order to give a more complete picture. The semi-structured technique is a hybrid of structured and in-depth interviewing, allowing greater compromise and ensuring that participants are guided, while permitting the researcher to obtain depth of information (Polit and Hungler, 1984).

Smith (1995) suggests that semi-structured interviews can be beneficial in allowing the participants’ self-story to manifest, and in facilitating an explanation of their psychological world. As the focus of qualitative research can be complex, using the semi-structured interview technique would allow the exploration of the nuances of issues, which could be sensitive, controversial or personal. Thus, it seems that because of the interplay between the interviewer and the interviewee, there is an opportunity to maximise the story being told.

Mathieson (1999) focuses on the central role of story building, especially within the health psychology field. Approaching the task of the semi-structured interview in this way enables the interviewer to develop and incorporate events as described by the interviewee, and then to re-interpret them within the course of the conversation. This function enables the delineation of space for persons within the healthcare system to make sense of, describe and validate their experiences. Shotter (1993) describes the interaction that takes place during the semi-structured interview as a specialised, collaborative pattern of verbal interaction.
It seems that if there is to be a natural flow in conversation within the interview, then attention must be paid to locating the data collection method within a theoretical framework, therefore ensuring use of an inductive approach and calling attention to social context (Mathieson, 1999). Integral to the development of the semi-structured interview is the need to ensure that it is an organised social discourse, with an emphasis on the participants' viewpoint and their ability to describe the situation from their own perspective. Locating the method within the theoretical and methodological framework outlined for this research (Section 3.4), will enable the direction of the semi-structured interview schedule to be developed alongside the aims of the study (Section 3.2). As a result, parents/carers and children participating in the study will be empowered to share their experiences and perceptions, with a unique opportunity for the development of knowledge in the field of children's mental health and stigma.

The advantage of employing this approach is that it allows for clarification of ambiguities, establishes greater depth, creates rapport and a collaborative approach with the participants (Bowling, 2002). This could be of specific relevance to sensitive subject areas. Knight et al (2003) used IPA and semi-structured interviews in their study on stigma and schizophrenia. They advocated that using such an approach enabled the discussion of issues of prime concern, whilst being responsive to the needs of a vulnerable group. Duncan et al (2001) employed a similar approach in their study on screening for Chlamydia in a genito-urinary clinic, and suggested that the participants benefited from a non-directive approach which enabled them to develop and elaborate their own narratives. One of the key emerging themes was that participants were able to talk freely about the stigma they experienced during the screening process.

The use of the semi-structured interview approach has particularly been suggested to facilitate the process of accessing views and perceptions of sensitive subject areas in
relation to parents/carers and children. Two studies that tackled sensitive areas in relation to the parent-child relationship employed semi-structured interviews, as a way of accessing parents' views. These studies examined difficult issues related to perceptions of parenting (Sidebotham and ALSPAC, 2001; Edmunds, 2005). Both studies advocated the necessity to use such an approach because of the sensitive nature of the topics for the parents involved.

4.4 Interviewing children: developing and using semi-structured interviews

Many methods for accessing children's views have been employed across psychology, health and sociological research. They vary between direct and indirect measures, and as discussed in Chapter Three, span both quantitative and qualitative methodologies. Within the field of mental health and stigma, methods have tended to be quantitative in nature, and whilst employing direct approaches to data collection, have tended not to focus on gaining in-depth narratives from younger children. As outlined in Chapter Three, this study is qualitative in nature and aims to seek a rich description of children's perceptions of mental health and stigma, as well as enabling them to discuss them within the added dimension of their own mental health need.

When considering the research framework, it was necessary to select an approach that would facilitate children to portray their stories and perceptions, through a responsive and non-threatening medium. Many of the considerations discussed in the previous section on semi-structured interviews with adults, also apply to children. However, there are some specific aspects in relation to data collection that will be examined in this section.

When choosing a method for data collection with children, there are a number of complexities that need to be addressed. The methodological framework of IPA, which
steers this study, suggests that semi-structured interviewing is the most suitable approach for data collection. However, the studies that utilise IPA with children are few (Smith and Dunworth, 2003). It would be difficult to simply employ the principles of semi-structured interviewing which have been developed in relation to adults, without consideration of the nuances of how younger children interact and respond to adults (Dockrell et al, 2000).

Kortesluoma et al (2003) highlight the importance of investigating the child's world of experiences, and the need to consider theoretical and practical approaches to interviewing children before embarking on a programme of research. Grieg and Taylor (1999) add a second dimension to the scenario, outlining that children are special people, and that they are different from adults in the way that they describe the world, therefore contributing a unique insight to the representation of the world across the life-span. In light of such distinctions, it is necessary to appraise and adjust the approaches used to elicit their perceptions and constructions. Whilst the interview approach should be consistent with the research paradigm selected (Geanellos, 1999), the process of developing a responsive methodology for children requires exploration of common factors and assumptions about interviewing children and regarding childhood.

A number of core assumptions require consideration, in relation to the development and undertaking of semi-structured interviews with children. Such core assumptions (outlined in Box 4.0) are imperative to the successful adaptation of the semi-structured interview for children in this study.
Box 4.0: Core assumptions in the development and employment of semi-structured interviews with young children (adapted from Kortesluoma et al, 2003)

- **Consideration of level of competence**
  The competence and ability of the child to present their thoughts, views and feelings

- **Skills required in capturing children’s experiences**
  Consideration of the influences and skills required, when adults conduct research with children

- **Legal and ethical aspects**
  Ensuring appreciation of the legitimate role of children in research

- **Approaches to empowering and motivating children**
  Ensuring children are informed participants in the interview process

- **The interactive relationship in the interview**
  Employment of techniques that create a relaxed and comfortable approach during the interview process

- **Formulation of age-appropriate questions and responses**
  Modification of interview techniques and questions to complement the child’s linguistic and cognitive ability, thus ensuring reciprocity

Evans and Fuller (1996) highlight the importance of preparation when interviewing children, and draw attention to a number of problems that may emerge during this process. These areas of concern, which are similar to those suggested by Kortesluoma et al (2003), relate to informed consent, variability of communication skills, eradication of worries or anxiety in children, the balance of power between interviewer and child, and rules of engagement.
Mills (2001) adds further considerations which have been deemed imperative when employing and constructing semi-structured interviews for children. She suggests three domains that should be appraised, which she refers to as the 'soft' qualities of the interview. These qualities are flexibility, sensitivity and delicacy, and are of particular relevance in relation to this study. They enable the researcher to be responsive and to follow-up issues with the children; acknowledge feelings within the interpretation; and enable access to a delicate social world, with the aim of capturing the child's perspective.

One of the fundamental aspects of IPA is the need to ensure that the participant is a collaborative party within the semi-structured interview process. This can have certain challenges in the adult research field, but requires even more detailed attention with children. It is also vital to acknowledge the added sensitivity of the subject area for adults and children alike. It is the acknowledgement of such factors, combined with those highlighted in the following section, that have driven the development of a specific data collection tool for the children participating in this study. The development of the tool is discussed in Section 4.7.

4.4.1 Techniques of engaging the child within the semi-structured interview

Grieg and Taylor (1999) discuss the pragmatics of undertaking interviews with children, and suggest that outside of the function of the interview, which is to bring about discourse on a given topic, it is necessary to employ a sense of rapport and engagement. They advocate, as do a number of scholars in the field (Morison et al, 2000; Lewis, 2002), that as children can be considered to be 'special' participants then special techniques should be employed. In particular emphasis should be placed on the environment in which the interviews are undertaken, as well as on the
integration of techniques to engage and motivate children. A number of studies which examined the interview process in the five to eleven-age-group, suggest that verbal and visual prompts can be particularly valuable in enabling children to address their feelings, perceptions and needs (Morison et al, 2000; Lewis, 2002; Kellet and Ding, 2004). Such techniques were suggested as constructive in overcoming the possibility of linguistic or communication difficulties (Priestly and Pipe, 1997).

The defining factors, when considering the adaptation of the semi-structured interview for the age group in this study, were related to critical phases in the child's development and the way in which they learn and participate. In addition, it is important to highlight that children in the sample were identified as having mental health needs; therefore, they may have had a degree of impairment in interaction, communication and concentration. Within the age group for this study, children are more inclined to be engaged by games, drawings and visual prompts, such as flash cards, pictorial or 'feelings' cards (Kellet and Ding, 2004). They are also likely to respond to task-oriented scenarios or story completion (Hill et al, 1996). Overall, there seems to be reluctance among researchers to interview children under the age of seven, due to concerns about the viability of data at this stage of development. More recent studies developed appropriate techniques to enable younger children to participate in research (Alderson, 2000; Morison et al, 2000). Of particular importance is the necessity to employ a range of flexible and participatory techniques. Use of participatory methods could enable children to optimise their contribution to the process, and give them an element of control within it, therefore participating on their own terms. Consideration of this kind of responsive partnership should enable children to express their views and perceptions in a relaxing and enjoyable manner, and could reduce the potential for power to be located with the adult, shifting the dynamics toward a more balanced relationship.
4.5 The context and location of semi-structured interviewing

Within any naturalistic research, i.e. research taking place within a familiar environment for the participants, there are certain considerations and challenges to overcome. Most of the issues presented here would apply in a similar way to both the parent/carer and child. An important aspect to consider when undertaking research in a naturalistic environment is to introduce choice to the participants in relation to where they would feel most at ease (Legard et al, 2003). Usually the venue would tend to be in the family home. However, allowing choice of venue might make participants feel more comfortable, especially if they wished to maintain confidentiality or did not feel at ease with being interviewed in their home environment.

Mayall (2000) describes the position of the researcher when undertaking research in a family home, suggesting that the dynamic of the researcher as a guest can be a situation with unclear parameters. The challenges that may arise from such a situation could be the potential for conditions of the interview to be set by the adult participants, thus impacting on the aims of the research. The possibility of interruptions, involvement of participants who do not meet the selection criteria, (for example, relatives or siblings), and the inability to undertake the interview in confidence with the participant could also result in flawed data. Mayall (2000) suggests that a possible approach to eradicating such a position is to discuss and establish ground rules and appropriate boundaries, for both researcher and participants, at the beginning of the interview. Morison et al (2000) support the approach of setting ground rules, as an effective way of establishing initial rapport, putting participants at ease, and raising concerns about the process.

An important aspect for consideration is the presence of significant others during the interview process. This aspect is particularly relevant in relation to the age and
vulnerability of the children in this study, and the rights of the parent to safeguard them. Morison et al (2000) suggest that the presence of a supportive parent can also serve to encourage participation and openness with the child, and could be beneficial to the interview process. Particular awareness is required where parents have a tendency to speak for the child or gate-keep responses, as access to children's true perceptions may be diminished. Explaining and agreeing the parent/carer's role in the child interview may be crucial in eradicating these obstacles from the outset (Kellet and Ding, 2004).

An invaluable approach to establishing clear boundaries and a useful lead into the interview process for both parents/carers and children, would be to rigorously explain the progression of the interview. Familiarisation with the logistics of the study, the semi-structured interview, timescale, equipment and recording methods can all assist in producing a more conducive environment, and also in reducing any anxieties (Morison et al, 2000; Lewis, 2002). Establishing a routine at the introduction of the interview is more likely to produce successful outcomes and give space to the participants to engage in the in-depth exploration of their perceptions and stories.

4.6 The role and skills of the interviewer

As semi-structured interviewing is responsive and reflexive to data collection, it seems reasonable to suggest that the interviewer should possess a range of skills and competencies, which can be applied to the interview scenario. One particular area for consideration is the necessity to recognise that some of the approaches thought pertinent to the study by the researcher, may not necessarily be appropriate for the people being interviewed (Mathieson, 1999). Thus, it is valuable for the researcher to be aware of their own values and beliefs when constructing interview schedules, and when undertaking the interview itself. An element of reciprocity
should be exercised, allowing the participant to be a collaborative partner in the process (Smith and Osborn, 2003). The researcher should develop specific skills around the interview schedule, and be able to facilitate a flexibility of approach that will ensure that all required angles of the research are incorporated into the interview. The construction of the interview schedule, discussed in the next section, is vital in ensuring the researcher knows when to probe further, or to omit questions that may already have been covered in the interview.

The ability to probe certain emerging issues, as the interview progresses, would require the interviewer to have a clear understanding and rationale of their personal involvement, the degree of their involvement, and the skills needed to establish rapport (Legard et al, 2003). The art of semi-structured interviewing is to enable people to participate. It is vital to ensure that the interview is perceived as a conversation, and therefore the emerging task of the interviewer within it would be to enable the interviewees to talk openly and freely (Robson, 1993). The specific skills required are: listening for meanings, allowing the participant to speak as much as possible, and ensuring that the questions are delivered in a clear and understandable format. In addition, it is important to ensure that the interview does not deviate too much from the schedule and the purpose of the research (Legard et al, 2003).

In this study, it was important to establish the role of the interviewer from the outset, especially as the research could touch on sensitive areas for the participants, or draw out new information that they have not previously considered. Here the roles of empathy and rapport are vital in ensuring that the experience of the subjects is positive and that they are able to participate fully. Thompson (2000) suggests that the interviewer should demonstrate interest, respect, an agility of response, and adaptability. In tandem with these qualities, the interviewer needs to set a scene of
calmness and demonstrate the ability to remain comfortable with the interview process, thus setting the interviewee at ease.

Additional skills and competencies are required when interviewing children, particularly those from younger age groups. A lot of guidance around the skills of the interviewer can be found in the literature on interviewing vulnerable children (Alderson, 1995; Lewis, 2002). Some of these issues are pertinent in this study, especially in the use of age-appropriate language, the ability to give clear explanations, and to enable children to engage in the process and respond to questions (McCrum and Hughes, 1998). It is also crucial for the interviewer to remain sensitive, especially when exploring personal topics. Being able to recognise when children do not wish to share some of their experiences, or to monitor the emotional state of the child and to deal with any resultant anxieties or distress are essential attributes. Hughes and Baker (1990) suggest that interviewing children requires the employment of specific techniques and abilities, and that the interviewer should be versed in the understanding of children's development, cognitive abilities, social skills and motivation. The possibility of variability in the presentations of children's problem areas, their skills and coping strategies could significantly influence the outcomes of the interview, in that they may impaired in participating fully and consistently throughout the interview. Therefore, understanding how to manage such circumstances should be taken into consideration when developing the interviewing techniques. As with any human interaction, it is imperative to ensure that the child feels that they are being listened to, thus enabling the building of confidence and a trusting interface (Dogra et al, 2002). The interviewer should be skilled in utilising reflection in order to clarify ambiguous responses and to demonstrate to the child an affirmation of understanding.
The range of tasks required of the interviewer appears to be complex; therefore, it seems that preparation of the process, consideration of the environment and interaction with participants, is paramount. These issues were considered fully when developing the research procedure for this study, and will be discussed later in Sections 4.7 to 4.8 of this chapter.

4.7 The development of the child data collection tool and the interview processes

Following consideration of the complexities of interviewing children aged between five and eleven years, and the few qualitative research studies that have been undertaken in the field of stigma and child mental health, it was deemed necessary to develop a specific research tool with which to collect the data from the child participant group. Critique of research in the field, outlined in Chapter Two, did not yield many pointers to the generation of specific questions, nor did it suggest a pre-existing data collection tool, suitable for the purposes of this study. This, combined with exploration of the few studies undertaken with children utilising IPA, and the extensive amount of literature on the challenges of interviewing younger children (presented in Section 4.4) prompted the need for the design and development of a data collection tool. The development of such a tool would need to take into consideration all relevant factors discussed earlier, in order to enable the children to elucidate their perceptions and views around the research questions. Learning achieved through the process of developing a specific tool could also be applied to the design of the interview schedule and questions, and the execution of the interview process for both the adults and children.

Evans and Fuller (1996) suggest that, when developing an interviewing process with young children, it is necessary to take into account the full range of issues that might
have an impact. These issues are discussed in Sections 4.4 to 4.6. In addition, the development of data collection tools, interview schedules and interview processes for both children and their parents/carers can be informed by the involvement of professionals or stakeholders, with expertise in this field (Hasson et al, 2000; Edmunds et al, 2005). Edmunds et al (2005) utilised a group of child health professionals to assist in the generation of major themes to be included a data collection instrument. The Commission for Health Improvement also employed a similar approach to consultation with a panel of expert professionals, to inform the development of a research tool and schedule for adolescents, which looked at their views of CAMHS (Attride-Stirling, 2002). In order to develop the techniques and questions in this study, a focus group was undertaken with early years and child-care professionals working with children with mental health needs, and their families. The following sections will present the procedure for the development of the interview process for both parents/carers and children, the development of the data collection tool for the children.

4.7.1 Using focus groups to develop the data collection process and the child interview instrument

When considering the best approach to consulting with professionals on their perceptions of talking to children and their parents/carers about mental health and stigma, and the development of the interview process and tool, a number of methods were considered. As the sole purpose of this approach was to elicit views and perceptions from professionals in order to develop a tool and to inform the direction of the associated interview questions, time-consuming methods such as individual interviews were rejected. Questionnaires were also considered, however, it was felt that they would not provide a rich source of information or opportunity for discussion or clarification. In addition, there was also the possibility of a poor response rate. The
nature of the inquiry meant that an approach which provided economy of timescale and opportunity for discussion, was required. When considering these criteria, the use of a focus group method was considered to be most appropriate.

Focus groups have been frequently used in qualitative research as a pre-pilot or research method development approach, as well as a stand alone research method (Bloor et al, 2001). Vaugh et al (1996) advocate that they can be most useful for preliminary exploration, where relatively little is known about a subject, and where they could contribute to determining contextual data. The focus group method provides an alternative to the semi-structured interview method, in that it can use open-ended questions to direct the discussion. It uses interaction between participants as a source of data and the researcher takes on the role of moderator, or facilitator of the discussion (Willig, 2001). The strength of the focus group is that it can mobilise participants to respond to each other's comments and contributions, thus providing rich data (MacDougall and Fudge, 2001). This process can allow the researcher to challenge, extend and develop issues, and provides a setting that can be less formal than an individual interview. The aim of the focus group in this study was to create an approach that could enable the researcher to talk to children and parents/carers about their perceptions. Utilising this approach would initiate a forum for in-depth discussion. The focus group would generate a unique opportunity to draw on professionals' knowledge and experience of children and child mental health, thus enabling the development of a responsive technique. Focus groups do have some limitations, however, which in this instance relate to the facilitator's skills in keeping the group on task and ensuring that all participants have the opportunity to express their views (Krueger and Casey, 2000).
4.7.2 Participant recruitment and focus group procedure

Krueger and Casey (2000) suggest that the participants in a focus group should be selected because they have certain characteristics that relate to the topic under discussion. With this in mind, the focus group in this study included a purposive sample of six professionals, where a key part of their role was to work with children and families on a day to day basis, both within the general population and with children with emerging mental health needs. Bloor et al (2001) suggest that the ideal size for a sample group is between six and eight participants, although the range can vary. Originally all six professionals consented to participate, giving a cross-sectional representation of the range of multi-agency professions that work with children across health, social care, education and the voluntary sector, however only five were available on the day of the focus group. Their professions included School Nursing, Health Visiting, Health Visiting management, Special Education Needs in mainstream schools, and Counselling with children and young people. They were selected opportunistically to participate in the focus group following previous contact with the researcher, when undertaking joint work with children and families with mental health needs. In this respect, they were known to have an understanding of children's mental health and of work with children and their families. The participants were invited to take part in the focus group, through telephone contact. They were then sent a confirmation letter (Appendix 2). The focus group took place in an appropriately sized room in the local CAMHS, and the incentive to participate was the provision of a lunch before the focus group was commenced.

On commencement of the focus group, the research protocol and aims were discussed with the participants. They were also briefed on the aims of the focus group and asked to consider their perceptions and views of how children and parents/carers might talk about mental health, in relation to the development of a data
collection tool and the interview process (the focus group schedule is presented in Appendix 3). The procedure for the focus group was explained, and each participant was requested to complete and sign a consent form (Appendix 4). The researcher and the group then determined group guidelines in respect of turn-taking, being listened to and confidentiality, which were recorded on a large piece of paper and displayed. The focus group was audio-taped and transcribed in full (presented in Sections 4.14 and 4.15).

4.8 Focus group findings and implications for the development of the interview procedure and the child data collection instrument

The method of data analysis employed was thematic content analysis (Glaser and Strauss, 1967; Burnard, 1991). This method is used to categorise and codify transcripts. The first task is to read transcripts in order to familiarise (saturate) oneself with the data, therefore avoiding fragmentation. The transcripts are then re-read and main headings (themes) noted, accounting for all the data. Following this, the data is coded under broad headings, using a cutting and pasting technique. The data is then subjected to a secondary analysis, wherein sub-themes are derived. Once all sections are compiled and all data is accounted for, the researcher writes a commentary linking examples together for each section. Validity was satisfied by employing two colleagues from the field, but independent of the study, to check the emerging themes for accuracy and consistency.

It should be noted that the data analysis method used here differs from the analysis method employed within the main study (Section 4.16). This is for two reasons. Firstly, IPA, which is employed as a framework for the main study, is not indicated for use with focus groups. This is because of the requirement to interrogate data from an
individual stance in the first instance (Smith, 2004), and this can be difficult to achieve where data contains a number of participants. Secondly, the depth of interpretation accomplished through IPA, was not required for this phase of the study, as the main purpose was to design and develop the research tool and procedure.

A thematic content analysis of the focus group transcript produced ten major themes, each containing a number of sub-themes (presented in Table 4.0). In the following section, the emerging findings from the focus group are presented, and the implications for the development of the child data collection tool and research procedure discussed. The order of the themes does not relate to order of importance, or the order in which themes emerged during the focus group. Whilst some themes reflect the general aspects of the focus group questions, others relate more directly to the requirements for the development of the tool and research procedure. In each case, the implications for the study are discussed. It should be noted that these themes are not mutually exclusive; there is some overlap between the data which fits within a number of themes. The sub-themes will be discussed within the context of their major theme. As each professional group was represented by one participant, the profession of the participants is not acknowledged in the illustrative excerpts from the transcripts, in order to protect identity.
Table 4.0: Major themes and sub-themes emerging from the focus group.

<table>
<thead>
<tr>
<th>Major theme</th>
<th>Sub-themes</th>
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<tbody>
<tr>
<td>1. Children's mental wellbeing and mental ill health</td>
<td>• Appearances</td>
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<td></td>
<td>• Actions</td>
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<tr>
<td></td>
<td>• Interactions</td>
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<td></td>
<td>• Feelings</td>
</tr>
<tr>
<td></td>
<td>• Attributes</td>
</tr>
<tr>
<td>2. Talking to children about mental health</td>
<td>• Language</td>
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<td></td>
<td>• Techniques</td>
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<td>3. Children's perceptions of mental health</td>
<td>• Difference</td>
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<td></td>
<td>• Fear</td>
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<td></td>
<td>• Blame</td>
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<tr>
<td>4. Influences on perception</td>
<td>• Experiences</td>
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<td></td>
<td>• Messages</td>
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<tr>
<td></td>
<td>• Feeling/emotions</td>
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<td>5. Stigma</td>
<td>• Guilt</td>
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<td></td>
<td>• Shame</td>
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<td></td>
<td>• Failure</td>
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<td></td>
<td>• Awareness</td>
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<tr>
<td>6. Getting/seeking help</td>
<td>• Service approaches</td>
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<td></td>
<td>• Introduction to mental health</td>
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<td>7. Professionals' opinions of services</td>
<td>• Skills of agencies</td>
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<tr>
<td></td>
<td>• Accessibility</td>
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<td></td>
<td>• Agency attitudes</td>
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<tr>
<td>8. Promoting family mental health</td>
<td>• Influencing mental health</td>
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<tr>
<td></td>
<td>• Knowledge</td>
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<td></td>
<td>• Responsibility</td>
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</tbody>
</table>
Table 4.0: Major themes and sub-themes emerging from the focus group (continued)

| 9. Children asking for help | • Experience  
|                           | • Communicating needs  
| 10. Perceptions of causes of children's mental health problems | • Relationships  
|                       | • Attitudes  
|                       | • Understanding  
|                       | • Stage/type of intervention  
|                       | • Trauma and resilience  

Theme One: Children's mental well being  
(Sub-themes: Mental well-being; Mental ill health)

This theme reflects the participants' view of mental health in children and also their perceptions of views children may have. It shows a distinction between the definitions of mental well-being and mental ill health, presenting the two issues as being polarised, with no reference to mental health as being seen on a continuum.

Within the sub-theme 'mental wellbeing', the participants offered a definition which includes four distinct components. The largest component is that of 'actions' and includes a description of outwardly displayed behaviours of a child whom they would consider to have good mental health. It was suggested that actions were probably the strongest indicator of a child's wellbeing. These would include smiling, skipping around, sharing, joining in with others, wanting to be around peers, helping one another and being involved with others. Participants considered that they were able to tell if children had good mental health by their physical presentation and activities they participated in, and that this would differ if they were unhappy. 'Actions' also appeared in relation to mental illness. However, in comparison to the picture
described previously, participants saw children as being isolated or withdrawn, or showing unwanted behaviours. They were described as having poor relationships with others, especially peers or friends.

"More often I think, their physical appearance is different, when they are happy". (Participant 1)

"...they can become very withdrawn or isolate themselves, or become a pain in class, and so it can go either way..." (Participant 2)

Participants considered that children would display their happiness or mental well-being through interaction with others. This involved being able to make friends and participate in reciprocal relationships. It was also suggested that the desire to please others and to be acknowledged in return indicated a child’s level of happiness. The participants considered that when children were functioning well, they also gained enjoyment from being given tasks to complete, having rules and boundaries. Having a role and a purpose contributed to self-esteem.

"...if they can say "oh well, I’ve got to go to bed at such a time and I’ve got to eat my breakfast". But in a way it’s not a complaint, it’s just a child really feeling more secure with that..." (Participant 3)

'Interactions' features in tandem with other components of this theme, and is intrinsically linked to them all. 'Interactions' included those with peers, adults and within the learning environment. Participants described that children needed to feel at ease with their interactions with others, and whilst these interactions are discreet, they were linked to children needing to be noticed and acknowledged, feeling part of
a bigger picture, being respected, and being acknowledged for their abilities and achievements.

"...it's the feeling that they are being listened to, that people are listening, friends are listening to them, teachers are listening or that their mum and dad are..." (Participant 4)

The smallest component within this sub-theme related to the description of feelings. The only word used by participants to describe feelings associated with good mental health was 'happy'. It seems that the word is used as a substitute for 'mental well-being' and was often used in place of 'mental health' or 'mental well-being'. No alternative words were offered. The word 'happy' appeared to be used in connection with the young age group of the study. This use of the term could indicate that children may feel more comfortable, or show more understanding of 'happy' as opposed to the term 'mental health'.

"...they love being given jobs that makes them really happy..." (Participant 4)

Within the sub-theme 'mental ill health', participants focused on 'feelings' to a larger extent and leaned towards defining mental ill health through the feelings experienced by children, especially sadness and anger. Some participants suggested that when children are mentally ill they experience some of these feelings and emotions most of the time, whilst others determined that emotions would be combined with outwardly expressed behaviours.

"I think it's those sorts of emotive feelings, you know, or perhaps they feel most of the time. They are feeling sad a lot of the time or angry or whatever..." (Participant 5)
However, whilst describing 'mental illness' by using the word 'sad', participants added that they thought it was acceptable to be sad, and that sadness is very important emotion for children. Although they seemed to be clarifying that mental illness is accepted, they did not highlight that this is a view held by children. The interchangeable use of 'mental ill health' and 'sadness', could indicate a commonly used phrase amongst children in this age group.

Another component of the sub-theme 'mental ill health' was 'appearances'. Participants indicated that children equate physical disability with not being 'normal', or with being mentally ill. A view they considered to be also held by the general population. They proposed that children identify people as being different through what can be seen, rather than what can be established as an emotion or feeling. This would connect with what is known about children's development and how the participants communicate within young children in this study. It might also explain the identification of behaviours as being intrinsic to both mental well-being and mental ill health throughout the data, and may be a good way of getting children to explain their understanding of mental health.

"...because they attempt to equate people with those kinds or disabilities as not being normal...you could have a limp or a disability, that is what they go for..." (Participant 3)

The component of 'interactions' appeared again, but this time it was mainly in relation to the effect of having mental ill health on important relationships. Participants suggested that children worried about the influence problems might have on their friendships and relationships, and how others saw them. They also stated that children measured their mental health against the quality of their friendships and interactions with others.
"I have a boy who has lots of problems and I saw him yesterday, and he said "I feel much better now I've got some friends..." (Participant 1)

Implications for the study

This theme suggests the need to consider inclusion of field notes/observations as part of the research process. As physical appearance plays a large part in portraying a child's mental health, then it follows that some of children's perceptions during the interview may be displayed non-verbally or described as actions. Within the framework of the interview it is also vital to get children to describe and define actions, so that use of reflection or repetition back to the children might be help during the interview, to clarify certain points or non-verbal interactions.

This theme also defines the value of relationships, therefore attention must be paid in developing the interviewer-child relationship before launching into the interview proper.

There is some emphasis on the way in which children define mental health and how they express feelings, indicating the need to enable them to define the words they use and the meanings they attach to them. This may lead to some inconsistencies between interviews, but could be addressed by a preliminary study. Children could be encouraged through use of activities or tasks. The participants frequently raise the value of children as active contributors, and so indicated that these techniques may motivate them throughout interview process.
Theme Two: Talking to children about mental health

(Sub-theme: Language; Techniques)

The ‘language’ sub-theme stresses the importance of using age-appropriate and accessible language when talking to children. It was determined by participants that children would not understand the words ‘mentally healthy’ or ‘mental illness’, and that they would find the concept very difficult to comprehend. This could perhaps result in them focusing on ‘illness’ and physical aspects, rather than the meaning of mental illness as an entity. Again, it was proposed that there may be some confusion over physical disability, and the connection with perceptions of abnormality.

"Perhaps we should be thinking of another word rather than mental". (Participant 3)

"Well, when they are quite young they wouldn’t really know what you were talking about at all. Even a lot of adults don’t, not until a few years ago anyway…” (Participant 1)

A list of alternative words was offered, however, this mainly proffered stigmatising language, which participants suggested children used in everyday conversations. Although they proposed that children might understand these words more, they suggested that it was not appropriate to use them in the study. They advocated that a more effective way of eliciting children’s perceptions was by focusing on feelings, again using the words ‘happy’ and ‘sad’. They also suggested that the interview schedules should include the words ‘mental health’ and ‘mental illness’ to determine children’s level of understanding of these phrases. Participants suggested that it would be better to try and establish how children wanted to talk about mental health. It was also considered to be paramount to establish what children felt safe with, suggesting that talking about mental health may be difficult for some of them.
"It is yes, feelings emotions... describing it rather than using the actual words isn't it?"

(Participant 5)

In the sub-theme of 'techniques', a range of them were proposed. Participants suggested that tasks would be especially useful, which relates to findings in Theme One. Techniques such as discussion of scenarios, sentence completion and asking children to describe people and behaviours, could be beneficial ways of gaining perceptions. In conjunction with this, it was deemed important to ensure that children knew they were being listened to and that their thoughts were acknowledged. Also getting children to describe their day might be helpful.

"... if you are just asking about one child and how they cope through the day, would you hear what the child's perception of illness is?" (Participant 5)

One participant said that using scaling questions might be a technique that children would understand and be able to identify their perceptions with.

"It would be better on a scale of one to ten of how you feel, I think it's quite a good way of showing them..." (Participant 4)

Implications for the study

The 'language' sub-theme emphasised the need to ensure that the tool includes age appropriate language, communication and use of local words, where appropriate, as this could vary from region to region. It is, therefore, important to ensure that piloting of the interviewing techniques allows children to define their own words when talking about mental health, before moving on to the main study. Techniques should also take into account suggestions of appropriate ways of engaging children, and should include a range of approaches to ensure children do not become bored or distracted.
However, when considering different techniques, it would be important to retain some flexibility to clarify or explore points raised by the children. Such flexibility should be incorporated into the interview schedule and process, to enable the execution of the interview within the framework of IPA.

Theme Three: Children's perception of mental health
(Sub-themes: Difference; Fear; Blame)

This theme reflects participants' views on what determines children's perceptions of mental health. The theme divides into three distinct sub-themes. The first of these highlights the argument of 'difference', which occurs within other themes. Within this sub-theme the participants underlined their observations of how children determine mental illness as different from the 'norm'. Professionals suggested that children determine those who have mental illness as being 'different' from them, regardless of whether the children themselves have mental health needs.

"...as they get older they become more aware of the world and that there are not nice people out there..." (Participant 1)

"That's right, you thought they were different, and maybe frightening?" (Participant 4)

On the whole, participants considered that children found physical illness or disability less stigmatising than mental illness. Participants proposed that when children tried to imagine themselves with mental illness, or others they knew who had mental health needs, they tended to describe their observations in physical terms, i.e. what they could see.
“...it's much more acceptable to have a physical disability than a mental issue...”

(Participant 3)

“...that's only because they haven't experienced anything different to be able to see something in a context other than that [physical disability]...” (Participant 5)

The second sub-theme represents professionals’ perceptions of children’s views of mental health, in relation to fear and blame. In the sub-theme ‘fear’, there seems to be a differentiation between fear of people with mental illness and fear for themselves. This was suggested in connection with their perceived expectations of someone who has mental health needs. The first component ‘fear’ is influenced by definitions given by those around the child and by the media, and the second component ‘blame’ is in relation to children fearing the consequences of having a mental illness themselves and being blamed for their problem.

“...I think they might associate it this way [mental illness], often because of the newspapers and the media and the way people talk...” (Participant 4)

“...I think that they are quite aware [of mental health and stigma], and I think that it corresponds with their feelings about themselves.” (Participant 3)

Within the ‘blame’ sub-theme there was a view that children were afraid of having difficulties, as they would be blamed for their behaviour. Participants also thought that children may think they had let their family down. There was some recognition that children can feel guilt at a very young age. Participants suggested that children with mental health needs often appeared to feel that they were being punished, because they were being treated differently.
"...and that they have been identified because of the way they have been behaving. They feel like they have been sent or that it is a punishment..." (Participant 2)

Implications for the study

The findings from this theme indicate that it is necessary firstly to elicit the meanings children attach to mental health, especially where they define it as being 'different'. It is necessary to carefully consider the words children use to describe this concept. This description appears as a sub-theme in a number of themes; therefore its regular emergence indicates the importance of establishing the definition held by the children in the study.

Secondly, the sub-themes of 'fear' and 'blame' should influence the way in which the interview techniques are administered. This is two-fold. Firstly, children may be afraid of what will happen to them during the interview, which may result in some reluctance to participate. Secondly, they may be anxious about divulging certain feelings and issues, which they may feel they could be punished for. This response may also stem from a fear of being categorised as having problems which they are frightened of, or can be blamed for. With this in mind, pre-interview preparatory work would be invaluable in reducing parents'/carers' and children's anxieties about the process. In addition, it may be useful to consider the way the study is introduced in the information letter to parents/carers and children.

Theme Four: Influences on perceptions of mental health

(Sub-themes: Experiences; Messages; Feelings/Emotions)

The sub-theme 'experiences', includes influences on perceptions that were relevant to both the child and the family. Participants suggested that involvement and support within the family are intrinsically linked, and this would have an influence on whether
there is a negative or positive perception of mental health held by parents/carers and children. For example, professionals suggested that the involvement of families in discussions about mental health issues, and being given the message that their opinions counted, would influence a positive regard for individuals with mental health needs. However, when considering this aspect further, professionals suggested that the aim of the interview should not be to prompt participants to give positive responses, but rather to give them space to determine their real views about mental health.

"I think that children are not happy, if there isn't communication, because in truth, they like being acknowledged. Being acknowledged, being listened to, that's right." (Participant 3)

Whereas some participants commented that when children's difficulties or problem behaviours are treated or labelled as 'bad', or where punishment was issued or children and families were not listened to, there could be a negative effect on perceptions or views.

"...So, its punishment, isn't it? Definitely, and it's totally reinforced by their parents..." (Participant 5)

Other influences on perceptions related to the experience of directly observing mental health problems. On the whole, participants considered that perceptions were likely to be discussed in a more positive way, where children and families had knowledge of, or a relationship with people who had mental health needs. This could be broadened to include experiences from outside the family home, such as at school.
"Absolutely, yes, and if it’s been done in the right way and someone has explained it [mental health] properly…" (Participant 1)

Participants considered that perceptions could become clouded where families seem to have a difficulty in understanding. This might be expressed by describing mental health as something that is not tangible, or something that is hidden. Some professionals suggested that there could only be a positive understanding in families where there had been a close relationship with someone who had mental health needs.

"…say they have a father who is depressed or a brother or there is a big issue within the family then, yes, they will probably understand a bit more about it [mental health need]" (Participant 4)

Again ‘difference’ entered into the equation. Professionals determined that families and children may continue to define those with mental health needs as being different to them. They proposed that this could also relate to parents’ childhood experiences, which are passed on to their own children, thus continuing the conveyance of negative perceptions. One participant explained how prejudicial images of children who may be considered to be different can be conveyed at school:

"…[An example of prejudicial language] there was a class that was called ‘JS’ and we used to call it ‘Junior Stupids’ and they were all kids who obviously had learning difficulties.’ (Participant 3)

The ‘Messages’ sub-theme interrelates with ‘Experiences’, in that it may have an influence on the child’s perception of mental health. Participants claimed that children’s perception of mental health is not only related to what they personally
experience, but also the way significant adults interpret and make sense of their experiences. In addition, the participants considered that this could be consolidated by the way knowledge was imparted to children and how views are communicated, i.e. the messages they give to children about mental health. Messages were also thought to be communicated by media images, or that they were obtained from societal influences of stigma.

"...you've just got to think of the last few years in the press all the hype about hyperactivity and how children eat a high sugar content, and immunisations has so confused parents. Then they think they better look at the colouring in the juice..."  
(Participant 2)

Implications for the study
The findings within this theme would suggest that children's responses to questions about mental health may be influenced by their experiences and the messages they have learnt from others. This would indicate the importance of ensuring the child is interviewed away from interruptions and family mediation, as this could have a bearing on how the child answers the questions. Children may find it much more difficult to talk about issues related to themselves, than they would when talking about a third party, or an anonymous character. These aspects could influence the way in which the interview is undertaken, i.e. the first half of the interview focusing on questions relating to the meanings of mental health and mental health problems in others, whilst in the second half the questions could relate to the child's experiences. This approach could enable the child to develop rapport with the researcher and to feel more confident when answering questions about more sensitive issues. It would be vital to observe for changes in confidence or difficulty in answering questions during a pilot study. Having an active role in discussions, with perceptions being listened to and valued, would need to be implicit within the process.
Theme Five: Stigma
(Sub-themes: Guilt; Shame; Failure; Awareness)

The theme of ‘stigma’ elicited some emotive comments from participants. The sub-theme of ‘guilt’ draws on observations from professionals which relate to the intense fear that children and families might experience when talking about mental health. Again, as with other themes, professionals determined that children and families identify ‘mental health’ with ‘mental illness’, which for them still carries a lot of stigma. Professionals expressed that such perceptions may arise from extreme views that had been communicated to them, or from the familiar, traditional stereotypes surrounding mental institutions.

“I think it’s seen as very polarised, you are either ok or you are off the rails and they are going to lock you up…” (Participant 2)

Parents were suggested to feel responsible for their children’s mental health problems, and this could also be communicated in the parent-child relationship.

“But also it’s human nature that we don’t want to feel guilt or responsibility. Sometimes I have phone calls from someone [parent] to air their grief and to use me as a scapegoat…” (Participant 1)

The sub-themes of ‘shame’ and ‘failure’ also emerged often. Professionals considered that these issues may influence the desire for children and families to participate in the research, as this was often what dissuaded them from asking for help.
"I did something years ago in [local community] and there were several parents who said they would like help, and when it came to the group, they didn't want to be seen. I said 'I'm really surprised because I thought you wanted this?' and she says, 'well I feel as though I am being labelled for having a failure’..." (Participant 1)

The largest sub-theme was 'awareness'. Professionals suggested there were both positive and negative aspects, however, there tended to be a bias toward the negative influences of awareness on perceptions of stigma. These negative influences on the stigmatising effects of mental health were considered to arise from many sources, including the attitudes of professionals, the community and within individuals. Participants suggested that young people’s perceptions were related to direct experiences of stigma and discrimination; this made them reluctant to seek help. Some of this was also thought to be in response to the understanding of mental health that significant adults have and portray to children.

"Even when I was qualified and went onto mental health, studied it...They think you are crackers immediately, they hear that word 'Mental Health', they don't want to understand things..." (Participant 2)

The participants suggested that asking children questions about mental health would be better accepted if the interview process was explained clearly and assurances were given. This related to some experiences they had in their practice. Some participants described situations where they had a greater attendance rate if time had been taken to explain to children and families. They projected that ideas about stigma were changing, but creating positive awareness would be a long process, and support mechanisms needed to be put in place to keep perceptions changing. Stereotypes were still considered to be prolific; these were often reflected in the media presentation and varied greatly between social classes.
“...because there is nothing like talking face to face to someone, you can send a letter, but you have actually got to say it for people to understand...” (Participant 5)

Implications for the study
This theme will influence the explanations that are given to children and families in the information letter, and also in the introduction to the interviews. Care should be taken in relation to confidentiality, reassuring children and families that the research is anonymous and will not affect the help they are given by the service. The introduction to the interviews should set the scene, whilst allowing children and families to ask any questions they wish to, in order to help them feel comfortable and informed. These findings should also influence the images used with children, perhaps indicating use of non-specific characters, for example, the use of friendly cartoon characters. Questions related to stigma would need to be asked in a sensitive manner, to ensure that participants do not experience stigma and discrimination as a result of taking part in the study.

Theme Six: Getting/Seeking help
(Sub-themes: Service approaches; Introduction to mental health)
The theme 'getting/seeking help' has two emerging sub-themes. The first relates to professionals' opinions of what encourages, or discourages children and families from asking for help. The second centres on the approach that services use when working with children. Professionals thought that going for help was an anxiety provoking experience for children, and this feeling influenced whether they had a negative or positive experience when getting help. Comments included the importance of involving children in discussion, and ensuring that they were aware that they also had a voice. The wait that children had for access to services was considered to have an influence on fear and anxiety. Also the pre-appointment
information given to children and families about what to expect from the service, would have an important role to play.

"I think that if you treat it sensitively and they understand where they are going and why, that it isn't anything terrible. That's my experience of the ones who have actually been pleased once they have been through it." (Participant 4)

"You can try and address this [anxieties about going for help] and then you lose them, most of them just can't address it. It's harder for families, particularly with younger children; they begin to think "Oh, they are just going to take the children off us."

(Participant 2)

The second emerging sub-theme highlighted the significance of how the concept of mental health is introduced to children and families. The way in which professionals and other adults talk about mental health and getting help was thought to have a profound effect on children's motivation to determine their own needs. In some instances professionals suggested that parents may have seen the use of CAMHS as an antidote to unwanted behaviours in the child. This pre-conception was thought to be used like a punishment, or a motivator for good behaviour. Participants suggested that this included the way that families understand mental health need and respond to it.

"I have actually heard parents threatening the child and saying "They will sort you out at [local CAMHS Service]..." (Participant 3)

Participants also suggested that the responses from children who said they needed help would be determined to some extent by the stage at which help was offered.
They proposed that children who had been offered earlier intervention actually responded to that intervention in a more positive way.

"I think, as well, we see older children, when they have talked about their experiences when they were younger…" (Participant 5)

Implications for the study
This theme determines the importance of ensuring that children and families have adequate information about the study, so that they can make informed choices about their participation. It is vital to ensure that a description of the proceedings of the interview is given to both children and families before commencing, and that they are encouraged to ask questions. Given that professionals considered that the length of wait might have a bearing on anxiety levels, it would be important to ensure that the length of time between being invited to participate and the interview is kept to a minimum. Participants regularly referred to the service by name, this is usually in conjunction with negative attitudes observed in children and families toward the mental health service. Consideration must be made as to where the interviews are conducted and the value of involving children and families in this decision making. Finally, it would be important to include a question in the interview schedule which relates to views of mental health services and stigma.

Theme Seven: Professionals' opinions of services
(Sub-themes: Skills of agencies; Accessibility; Agency attitudes)
Participants determined that services for children with mental health problems should not just rely on specialist CAMHS, but also on services that work with children on a day to day basis. Participants proposed that in order to prompt a change in children's and families' perceptions of mental health, it was vital to start with educating the
frontline professionals (Tier 1). This included knowledge and skills, early identification, intervention and prevention.

Other issues considered in the sub-theme of ‘accessibility’, including improving knowledge about services and CAMHS joining forces with less stigmatising organisations. The final sub-theme acknowledged that agencies still have practices or attitudes towards children with mental health needs, which continue to be inadvertently stigmatising.

"I think that the whole way forward has got to be doing something that would help them [children], and changing the emphasis … because the more contact people have with it [mental health], the better understanding they will have and the greater willingness to actually acknowledge that there are problems and try to do something about it [stigma]..." (Participant 5)

Implications for the study
This theme has little emphasis on how the interviews are delivered. However, it may be valuable to include a prompt in the interview schedule about how children and families would like to receive help, or what they think would work for them.

Theme Eight: Promoting family mental health
(Sub-themes: Influencing mental health; Knowledge; Responsibility)
The discussion mainly related to the influence that parenting style was seen to have on children's mental health. This issue was also expanded to the approaches and interventions used by schools. Overall, this related to the techniques used to communicate with children more effectively, skills in setting rules and boundaries, and giving adequate explanations to both children and parents. Participants stated
that if these things were in place from the outset then, they would be better placed to promote mental health. The second sub-theme complements the first and has an emphasis on knowledge about mental health. Participants highlighted the importance of knowledge about mental health and how it can assist in prevention and promotion of mental health, in school and at home. The final sub-theme discusses the concept of responsibility for children's mental health. Participants stated that there are only small numbers of professionals who have an interest in child mental health. They suggested that the remedy for this should be the move to having designated professionals, who are responsible for defining mental health need and promoting mental health in the community.

"I think even when you are pregnant. It's [mental health] a way of life then. I think teach children through until they are pregnant from day one, because you have such a lot of post-natal illness. Really if you help right through from the beginning and talk to them, because that is what you have to do…" (Participant 2)

"There might be a few selected people who have got an interest in special needs work, but on the whole I think it should be much more available to them…"

(Participant 1)

**Implications for the study**

Although this theme has minimal implications for the study, the first sub-theme could influence the way in which interviews with children are structured (including the environment) to ensure maximum participation. The second sub-theme would suggest that there is a need to explore how knowledge is gained about mental health, within the interview schedule.
Theme Nine: Children asking for help

(Sub-theme: Experience; Communicating needs)

Although this theme does not contain a large amount of data, there were two emergent sub-themes. The first referred to the impact a child's experience has on their ability to ask for help. Participants suggested that this could be negative or positive, and was influenced parents responses to the child's problems, or the way concerns about seeking help were communicated.

"I saw a young boy who is 19 now, he's got mixed up with the police and is on probation. It's sad because he is aware of the way he got but, he said he has been wanting help since he was 10 when his dad committed suicide, he has realised that is when it all went wrong..." (Participant 5)

The second sub-theme relates to communication. Participants suggested that children sometimes communicate their desire for help in the way they behave.

"...Well, they ask for help by the way they behave..." (Participant 1)

Implications for the study

This theme will have little impact on the main study; however, the second sub-theme indicates the need to consider using field notes or to use reflective techniques within the interview process. This may assist in supplementing the data, especially as the sample includes a young age group who may have difficulty in communicating their perceptions verbally. It may also be valuable to ask children to describe examples of actions and behaviours which relate to mental health, instead of relying on abstract questions which may not always be easy to comprehend.
Theme Ten: Professionals’ perceptions of causes of children’s mental health problems

(Sub-theme: Relationships; Attitudes; Understanding; Stage/type of intervention; Trauma and resilience; Blame)

‘Relationships’ related to the family dynamics and the parent-child relationship, with participants suggesting that this could have an influence on the child’s mental health.

“It could be a simple fact, as I say, because it obviously happens everyday, it could be Mum and Dad are getting a divorce and they are 8 years old and they need help through their anger…” (Participant 3)

The sub-theme ‘attitudes’, which overlaps with a previous theme (promoting child mental health), again comments on the attitudes parents, professionals and even society has toward children and their mental health. These mainly include, lack of consistency or firm boundaries and poor communication with children. Participants described child care as being of low priority for adults in contemporary society, and that this in turn could lead to mental health problems. ‘Understanding’ relates to the lack of education and knowledge that children, parents and professionals have on mental health. Participants stated that lack of knowledge resulted in blurred or inappropriate opinions about mental health, which in prevented mental health needs from being tackled early. This was also linked with the sub-theme of ‘stage/type of intervention’, which highlights the necessity to identify problems early to prevent the development of more severe problems.

The final sub-theme of ‘trauma and resilience’ described participants’ perceptions that most mental health problems are caused by traumatic life events. They proposed, however, that these may vary in degree of severity, and that children’s reactions to
them were based on their resilience. Professionals determined that children also identified these events as the cause of their problems.

"...Well, if they have these problems children are isolated at times, and find it difficult to keep friendships, these are the children who are bullied..." (Participant 1)

"I think most of them believe it's them, even if they are not saying that they believe it's them or they have contributed to it in some way" (Participant 3).

Implications for the study
This theme will have an emphasis on the questions which relate to children's perceptions of mental health and the causes of their problems. It is important to examine the way the questions are framed to ensure that children do not think that they are being blamed for their problems – this may influence their answers and also make them reluctant to seek further help. This theme prompts the need to include a question in the interview schedule asking children and parents about the impact that mental health problems may have on their quality of life.

4.9 Developing the interview process, child interview tool and the interview schedule
Following further examination of the focus group findings, three distinct areas arise. These areas relate to considerations on the development of the interview tools, techniques and process. When combined with the critique of the literature related to the interview process and techniques with children, the findings from the focus group informed the development of the instrument and approach used in the study. The following sections will discuss the focus group findings and implications for the study,
and will present the emergent processes to be employed in relation to the interview process, the development of the child research tool and the interview schedules.

4.9.1 Emergent findings and the development of the interview process

In both the literature around the interview process discussed in this chapter, and the findings from the focus group with professionals, there are distinct issues that emerge which are crucial to the development and successful application of the interview process in this study. Table 4.1 (page 123) draws together the key findings elicited from the focus group and highlights the implications for the development and implementation of the interview. The table is divided into three sections: Pre-interview preparation, commencement of the interview, and the interview process:

- **Pre-interview preparation**

  Both the related literature and the focus group findings indicate the need for substantial pre-interview preparation. This is particularly pertinent in this study, as the topic under research is thought to be sensitive, with reluctant or anxious participants. The issues of recruitment, and the development of informed child and adult participants, will be addressed in the invitation letters and information sent to both children and parents/carers, and the subsequent appointment confirmation letters. The pre-interview information will also allow for a choice of venue for the interview and should outline consent, confidentiality, and the right to withdraw from the study without prejudice. All these areas were highlighted in the focus group as a possible cause of undue anxiety to the participants. The recruitment procedure for the study is outlined in Section 4.11.3.

- **Commencement of the interview**

  The emphasis of the findings indicates the need to put the participants at ease. To enable the participants to take part in the study in a relaxed manner and in a situation conducive to their sharing of thoughts and views, the protocol for commencement of
the interview indicates careful planning, with full explanation of the procedure. This approach should contribute to building of the rapport required between interviewer and participant relationship. In addition, the findings of the focus group produced discussion around the adult-child relationship, adult-child power imbalance, and also the safety of the child. The development of joint boundaries and rules will assist participants to be part of the process, and will establish the course of the interview from the outset. The researcher will ensure that parents and children are consulted about the need for a significant adult to be present at the interview with the child, therefore, safeguarding participants and reducing anxiety.

- **The interview process**

The focus group findings indicate the need to ensure that participants feel able to interject or to clarify the process. This should contribute to a successful response to interview questions. They also highlight that talking about mental health can be an emotive experience, particularly for children and families who have experienced problems. The ability to reiterate process, rules and boundaries will be engaged throughout the interview, to enable safeguarding of the participants and the facilitation of the interview process. The findings also indicate that children may not always express their views verbally; therefore, the implications highlight the need to supplement or assist children to contribute, when they express their views non-verbally. Two approaches to achieving this could be through the use of field notes to supplement transcripts, or through clarification and reflective techniques. In this study, the researcher will use the latter technique. The justification for this is that analysis of field notes is thought to be difficult within an IPA framework, as the aim is to understand meaning elicited during conversation with individuals (Smith, 2004). However, during analysis in the IPA framework, the researcher can also interpret their own responses, as well as those of the participants; therefore, the use of reflection/clarification techniques will ensure that children's non-verbal comments are included in the data.
<table>
<thead>
<tr>
<th>Theme</th>
<th>Considerations from findings</th>
<th>Implications for interview process</th>
</tr>
</thead>
<tbody>
<tr>
<td>1, 4, 5, 6, 7, 9</td>
<td>Research may be viewed as stigmatising by participants. Children and parents may be encouraged to participate, if fully informed.</td>
<td><strong>Pre-interview preparation</strong> should be undertaken to reassure children and parents of the process and to develop confidence in the approach. Preparation should include a full description of the research in an introductory letter for both the child and the parents. Confidentiality and consent to participate should be explained in the invitation letter and at the beginning of the interview. Choice should be given to the family about where they wish to be interviewed.</td>
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<tr>
<td>1, 3</td>
<td>Children’s confidence is related to their perception of the relationship they have with the adult.</td>
<td><strong>Commencement of the interview</strong> should include introduction to equipment, showing participants what they will be doing, including the process and timeframe. This should assist in building rapport with the interviewer. The introduction should allow questions and ensure that participants are familiar with the process.</td>
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<tr>
<td>6</td>
<td>Parents may have concerns about child’s safety within research process.</td>
<td>The child should be given a chance to undertake the interview on their own or without cues from others, especially influential family members. However, care must be taken to determine the most comfortable place for the child to undertake the interview and that parents/carers are reassured of safety.</td>
</tr>
</tbody>
</table>
Table 4.1: Summary of emerging findings from the focus group and implications for the research process (continued)

<table>
<thead>
<tr>
<th>Theme</th>
<th>Considerations from findings</th>
<th>Implications for interview process</th>
</tr>
</thead>
<tbody>
<tr>
<td>1, 4, 5, 6, 7, 9</td>
<td>Children's responses can be influenced by experiences and messages from others. Parenting styles influence responses from children.</td>
<td>During the Interview process, there should be consideration of the use of reflection/clarification within the interview to verify meanings with participants. Ground rules and boundaries should be established and reiterated with participants, during the interview.</td>
</tr>
<tr>
<td>6, 8</td>
<td>Children's perceptions may be displayed non-verbally or through actions.</td>
<td>Consideration of use of field notes, where required, to add to verbal reports. Developmental age of the child and capacity for attention should be considered. Reflection/clarification techniques can be employed during the interview to confirm non-verbal interactions.</td>
</tr>
<tr>
<td>5</td>
<td>'Mental health' carries intense emotions and fears for participants, who may be reluctant to participate.</td>
<td>It may be useful to establish process, rules and boundaries for the interview from both the interviewer's perspective, and from the child and family's perspective. Time should be allocated to enable parents/carers and children to ask questions, and to debrief or deal with any concerns ensuing during the interview. Interviews should be kept as short as possible to reduce boredom and anxiety in children.</td>
</tr>
</tbody>
</table>
4.9.2 The development of the child interview tool

The findings from the focus groups and consideration of the literature indicate the importance of using a range of engaging techniques with young children. The key findings from the focus group and implications for the child research tool are summarised in Table 4.2 (page 128).

On consideration of the findings and the literature related to engaging children and establishing their perceptions, it was concluded that a colourful story-board approach would be an appropriate way of eliciting the children's views. Participants in the focus group often referred to the adult-child power imbalance and the rapport between interviewer and child, suggesting that direct approaches may cause anxiety, or may prompt the child to feel that they have to answer in a certain way. Literature related to engaging children often advocates story-telling and 'third person' techniques as a productive way of enabling children to express their views (Hill et al, 1996; Liabo et al, 2002). The third person technique allows the child to join in a process that does not involve responding to an adult, but in telling a story to a fictitious character, therefore improving collaboration, and reducing anxiety and the desire to give answers they think that adults want to hear.

The findings from the focus group also suggest that younger children and those with mental health problems may have more difficulty in contributing and concentrating. Therefore, a range of interactive tasks should be included. These should incorporate activities such as games and drawings for children to explain their views.

In light of these considerations, a tool was developed. This was set around a story created by the researcher, entitled 'Spacey and Jupiter's mission'. Spacey and Jupiter's mission (presented in Appendix 5) is a cartoon-based storybook with
activities, which features two friends; Spacey (an alien) and Jupiter, his robot friend. They are sent to earth by their superior (a character called ‘the Boss’) to find out about boys and girls in relation to perceptions about mental health, their experiences of mental health problems and going for help. The story engages children by asking them to help Spacey and Jupiter in completing their mission, centred on specific questions, and reporting back to their boss, based in outer space. The two friends know nothing about children or mental health, so the aim of the story is for children to help them collect their data. The story incorporates media for recording the data, in the form of ‘Mission reports’ (Appendix 6), if children wish to use them. There are also various activities within the story, which children can choose to complete. These include laminated flash cards of a range of feelings/emotions, (examples are presented in Appendix 7), some blanks cards if children wanted to draw their own feelings and some drawing exercises. The audio recording equipment is incorporated into the ‘Mission’ as the main way of recording the data required from the children. At the end of the story the children are presented with a ‘Space certificate’, as a means of rewarding them for helping with the study (Appendix 8). This aspect was highlighted as important by participants in the focus group.

Specific consideration was given to the images portrayed around each of the questions in the ‘Mission’, thus ensuring that there were no implied suggestions about the answers required from the children. Children were informed that there were no right or wrong answers, and that the characters in the story were interested in their point of view. The concept was designed following examination of a number of pictorial storybooks suggested to be appropriate for the five to eleven years age group in this study. The characters were designed to engage children right across this age range, and contained additional points of interest or humour, which could be pointed out by the researcher as a means of engagement, depending on the age of the child. For example, when using humour to engage an older child, Jupiter, a female robot,
was introduced as Spacey's girlfriend, or the Boss was described as looking like the researcher's superior. Having such flexibility within the story required the researcher to utilise certain skills, which are discussed in Sections 4.4 and 4.6.

The story can be delivered in two ways; either by the researcher acting as the story teller, or as a workbook which children can read themselves, with assistance from the researcher, if required. In addition to the storybook acting as the interview tool, the role of the researcher is to facilitate the process, ask supplementary questions (Appendix 9) where necessary, and use reflection and clarification techniques, as discussed in 4.9.1. The questions in the story related to the interview schedule designed for parents/carers, which is presented in Section 4.9.3. The language used is age-appropriate, and the cartoons, drawn by a graphic designer under instruction from the researcher, are colourful, child friendly, non-threatening and include images of children from different ethnic backgrounds and genders. In addition, where the child uses drawings in the 'Mission', the researcher encouraged dialogue about the drawings, or asked questions to assist the child in describing the drawings in order to capture their views for the audio recorder.

Once the concept and proofs for the story were completed, several consultations were undertaken with professionals in the child care and child mental health field, and also with children of friends and family, to ensure the story was appropriate for use with the age group in the study.
<table>
<thead>
<tr>
<th>Theme</th>
<th>Considerations from analysis</th>
<th>Implications for techniques employed within the interview tool</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Children specifically like being given tasks to complete</td>
<td>Engage and enable children to describe and define actions through use of techniques that include tasks and activities, such as games, drawings or puppets. A range of media will enable the child to explain their perceptions. They should be encouraged to use choice in the activities they undertake. Consider use of story board technique to collect information.</td>
</tr>
<tr>
<td>2</td>
<td>Children like to be 'noticed' for achievements</td>
<td>Consider a reward for participating in the study, e.g. a certificate.</td>
</tr>
<tr>
<td>3</td>
<td>Use of local and age appropriate language</td>
<td>Researcher to pay attention to 'local' language and words used according to the child's age group.</td>
</tr>
<tr>
<td>5</td>
<td>Children may feel afraid to divulge feelings and issues because of fear of being blamed or punished</td>
<td>Use of 'third person' techniques can be beneficial in giving the child confidence to answer. This technique may eradicate the need for children to feel that they are answering questions for adults' benefit. The use of cartoon characters may be useful in providing the 'third person' approach.</td>
</tr>
<tr>
<td>1</td>
<td>Adult-child power imbalance</td>
<td>Consider the introduction of a concept that the cartoon character knows nothing about the child and wants to understand things from his/her point of view. This can reduce the power imbalance.</td>
</tr>
</tbody>
</table>
4.9.3 Generating the interview schedules for parents/carers and children

The combination of the research questions for this study, findings from the focus group (presented in Table 4.3, page 131) and literature discussed in Chapter Two led to the generation of the following suggestions for inclusion in the interview schedule.

Interview schedules were designed for both parents/carers and children that would largely follow the same set of questions. Although the data elicited from both groups of participants may be different, and the levels of understanding in adults and children may be diverse, the aims of the research are to explore the same issues. Using a similar approach for both groups, would also provide the opportunity to discuss any areas of interplay in the views of the two sets of participants, should any arise. The justification for the schedules and the ordering of questions was also generated from the findings of the focus group.

The questions in the schedule were divided into two sections. The first section includes explorations of the meanings of mental health and stigma, mental illness and experiences of mental health problems. The second section focuses on the personal experience of the child’s mental health problems, expectations of CAMHS, and the experience of seeking help. Analysis of the data suggested that more sensitive and personal questions may be better placed in the second half of the interview, when rapport with the interviewer has been established.

The main difference between the adult and child schedules is that the parents/carers will prompted about their views on stigma, if these do not emerge during the interview, whereas children may not understand the concept. The analysis of the data would hopefully identify more subtle views about stigma that are not overtly stated by either group. The prompts around mental health in the adults’ interview will focus on the
experiences they have with their children, rather than their own mental health, as the aims of the study are to specifically explore children's mental health.

Additional questions within the child research tool will include the exploration of the word 'healthy', in addition to the exploration of the meanings of 'mental health' and 'mental illness'. This was suggested by the findings of the focus group, as children may be able to describe the meanings of 'healthy' but not 'mental health'. Using this question would enable the examination of the level of understanding about a similar concept of health. Liabo et al (2002) found that children of a similar age group to this study were able to understand the concepts of 'health' and 'unhealthy'. Using this question at the beginning of the children's interview should also present them with a question that they should not find too difficult to answer.

In order to assist children participating in defining the meanings of mental health, and their experiences of mental health problems, a question focusing on understanding and knowledge of related feelings and emotions was included. In order to prompt children's views around this, a game using flash cards with feelings and emotions was also included in the story, as mentioned in the previous section (Appendix 7). The words used to determine feelings and emotions were derived from research by Harris et al (1987 and 2005) and Harris (2000) on emotions consistently expressed by children aged from five to fourteen years. The emotions used included those consistently identified in children up to ten years (Appendix 10).

The interview schedule for the parents/carers is presented in Appendix 11 and the child interview tool and supplementary schedule are presented in Appendices 5 and 9.
Table 4.3: Summary of emerging findings from the focus group and implications for interview schedule

<table>
<thead>
<tr>
<th>Theme</th>
<th>Considerations from analysis</th>
<th>Implications for interview schedule</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>Talking to children and parents about mental health.</td>
<td>Interview schedule will allow children/parents/carers to identify and define the words, feelings and actions that they would use in relation to health, mental health and mental illness.</td>
</tr>
<tr>
<td>3</td>
<td>Professionals suggest children perceive mental health as being 'different'.</td>
<td>Regular emergence of 'difference' suggests that the interview framework needs to consider the words used by children/parents to identify this concept and to establish its importance with them. Also to consider participants' experiences of mental health needs and problems, both for themselves and for others.</td>
</tr>
<tr>
<td>4</td>
<td>Children's responses can be influenced by experiences communicated by adults.</td>
<td>It may be difficult to separate adult's experiences from children's responses. Parents/carers should be given a similar set of questions to children, in order to examine interplay and meanings for the two groups.</td>
</tr>
<tr>
<td>5</td>
<td>Stigma can evoke feelings of guilt, 'shame', 'failure'.</td>
<td>The schedule should include questions related to how the child/parent/carer may perceive mental health and stigma, and their experience of seeking help.</td>
</tr>
<tr>
<td>Theme</td>
<td>Considerations from analysis</td>
<td>Implications for the interview schedule</td>
</tr>
<tr>
<td>-------</td>
<td>-----------------------------</td>
<td>----------------------------------------</td>
</tr>
<tr>
<td>10</td>
<td>Individual and societal attitudes can contribute to mental health problems in children.</td>
<td>Interview schedule to include questions around the cause of mental health problems in children, and experience of mental health problems in self and others.</td>
</tr>
<tr>
<td>10</td>
<td>Lack of knowledge and understanding contributes to the severity of mental health need, including being discriminated against and blamed for the problems.</td>
<td>Interview questions to explore knowledge about mental health and feelings about being discriminated against or blamed. Researcher needs to ensure that the emphasis of the questions in the schedule do not elicit feelings of blame or discrimination on the part of the child or parent/carer.</td>
</tr>
<tr>
<td>6</td>
<td>Parents/carers and children can be discouraged from seeking help due to anxiety, previous experiences and blame.</td>
<td>Interview schedule should include questions around the meaning of seeking help, expectations of services and what participants think can help them with their problems.</td>
</tr>
</tbody>
</table>
4.10 The research procedure: pilot study

The study was undertaken with children aged five to eleven years following their first referral to CAMHS, and with their parents and carers, using the interview process and semi-structured interview tools outlined in Section 4.9. Prior to commencing the main study, it was deemed necessary to pilot the interview process, tools and schedules with five children and their parents/carers in order to make final adjustments before proceeding with the main study. The sampling and recruitment process were the same as those determined for the main study, and can be found in Sections 4.11.2 and 4.11.3.

The pilot study was undertaken in order to examine the following issues related to the research process:

- Ensure that the pre-interview information and discussion are appropriate.
- Observe for and clarify emergence of possible anxieties experienced by the participants, therefore, increasing informed choice and participation.
- Ensure that the language used during the interviews is age appropriate and locally determined.
- Consider the appropriateness of techniques used to engage children in the interviews, i.e. the story, games and activities.
- Consideration of any images used within the interviews, ensuring that they are non-specific, non-stigmatising characters.
- Examination of the interviewer/participant relationship, as both children and parents/carers may find mental health a difficult subject to talk about.
- Consideration of how the questions are framed and delivered to ensure a non-stigmatising, non-blaming approach.
- Involvement of the child and parent in determining the most appropriate place for the interviews.
• Ensure that children and parents are able to be seen separately, alternatively consider the dynamics of being interviewed in the same room.

• Ask children and families about their opinions of techniques used.

Following each set of interviews, the above issues were considered and notes were made. The resulting implications identified in the pilot study are described in the following section.

4.10.1 Pilot study implications for the main study

The interviews undertaken with five sets of children and their parents/carers in the pilot study were considered in relation to the aspects outlined in Section 4.10, and did not require any immediate or substantial areas for change. Both children and parents/carers were fully engaged in the process, and seemed comfortable with the explanations and information. The interview schedules facilitated the exploration of the research questions, and all children said they enjoyed the story approach. The only two emerging implications arising from the considerations set out in Section 4.10 above, related to the following:

**Implication 1:** Although parents/carers had previously consented to the interviews they had often forgotten the purpose of the study by the time of the interview. In order to reiterate the purpose of the study, an appointment confirmation letter was sent to participants (Appendix 12).

**Implication 2:** On some occasions children struggled to identify the feelings on the flash cards, and a couple of children wanted to draw additional feelings that they could not find in the selection. In order to make the feeling cards more accessible to children, a crib sheet with words associated to the feelings was designed (Appendix 13) and also some blank laminated feeling faces (which used the same outline as the feelings cards presented in Appendix 7), so that children could design their own.
As these adjustments were minor, and were not considered to affect the content of the data collected, the data obtained from the first five sets of interviews was subsequently included in the data set for the main study.

4.11 The research procedure: main study

The following section presents the setting, target population and sampling process of the main study, followed by the descriptive characteristics of the sample groups. The framework for recruitment and the interview process are then described. The main study utilised the research process, research tools and the semi-structured interview schedules presented and discussed in the earlier in this chapter, and included the minor adjustments arising from the pilot study.

4.11.1 The setting, local context and target population

This study was conducted in an area of the East Midlands, England. The location includes an inner-city area and several surrounding sub-urban communities.

The area has a population of around 311,000. The population is culturally diverse with a higher black and minority ethnic community than the national average. There are estimated to be 70,109 aged under 18 years living in the study area, and it is estimated that about 50% of these children are from black and minority ethnic groups (Oakley, 2004). The inner-city areas in the North and East have the greatest cultural diversity. There are large council estates in the West and South of the city, with mainly white residents. Within the study area there are also some affluent sub-urban areas. The inner-city and some of the semi-urban communities are identified as having higher levels of deprivation, which have attracted several targeted funding initiatives to meet the needs of both their adult and child populations.
There are two Primary Care Trusts (PCTs) and one Local Authority that commission services on behalf of their population. These partners, along with colleagues from Education, child health services and non-statutory agencies, work together to determine the strategic direction and development of child mental health services for the area. The model for delivery of the child and adolescent mental health services is closely aligned to the four tier model for CAMHS outlined by the Health Advisory Service (1995) (Appendix 1).

Over recent years there has been significant investment in the development of knowledge and capacity of services at Tier one (universal services), and in the multi-agency provision in the community for children with emerging mental health needs at Tier two.

The specialist CAMHS service is located at Tiers two to four. It provides a service across three Local Authority areas, including the area selected for this study, plus a semi-rural and a rural area. There are three community out-patient teams consisting of multi-disciplinary professionals and two specialist out-patient teams, one for children with Learning Disability, and one for young people who are looked after or involved in offending behaviour. At Tier three, there is a specialist day resource for children aged 11 and under, and at Tier four an in-patient facility for adolescents. This study will focus on the children referred for the first time to the community out-patient CAMHS teams responsible for the areas outlined above.

Children can be referred to the service through a number of routes. General Practitioners (GPs) tend to be the most regular referrers, but referrals can come from the multi-agency teams which are located at Tier two, Paediatricians, or from Educational Psychologists. The criteria for referral are centred around those children whose mental health problems are becoming persistent, are impacting significantly on
the child’s quality of life, or where there is the possibility of an underlying mental health disorder. Lower level mental health needs are usually assessed and treated by the multi-agency teams in the community or by practitioners in Tier one, with support from the specialist CAMHS teams.

Children are referred to the service by a letter outlining the mental health concerns. The referral is discussed at a multi-disciplinary CAMHS meeting and the need for a service is determined. If children are deemed appropriate to receive a service from specialist CAMHS, they will be sent an appointment for assessment.

It is difficult to give a precise figure for the level of child and adolescent mental health need in the study location, as no accurate figures have been collected locally. Based on the research undertaken by Kurtz (1996) on projected prevalence at each tier of service, the possible levels of need are outlined in Table 4.4.

Table 4.4: Level of mental health need and projected prevalence by tier (adapted from Kurtz, 1996)

<table>
<thead>
<tr>
<th>Tier of CAMHS Provision</th>
<th>% expected (Kurtz, 1996)</th>
<th>Projection for the Study Area</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Child Population</td>
<td>n= 70,109</td>
<td>n= 70,109</td>
</tr>
<tr>
<td>(Under the age of 18)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tier 1</td>
<td>15%</td>
<td>n= 10,516</td>
</tr>
<tr>
<td>Tier 2</td>
<td>7%</td>
<td>n= 4,908</td>
</tr>
<tr>
<td>Tier 3</td>
<td>1.85%</td>
<td>n= 1,297</td>
</tr>
<tr>
<td>Tier 4</td>
<td>0.075%</td>
<td>n = 52</td>
</tr>
<tr>
<td>In-patients</td>
<td>0.02%</td>
<td>n = 14</td>
</tr>
</tbody>
</table>
A local needs assessment for the area (Oakley, 2004) suggested that referral rates to CAMHS would be significantly higher in the inner-city, than in the surrounding semi-rural and rural areas. This was found to be true for one of the PCT areas responsible for commissioning CAMHS, with a referral rate of 10 per 1000, whereas in the other PCT area the referral rate was 4.9 per 1000. The reason for the lower referral rate was not determined, however, the majority of people from black and minority ethnic groups were living within this PCT’s boundaries and it is possible they may not have accessed CAMHS. This could be due to a number of reasons, including services not being culturally sensitive and competent (Malek, 2004), therefore perceived not to be appropriate to meet the needs of minority ethnic groups.

The target geographical area is small, yet there are high rates of referrals, enabling the increased possibility of successful recruitment within a manageable timeframe and limited requirement for travel. This study frame would allow the generation of a representative sample group from a range of social circumstances, particularly as CAMHS was conversant with the research protocol and staff were willing to assist in the recruitment of the sample group on behalf of the researcher.

4.11.2 Sampling strategy

The sampling strategy this research employed a non-probability, purposive sampling methodology (Patton, 2002; Ritchie et al, 2003). In qualitative research, most studies tend to opt for a non-probability sample, as the intention is not to select a particular sample in order to give a true representation of the population; this is known as probability sampling. Probability approaches are generally used in quantitative research to produce a statistically representative sample (Ritchie et al, 2003). Qualitative research usually adopts non-probability sampling, where participants are intentionally selected to reflect particular features, or to represent certain groups.
There are many approaches to non-probability sampling. The three main sampling approaches are purposive, theoretical and opportunistic sampling (Bryman, 2001; Patton, 2002). Purposive sampling allows the selection of participants based on specific criteria, in order to answer a particular research question. Theoretical sampling enables the selection of people who might assist in the testing of a particular theoretical construct, whilst opportunistic sampling allows the researcher to take advantage of opportunities when choosing participants (Patton, 2002).

As the intention of this research was to understand the meanings of mental health and stigma held by primary school aged children and their parents/carers, the purposive approach employed was to select participants from a homogenous group, using particular criteria. The study aimed to develop an understanding of perceptions of children with mental health needs. Employing homogenous sampling techniques would enable the selection of a group which should yield data that gives a detailed picture of a particular phenomenon. Ritchie et al (2003) suggest that such an approach should allow for a comprehensive exploration of social processes and context. This is chiefly suited to a small-scale, in-depth study. Utilising such an approach is particularly relevant to this study, as it enables the exploration of the phenomena related to mental health and stigma, and allows for the examination of context, thus embracing the philosophical perspectives chosen to steer the study.

The sampling strategy criteria were set in order to facilitate the selection of participants who would enable the consideration of the research questions, and the principal aims and objectives of the study. The selection criteria for the sample are shown in Box 4.1.
Box 4.1: Purposive sampling criteria for the research

1) Children in the sample must be aged between five and eleven years of age
2) Children are not eligible to attend secondary school
3) Children have been referred to the specialist CAMHS for the first time
4) Children should not have attended CAMHS for their first appointment, before the research interview
5) Parents/carers related to the children, who consent to participate in the research, will form the adult sample group

The selection criteria were chosen to ensure that key elements of the research topic were covered, and to enable exploration of the particular aspects of the research questions. Selection criteria two, three and four were chosen to try to ensure that participants were not influenced by the views of an 'older' and more developed view of mental health, or by having attended the service already, which may have altered the emphasis of their perceptions.

The aim of the research was to recruit 20 children to the sample, who had been referred consecutively to the specialist CAMHS teams, as well as their parents/carers, who consented to participate. The sample was purposeful in that it targeted a specific group, according to the selection criteria. A consecutive group was chosen to ensure that one particular feature of the child or family was not selected over another, thus allowing for representation of the families accessing the service. However, the sampling strategy was flexible, as it was based on the acquisition of consent, or 'opting-in' of participants. Issues around consent will be discussed later in this chapter (Section 4.13.2). The parent/carer group consisted of 23 parents/carers related to the
children. Although there was the potential for a larger group, if all related parents/carers had wished to participate, some parents declined to take part.

In the context of the IPA framework, this sample group is high. Smith (2004) suggests that IPA can be undertaken with very small samples. However, it was also important to achieve a state of saturation in the data, i.e. so that no new themes emerged (Morse, 1995). As each interview was analysed in sequence, it was possible to identify at what point saturation occurred. It became apparent that saturation had occurred at around 15 interviews; however, continuation to 20 participant family groups ensured that this was verified.

4.11.3 Recruitment procedure

In order to access the sample from the target population, a meeting was held with the two multi-disciplinary CAMHS teams to discuss the research protocol, and to identify the most appropriate approach to recruit the sample. The relevance of the research and the anticipated benefits to children's mental health on a national and local level were also highlighted. The teams authorised the study to proceed and offered the services of their administrator to invite families to participate in the research. The teams were particularly keen to use this approach to ensure that confidentiality was not breached. This approach ensured that the researcher did not have sight of the non-consenting families details. As the research was centred on a potentially sensitive subject, this offered protection to the families not wishing to participate.

The CAMHS team administrator selected the children to participate based on the selection criteria outlined in Box 4.1, following a discussion of the referral at the CAMHS team meeting, and prioritisation of the referral for assessment by the CAMHS team. The administrator would then send a letter to the parents/carers outlining the
purpose of the research (Appendix 14) together with a consent form (Appendix 15). Also included was a letter to the children, which was left open so that parents/carers could see the contents (Appendix 16), thus enabling them to decide how they discussed the research with the children. The letter to children was devised using age-appropriate language, with pictures communicating certain aspects of the research and the procedure. If the parents/carers decided to participate, they would complete the attached reply form and return it to the administrator, in the pre-paid addressed envelope provided.

When the parents/carers had consented in writing, the researcher was given details of the family, who were then contacted by telephone to arrange an appointment. Subsequently, a letter was sent to confirm the details with the parent/carer (Appendix 12). The confirmation letter was phrased in such a way as to reassure parents about the research and to encourage attendance for the interview. Using such an approach seems to have assisted in the very low non-participation rate, with only two families not being present for the appointment. On the occasions where telephone details of the family were not available the researcher sent an appointment letter, and the family were asked to contact the researcher if the appointment was not convenient.

A total of 72 families were invited for interview, selected from consecutive referrals to the service, meeting the sampling criteria, over a period of three and a half years. Out of the 72 invitations, 28 parents/carers (38.8%) consented to participate. Three of the interviews were discarded due to the families already having had some previous contact with CAMHS; three families did not respond to telephone calls to make appointments and two were not available on the appointment date. This resulted in a final sample group of 20 children with their associated parent/carers (n=23). It is difficult to speculate on the reasons for not wishing to participate; however, it may be plausible to suggest that this could have been related to either personal choice or the
sensitive nature of the research subject. In addition, the families were given the choice to opt-in to the research, for ethical reasons. Sometimes families can be reluctant to opt-in to research as they can feel under pressure from every day issues, or they feel they do not have the time to participate. Given that there are high levels of stigma experienced in the general population (presented in Chapter 2), these feelings may be more intense amongst those families seeking services for mental health problems.

4.11.4 The semi-structured interview procedure

The procedure for conducting the semi-structured interviews, following recruitment of the participants included all aspects discussed earlier in this chapter, which incorporated the approaches and techniques identified from the focus group findings. The interview procedure followed the framework presented in Figure 4.0. The interviews lasted between 45 minutes and one hour with each participant, and they were audio recorded on a conference recorder and transcribed in full. Recording and transcription within the study are presented in more detail in Sections 4.14 and 4.15, at the end of this chapter.
Figure 4.0: Procedure framework for undertaking semi-structured interviews

**Stage 1: consent and understanding of research**
- Discussion around the aims and purpose of the research study with participants
- Information to be given about the interviewer
- Opportunity for questions around the study
- Determination of rules, boundaries and expectations of the interview process for both participants and researcher
- Confirmation of anonymity, confidentiality and consent to participate

Participants may choose not to continue

Stage 2: procedure during interviews
- Familiarity with research tools and recording equipment
- Reassurance of confidentiality around recordings and transcripts following interview
- Participants to be interviewed separately
- Discussion around role of any other parties that may wish to attend the interviews e.g. parent attending child interview
- Confirmation of approximate time commitment for the interview

Participants wish to continue

Stage 3: completion of interviews
- Following the interview, participants to be thanked for their time
- Children participating to be given certificate for helping
- Dissemination of findings to be discussed with participants
- Participants to be asked if they wish to receive a report
- Timescale for completion of the study advised
- Participants to be given opportunity to ask any final questions

Terminate interview and thank participants for their time
4.11.5 The framework for describing the characteristics of the sample.

Twenty children (n=20) and their consenting parents/carers participated in the research (n=23). Two sets of children (n=4) in the group were siblings, both referred to the service at the same time, and were interviewed separately.

To enable an illustration of this sample group, basic descriptive information about the participants was collected by a specifically designed pro-forma (Appendix 17). The questions were integrated into the interviews undertaken with the parents/carers and the child, and collated post-appointment. As the researcher did not have access to information from the CAMHS team or the child’s case notes, it was necessary to collect information in this way. Descriptive information was only collected in relation to those who had consented to participate in the study, thus protecting families who wished to opt out.

In addition, further information was collected from parents/carers about their children, to describe their characteristics in relation to the level of perceived mental health need. In order to facilitate this, parents/carers were asked to complete the Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997) (Appendix 18), which was sent to them prior to the appointment with their confirmation letter and collected from them at the interview. The SDQ and the descriptive data will be presented and discussed in Section 4.11.6 of this chapter.

The descriptive data was analysed using SPSS package Version 12.0 (Statistical Package for the Social Sciences). Although it would have been interesting to compare the characteristics of sample groups, the exclusive intention of the data collection was to establish a profile of the children and parents/carers participating in this qualitative study. Due to this principal aim of the research, and the sample being small in size, it
would have been of limited relevance to perform a statistical analysis of the data. However, the basic descriptive data should enable the reader to develop a more detailed picture of the sample and on the emerging interpretation of the findings presented in Chapter Four. The characteristics of the children and parents/carers participating in the research are described in following the sections (4.11.6 and 4.11.7).

4.11.6 Descriptive characteristics of the child participants

Descriptive characteristics related to the age, gender and ethnicity of the children in the sample were collected during the interview and are discussed in this section. In addition, information related to the number of siblings living in the family home was collected to illustrate the different settings in which the children lived. The characteristics of the children participating (n=20) in the study are presented in Table 4.5.

The children in the sample were distributed fairly evenly across the age range selected for the study, with 45% of children in the 5-8 year age band and 55% in the 9-11 years age band. The mean age of the participating children was 8.1 years. The gender distribution was dominated by males, with only four of the group being female (20%). Green et al (2005), in their survey of child mental health disorders in Great Britain, found that boys had a higher prevalence of any disorder (10.2%) than girls (5.1%). Whilst the percentage of disorder in boys is almost double, it would not account for the difference in the gender of the sample group.
### Table 4.5: Descriptive characteristics of the child participant group (n=20)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td><strong>Age (range 5-11 years)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5-8 years</td>
<td>9</td>
<td>45</td>
</tr>
<tr>
<td>9-11 years</td>
<td>11</td>
<td>55</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>16</td>
<td>80</td>
</tr>
<tr>
<td>Female</td>
<td>4</td>
<td>20</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White British</td>
<td>16</td>
<td>80</td>
</tr>
<tr>
<td>African Caribbean/White British</td>
<td>3</td>
<td>15</td>
</tr>
<tr>
<td>Indian/White European</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td><strong>Siblings living at home</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Zero siblings</td>
<td>4</td>
<td>20</td>
</tr>
<tr>
<td>1 sibling</td>
<td>12</td>
<td>60</td>
</tr>
<tr>
<td>2 siblings</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>3 siblings</td>
<td>2</td>
<td>10</td>
</tr>
</tbody>
</table>

The representation of black and minority ethnic groups within the sample does not seem to reflect the characteristics of the localities included in the study, described in Section 4.10.3. This could be for a number of reasons, including the possibility that there is a lower rate of black and minority ethnic groups wishing to access or being referred to the child and adolescent mental health service, or not wishing to participate in the study for reasons of personal choice, or associated stigma. In the Census 2001,
data related to the general population indicated that the white population was at 92.1% and the mixed heritage population, being the fourth largest group, was at 1.2% (National Statistics, 2001). Thus, at 20% (n=4) of the overall sample, the children of a mixed heritage do show a higher representation in comparison to the general population. It is difficult to ascertain the characteristics of those invited who did not participate in the study, as the researcher did not have access to data regarding those not wishing to participate, for confidentially purposes. There are, nevertheless, a number of ethnic groups not represented. It should be noted, however, that the aim of the study was not to examine the perceptions of the children in relation to gender or ethnicity.

The majority (60%: n=12) of the children in the sample lived with at least one other sibling in the family home, with 40% living with two or more siblings at home. The range in the sample included the participant being an only child (n=4) to living as part of a sibling group of four. Green et al (2005) found that 26% of children with conduct disorders lived in a household with large sibling groups of four or more, whilst children with emotional disorders tend to live in a household of three or more siblings.

4.11.7 Descriptive characteristics of the perceived mental health needs of the child participant group

The data collected via the Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997) was gathered solely for the purpose of illustration, in order to place the children of this study in the context of previous studies that have taken place in the general population (discussed in Chapter 2). The SDQ was chosen for this purpose at it is a commonly used and validated screening questionnaire (Goodman et al, 2000)
The Strengths and Difficulties Questionnaire (SDQ) is a brief behavioural screening questionnaire which includes questions about 25 attributes, some from a positive and others from a negative perspective. The 25 items are divided between five scales of five items each. The five scales enable the generalising of scores for conduct, hyperactivity, emotional problems, peer problems, and pro-social behaviour; all but the last are summed to generate a total difficulties score (Goodman, 1997). There are three versions: one for self-reporting in ages 11-17, and two for the parent or teacher to complete, related to ages 4-10 and 11-17. In this case only the parent report for ages 4-10 was used (Appendix 18).

The total SDQ scores can be classified according to established norms (cut-offs), which define the level of 'caseness', i.e. whether or not the score would fall into the realms of producing a possible clinical diagnosis for the child. The scores are then grouped within three domains – normal, borderline and abnormal. The scores can also be used to demonstrate which areas the children's needs might be related to. Scores falling into the abnormal score band would be considered likely to identify probable 'cases' for mental health disorders. Goodman (1997 and 1999) undertook several studies using the SDQ and found that approximately 10% of a community sample, i.e. those not perceived as having a mental health need, would fall into the abnormal band, with a further 10% falling into the borderline band. It has been suggested that prediction of mental health disorder is more reliable when employing multi-informants (Goodman et al, 2000). However, in this study the purpose was to portray the characteristics of the mental health needs of the child participants, from the parents'/carers' perspective. The criteria for interpreting the scores (Goodman, 1997) can be found in Appendix 18.
Table 4.6: Description of the level of mental health need of the child participant group, assessed via the SDQ (Goodman, 1997)

<table>
<thead>
<tr>
<th>Band</th>
<th>Total Difficulties</th>
<th>Hyperactivity Problems</th>
<th>Emotional Problems</th>
<th>Conduct Problems</th>
<th>Peer Problems</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abnormal</td>
<td>85% (n=17)</td>
<td>70% (n=14)</td>
<td>60% (n=12)</td>
<td>55% (n=11)</td>
<td>75% (n=15)</td>
</tr>
<tr>
<td>Borderline</td>
<td>5% (n=1)</td>
<td>5% (n=1)</td>
<td>20% (n=4)</td>
<td>25% (n=11)</td>
<td>5% (n=1)</td>
</tr>
<tr>
<td>Normal</td>
<td>10% (n=2)</td>
<td>25% (n=5)</td>
<td>20% (n=4)</td>
<td>20% (n=4)</td>
<td>20% (n=4)</td>
</tr>
</tbody>
</table>

In Table 4.6 above, children were found to have high rates of mental health problems reported by parents/carers, at a rate of 85% (n=17) of the child group falling into the abnormal category. This category could indicate the probability of the presence of a diagnosable mental disorder. When compared to prevalence studies in the general child population for this age group determined by Meltzer et al (2000), which was established at a rate of 8.2%, it would suggest that parents/carers were accessing specialist CAMHS appropriately, as their children were experiencing high levels of mental health need. The higher levels of need in children seem to be located in the Peer Relationship problems and Hyperactivity categories, followed by the Emotional and Conduct problems categories.

Of interest is that a small percentage (10%: n=2) of the children were reported by their parents/carers to have needs within the normal range, and 5% (n=1) at a borderline level. This is supported by the work of Kurtz (1996), who suggested that 15% of mental health needs in children were appropriate for Tier one intervention.
Although the SDQ scores suggest that 15% of children may not have a diagnosable mental health disorder, all parents/carers interviewed established that they had sought help from specialist CAMHS, as they considered that their children had mental health needs. The parents'/carers' reasons for accessing help will be described in more depth, within the findings of the main part of the study (Chapter 5).

The data was also analysed in relation to the number of problem areas the children were perceived by parents/carers to be experiencing, in order to demonstrate the complexity of their mental health problems (often defined as co-morbidity of more than one type of problem). Table 4.7 presents an illustration of the complexity of mental health needs, within the sample group.

Table 4.7: Illustration of children assessed to be in cumulative 'abnormal bands' indicating the presence of mental disorder, via the SDQ (Goodman, 1997)

<table>
<thead>
<tr>
<th>Number of Bands in which children scored 'abnormal'</th>
<th>Number of Children (n=20)</th>
<th>Percentage</th>
<th>Cumulative Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Four bands</td>
<td>n=8</td>
<td>40%</td>
<td>40%</td>
</tr>
<tr>
<td>Three bands</td>
<td>n=4</td>
<td>20%</td>
<td>60%</td>
</tr>
<tr>
<td>Two bands</td>
<td>n=3</td>
<td>15%</td>
<td>75%</td>
</tr>
<tr>
<td>One band</td>
<td>n=2</td>
<td>15%</td>
<td>90%</td>
</tr>
<tr>
<td>Zero</td>
<td>n=2</td>
<td>10%</td>
<td>100%</td>
</tr>
</tbody>
</table>

As can be seen from Table 4.7, the rate of children perceived as having one or more problem areas was 90% (n=18). Over half (60%: n=12) of the children participating in the research had three or more problem areas. The combination of the descriptive
data presented in Tables 4.6 and 4.7 indicates that the children in this sample experienced high levels of mental health problems in comparison to the general population. This illustrates the distinctiveness of the sample group and its potential to contribute new information to knowledge around mental health and stigma. Such knowledge will contrast with the research that has been undertaken so far, with children in the community, who have not been identified as having mental health needs.

4.11.8 Descriptive characteristics of the parent/carer participants

The descriptive characteristics of the parent/carer group illustrate the diverse social backgrounds of the sample (presented in Table 4.8 overleaf).

The age range of the parent/carers was between 30 to 56 years old. This included three grandparents. The majority of parents/carers were aged between 30 and 40 years of age (n=14), and five participants were aged between 41 and 50 years. Only one participant was aged over 51 years. Of interest is the mature age of the parent/carers who consented to take part in the research. Given the young age of the children in the sample, the parents/carers could have been from a younger age group; however, it is not possible to draw conclusions about this, as no data was available regarding those who declined to take part in the study.

As illustrated in Table 4.8, children lived in a range of settings, which included being cared for by grandparents (n=3). Out of the 23 parents/carers, four couples consented to be interviewed. Although 12 of the group were married or co-habiting, the remainder of the participants' partners declined to be interviewed. Ten of the parents/carers were single, either never having been married, or having been divorced or separated.
Table 4.8: Descriptive characteristics of the parent/carer participant group (n=23)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Number $n$</th>
<th>Percentage %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>6</td>
<td>26.08</td>
</tr>
<tr>
<td>Female</td>
<td>17</td>
<td>73.92</td>
</tr>
<tr>
<td>Age (range 30-56 years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>30 – 40 years</td>
<td>14</td>
<td>60.86</td>
</tr>
<tr>
<td>41 – 50 years</td>
<td>5</td>
<td>21.73</td>
</tr>
<tr>
<td>51+</td>
<td>4</td>
<td>17.39</td>
</tr>
<tr>
<td>Relationship to Child</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>15</td>
<td>65.2</td>
</tr>
<tr>
<td>Father</td>
<td>4</td>
<td>17.39</td>
</tr>
<tr>
<td>Grandmother</td>
<td>2</td>
<td>8.69</td>
</tr>
<tr>
<td>Grandfather</td>
<td>1</td>
<td>4.34</td>
</tr>
<tr>
<td>Non-biological father</td>
<td>1</td>
<td>4.34</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White British</td>
<td>22</td>
<td>95.65</td>
</tr>
<tr>
<td>East Indian</td>
<td>1</td>
<td>4.34</td>
</tr>
<tr>
<td>Employment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Senior management/executive</td>
<td>8</td>
<td>34.78</td>
</tr>
<tr>
<td>Homemaker</td>
<td>5</td>
<td>21.73</td>
</tr>
<tr>
<td>Care/public sector</td>
<td>5</td>
<td>21.73</td>
</tr>
<tr>
<td>Self-employed</td>
<td>3</td>
<td>13.04</td>
</tr>
<tr>
<td>Retail</td>
<td>2</td>
<td>8.69</td>
</tr>
</tbody>
</table>
When the data was combined, it accounted for 43.46% of the children living with lone parents; this is higher than the national average, which the 2001 Census determined to be 22% (National Statistics, 2001). All of the single parents were female; this included divorced and separated parents. The percentage of married participants was 52.17% (n=12). This is higher than the national percentage which the Census determined to be 44.8% (ibid). The rate of single, divorced and separated people was determined, by the census, to be at 46.9% in 2001.

Again, the representation of black and minority ethnic groups was not very diverse, with 95.65% of the parent/carer participants being white British (n=22) and 4.34% being East Indian (n=1). The parents/carers of children in the sample from other ethnic groups had either left the family home or declined to participate. Parents'/carers' employment status included a range of occupations, the most frequent being senior management or executive positions (n=8), working in the public sector (n=5) and homemakers (n=5). The remaining participants were self-employed or worked in retail (n=5).

4.13 Ethical considerations

Conducting any research involves the consideration of the intrinsic or fundamental values asserted, in relation to the rights of those participating, and the possible consequences and actions on the part of the researcher or the research (Homan, 1991). These issues are especially relevant where research is conducted with human subjects. The rigour of the ethics employed has a bearing on the rigour of the methodology and procedure which guides the study. Even the best designed research study can be dissented, where there is not adequate consideration of the underpinning ethics (Hancock, 2000). Where such instances occur, research outcomes can fail to add to meaningful knowledge to theory or evidence base.
The role of participants differs within qualitative research to that of the ‘subject’ within quantitative studies. Methodologies and techniques employed in qualitative research can often enable participants to investigate personal realms that had not previously been explored. In this respect, the aim of meticulous consideration of ethics is to ensure the safeguarding and protection of those taking part in the research. In addition, with specific relevance to this study, is the consideration of an extended view of ethics, making changes to attitudes, beliefs or organisational processes (Willig, 2000). The exploration of meaning for participants, in relation to children's mental health, aims to assist in making suggestions for improvements to approaches and systems. This potential outcome, therefore, aims to deliver positive benefits for the participants and other members of society, in the long term.

Specific ethical issues arise in relation to this study. The three groups of participants involved will have some similar and some different requirements from a robust ethical framework. Some issues are particularly pertinent in relation to the young age of the children and the sensitivity of the research topic. When establishing the ethical implications for any participant, regardless of age, specific principles must be considered (Lindsay, 2000). These principles relate to:

- Respect for the person's rights and dignity
- Their level of competence and understanding
- The responsibility to the participants, in relation to being fully informed
- The integrity of the research, in terms of openness and transparency

In addition, are the particular considerations which relate to children participating in the study, which include the need to safeguard them and to ensure that they are as conversant with the process as possible, thus avoiding them becoming unwitting participants (Alderson, 2004).
The following sections will begin with presenting the process for ethical approval and will proceed to examine particular ethical considerations in relation to the research participants in general, then more specifically for the child participants involved.

4.13.1 Ethical approval

The research proposal and ethical approval form were submitted to and approved by the Local Research Ethics Committee (LREC), with some minor adjustments. The committee stated that the study was an important piece of research, however, some points of clarity were raised in relation to adjustments to the information available and consent for the participating children.

In response to the first point of clarity, a letter was prepared for children, which included pictures and visual prompts (Appendix 16). The second point of clarity related to consent in children. The main format of obtaining consent for the children was through their parents, however, further discussion around the research was undertaken with the child at the beginning of the interview process. They were informed that if they did not wish to participate then they could withdraw, without any implications for them. All children gave verbal consent which was audio recorded, and none of them decided to withdraw from the interview, once it had commenced.

In addition to the LREC approval, written approval was also sought and confirmed from CAMHS and the NHS Trust.

4.13.2 Informed consent

Obtaining informed consent from research participants is imperative. Ensuring they are given good quality information on which to make a choice about participating, encapsulates a number of considerations. Being informed means having access to a
full description of the research, its aims and benefits, how the data might be used, and the role of the participants within it. In addition, there is a need to ensure that the participants understand that this is entirely voluntary, and that they can withdraw at any time, without any prejudice to them or the services they might receive in the future (Lewis, 2003).

In this study, families were sent invitation letters which contained a full description of the study, the issues highlighted above, and a consent form (Appendices 14, 15 and 16). Two aspects related to informed consent required closer consideration. The first highlighted the need for consent to be an ongoing throughout the interview procedure, and the second being related to giving consent for their children to participate.

The first issue relates to the decision of the researcher to incorporate the continuous evaluation of informed and ongoing consent in the research process. This was applied to both adults and children. Lewis (2003) suggested that informed consent should be continuously assessed and sometimes renegotiated. Although participants gave their written consent prior to the interview appointment, it was felt that the concept of consent should not be assumed to be absolute. In this respect, all participants, including those who took part in the focus group, were reminded of the aims of the study at the beginning of the interview process, the procedure and their right to withdraw at anytime. Consequently, they were supported to give consent for a second time, prior to commencing the interviews. In combination with this, was the need for the researcher to continuously review and monitor the process of the interview and to terminate the proceedings if they considered the participant to be anxious, distressed or vulnerable.

Whilst all of these considerations apply to children, there are some specific issues that should be applied to obtaining consent. Consent is a controversial issue in relation to
research with children. Whilst legally, parents can give consent for their children to take part in the study (Alderson, 2004), the main concern is to ensure that they have the choice to participate and that they understand the process and what is required of them (Grieg and Taylor, 1999). As outlined in the Children Act (HM Government, 2004), children and young people under the age of sixteen can give consent for treatment, if they are considered to be Gillick competent. That is, if they are considered to have sufficient understanding and intelligence to consider what is being proposed. However, the youngest age at which this is possible has not been established. Guidance on children's participation in non-therapeutic research suggests that the research should only be undertaken where 'the risk to the child is negligible' (Dimmond, 1996: 177). The particular concern within this research was that, whilst children's views are important to acquire, the detection of negligible risk may not be easy. The topic within this study has already been established as a sensitive one. When this is combined with the possibility of the children having a mental health problem, the process has the potential to enhance vulnerabilities. As a response to such concerns, particular skills and processes were adopted in this study to ensure that children were safeguarded.

In order to satisfy these concerns, the process of 'assent' was adopted. Assent refers to the child's agreement to participate, where consent has been given (in this case the consent of the parent or carer). Lewis (2002) suggests this is a beneficial approach when researching younger or vulnerable children. In order to satisfy the assent, four points were clarified prior to commencement of the interview:

- Information about participating
- Knowledge about the right to withdraw
- The child's role
- The intended outcomes of the research
Just as these points were presented to adult participants, they were also incorporated into the process with children. In addition, the specific skills of the researcher in relation to communication with and assessment of children were applied. It must be acknowledged that, in light of the age of the children and the topic under research, such skills are vital in ensuring the protection of children. If a child had become distressed during the interviews, then the interview would have been terminated and the necessary steps of discussion with the parents/carers and the child implemented.

4.13.3 Anonymity, confidentiality and protection from harm

Points of anonymity and confidentiality were made clear to participants. In respect of anonymity, participants were reassured both before and on commencement of the interview that any means of identification would be removed from the data, and that no-one but the researcher would have information to their details. They were also reassured that transcribers would not have access to information about them, that names and address details would be removed from data, and that they would be given a pseudonym. Following transcription and analysis, they were advised that recordings would be destroyed and that transcripts would be kept securely.

‘Confidentiality’ means avoiding the attribution of comments, in reports or presentations which can be linked to participants (Lewis, 2003). This can be either through direct attribution, where information is linked to a role or name, or indirectly, by a collection of characteristics which might identify an individual. Care was taken to ensure that any data presented in this research could not be directly or indirectly attributed to its originator. Confidentiality can be difficult where data collection takes place in a group; however, as discussed early in this chapter, excerpts used to illustrate the findings from the focus group do not identify the profession of the participants.
A more specific aspect of confidentiality which can be difficult to sustain, is where the researcher discovers information or observes something which might suggest the child is at risk either to himself, to others, or by others. In this respect the information must be imparted to the appropriate authorities. In order to follow child protection policies, both children and adults were informed that confidentiality could not be guaranteed and that information of this nature would need to be duly reported.

Another issue related to confidentiality/privacy regarding children is the consideration of whether parents/carers should be present during the interview with the child (Lewis, 2002). In this study it was preferable for children and parents/carers to be interviewed separately. The procedure was for parents/carers to be interviewed first, followed by the child. The process of being interviewed alone was explained to participants, and in all but one case, this was granted. The adults were re-assured of the researcher’s skills and qualifications, and verification of current nurse registration and university identification were provided to the participants. Where the parent/carer wished to be present, then the boundaries of their presence were set, in order to have minimal impact on the interview.

4.13.4 Vulnerable participants and protection from sensitivities

Consideration of the sensitivities of some research topics and the possibility of uncovering difficult or painful experiences must be acknowledged within this study. As addressed in the earlier section on consent, it is necessary for the researcher to employ skills to detect signs of discomfort. If such evidence of discomfort is identified, then the role of the researcher should be to stop the interview and check whether the participant wishes to continue (Lewis, 2003). Such an instance was detected with one child participating in this study, and the interview was initially stopped. However, after
he was offered some reassurance, he indicated that he wished to continue. The researcher remained after the interview in order to respond to anxieties and to enable the child to de-brief and return to everyday conversation. Lewis (2003) suggests that it should be made clear to participants that the researcher's role is not to counsel or advise. However, in this study the researcher was equipped with information about local services, should the necessity arise.

4.13.5 Protection of the researcher

The final consideration relates to the safety of the researcher (Social Research Association, 2001). As this study involved appointments in the participants' homes, sometimes in the early evening, protocols were put in place to ensure safety. On attendance, the researcher's personal assistant was informed of the address, and expected duration of the interview. The personal assistant was informed of the researcher's arrival at the venue and again on exit from the appointment. The personal assistant was briefed to call the researcher's mobile phone, if they had not been contacted within 15 minutes after the expected conclusion of the interview. If they did not receive a response from the researcher, then they were instructed to contact the police, giving details of the address. The researcher also conducted a risk assessment of the venue before and on entering. On one occasion, when the door was answered by a youth who was curt in his responses, the researcher decided to immediately terminate the appointment. On the whole, participants were very welcoming, accommodating and a pleasure to work with.

4.14 Recording the interviews

In order to carry out a thorough analysis of the data within the IPA framework, interviews were audio recorded. IPA and other qualitative methods of analysis require that data is transcribed 'verbatim' (Section 4.15) (Willig, 2000; Legard et al, 2003).
Alternative methods of manual recording such as field notes were considered not to be appropriate, as they would not facilitate the levels of analysis and interpretation required in IPA (Legard et al., 2003). Although video recording is another useful means of eliciting information, this was rejected on two counts. Firstly, using a video was thought to be too intrusive for families when talking about sensitive issues, and especially in respect of the children's young age. In addition, McCrum and Hughes (1998) suggest that it is important to minimise the impact of technology when trying to obtain rich material from children. They propose that the use of technology should be fully explained to children, but not influence material collected. Secondly, because the data required for IPA is around dialogue, then video recording, which could prove hard to transcribe especially with the added visual dimension, would not be appropriate for this research. In this respect, audio recording was considered to be more neutral and less intrusive. Willig (2000) suggests that, in order to ensure that being taped is a comfortable experience for the participants, a full explanation of why recording is necessary, and a demonstration of the equipment should reduce any anxieties. In order to combat inadvertent concerns for participants, an explanation of the need for recording and familiarity with the equipment was incorporated into the research procedure. Although it is not unusual for participants to refuse to be recorded (Smith, 2003), all participants agreed to the procedure, and appeared to be comfortable with the equipment during the interview. Participants were reassured that the tapes would be destroyed once the interviews had been transcribed.

The use of audio recording equipment allowed the researcher to devote all attentions to the conversation, whilst capturing information required. Such an approach is considered especially beneficial in enabling the interviewer to probe, clarify and follow-up on particular issues. Being able to concentrate on the interview process allowed the building of good rapport, initiation of eye contact and development of a more natural conversation. Smith (2003) offers a word of caution, however, suggesting that
audio recordings should not be 'reified', i.e. considered to represent the full account from the participant. It must be acknowledged that, although reflection was used within interviews, and the interviewer's dialogue was used as part of the data, the recording will not capture non-verbal communication in its entirety. In this respect, recordings can not be considered to be an entirely objective record, but a good way of capturing a rich verbal account.

4.15 Transcription of audio recordings

In order to undertake detailed analysis of the recorded data, it is necessary to make a permanent record through transcription (Pigeon and Henwood, 1996). The semi-structured interviews in this study were transcribed 'verbatim', that is the whole interview was transcribed, including the interviewer's questions, false starts, significant pauses, laughter and repetitions. This form of transcription is the convention within IPA (Smith, 2003). The level of transcription required in IPA is generally at a semantic level, rather than using the prosodic approach to transcription required in discourse or conversational analysis (Willig, 2000).

The audio tapes were transcribed by three administrators with experience of transcribing, who were reimbursed for their contribution. None of them had specific connections to this research. Each administrator was given training by the researcher before transcribing the recordings in full. The interviews were transcribed with a wide margin on either side, so that notes could be made during the analysis, and each line was numbered, in order to facilitate recording of key themes and concepts. An example of the transcription format is presented in Appendix 19.

Poland (1995) highlights that errors are frequently made during transcription, leading to the inadequate representation of the participants' views and experiences. The
quality of research outcomes can be influenced by the quality of the data, therefore, accuracy within transcription is paramount in increasing their validity and reliability. In order to prevent such possible challenges to transcription quality, the transcribers were under instruction to make transcripts in verbatim, discouraging any deliberate alteration or ‘tidying up’ of the data. Other such alterations or errors in data can be caused by accidental alteration or incorrect punctuation. The procedure employed to combat such errors or flaws was the review and correction of each transcript, in comparison to the original recordings. The researcher corrected the transcripts whilst listening to the tapes. Common errors arising were misinterpretation of the emphasis of dialogue and omission of certain words or phrases by mistake. A remedy for such occurrences was for the researcher and the transcribers to go through a recording together, so that the process and emphasis of the data could be discussed. Although the process of checking transcripts can be time consuming, it does form the first stage of the process of analysis in IPA (discussed in Section 4.16), therefore enables the researcher to become familiar with the transcripts as spoken, as well as with written dialogues.

4.16 Data Analysis

The IPA framework used throughout this study, contains an explicit data analysis strategy, which forms part of the overall methodology. Smith (2003) advocates that within IPA, the role of the researcher is to understand the contexts and complexities that meanings have for the participants. This involves the researcher engaging in an interpretative relationship with their transcripts. However, obtaining and interpreting meanings for participants is not always readily accessed, or overtly represented in dialogues. In order to develop such levels of interpretation, the process of analysis would need to involve a distinct process of engagement with the texts. Willig (2001) suggests that an important step in getting in touch with the individuals’ life-world,
within any phenomenological research, is to become familiar with data. This can be achieved by using an ‘idiographic’ approach, which involves the extensive analysis of each individual case, one by one.

As presented in Section 4.1.2, the ‘idiographic’ stance is integral to IPA, in that it enables a quality of outcome within the research representing the perceptions of the individuals taking part, before interpreting the meanings across the groups being researched. Although the analytic process adopted within IPA appears similar to the process in grounded theory (Grigoriou, 2004), there is one distinct difference. Willig (2001) explains that, where grounded theory enables the study of social processes and develops theories, IPA allows the researcher to gain insights into the way that participants make sense of their own world. This is specifically complementary to this study, as the aim is to explore what mental health means for the participants from their point of view, rather than to examine the social aspects surrounding them, which may determine their experience. In light of this aspect, the analysis strategy within IPA allows the researcher to enter into the participants' world and to explore the emerging meanings. In a similar way, IPA is thought to share some features with discourse analysis (Potter and Wetherall, 1987) in that it has a commitment to the significance of language. However, where discourse analysis is more concerned with defining verbal reports as functional behaviours in their own right, IPA is concerned with exploring the underlying thought processes or cognitions, expressed in dialogue. It is the identification of such differences that provide the justification for the use of IPA, as an appropriate approach to analysis of the data arising from the research question.

As IPA is a relatively new qualitative methodology, Smith et al (1999) suggest guidelines for the analytic process. They emphasise that the guidelines are not definitive; therefore the researcher may adapt the suggested approach to complement their study and way of working. Being able to adapt the approach in such a way
should allow for continuous evaluation of personal views and interpretations, in
relation to this study. The process of analysis in IPA begins with the scrutiny of each
individual case, and then moves through a method of cross-case analysis to establish
common themes. The analytic procedure applied to this study is described in detail in
the following section.

4.16.1 The data analysis strategy in IPA

The IPA data analysis strategy, employed within this study involves a number of
stages within which analysis and interpretation take place (Smith et al, 1999). These
closely follow the characteristics of IPA presented in Section 4.1.2.

Stage 1: Idiographic analysis of individual cases: initial identification of themes

The transcripts were read and re-read a number of times, in order to gain an intimate
connection with participants’ accounts. The purpose of re-reading transcripts is to
ensure that becoming familiar with the data will enable the establishment of concepts,
and new insights into the participants’ views (Grigoriou, 2004). In addition to the
framework for analysis suggested by Smith (1996), the researcher also listened to the
original audio recordings, in order to become more familiar with the spoken dialogue
and to acknowledge points of emphasis within the interviews. Each case was
analysed in turn. However, stages 1 to 3 were completed for the first case, before
moving on to the analysis of subsequent cases. The left-hand margin of the transcript
was used to identify and to note areas of interest or significance. The importance of
using the left hand margin in this way was to summarise the participants’ views and
concepts. This enabled the researcher to draw associations throughout the dialogue,
to identify connections within the data and with the research question, and to make
preliminary interpretations.
Once satisfied that the transcript had been thoroughly interpreted through this process, the right-hand margin was used to identify key words or themes which related to the summaries presented in the left-hand margin. The themes identified at this stage were not intended to be definitive, but to indicate concepts arising within the data. During this stage of analysis, all of the text, including the interviewer's dialogue, was treated as potential data, as it might reflect or clarify the participants' views, or could impact on participants' responses. Viewing the data in this way was particularly pertinent to the children's transcripts, as the approach used in the semi-structured interviews included the techniques of reflection and clarification, where children used non-verbal communication or their contribution was ambiguous.

Stage 2: Determining connections across themes
Following on from stage one, any emerging themes identified within the first transcript were then transferred to a separate sheet of paper. The themes were then re-analysed to identify connections. The connections between themes were subsequently grouped into clusters, and super-ordinate concepts were determined. Each cluster of sub-themes was then arranged under their respective super-ordinate theme, thus bringing together the associated sub-themes under one descriptive heading. This process enabled the ordering of the concepts emerging from the data.

As the super-ordinate themes and their clusters were developed, they were checked back against the originating transcript to ensure they provided an appropriate description of the connections and concepts within it. The function of this stage was to ensure close interaction between the researcher and the text, in order to develop an understanding of what the person was trying to say, and to draw upon one's own interpretation of this (Smith, 1996 and 2003).
Stage 3: Developing a table of master themes

The super-ordinate themes and their clusters were then ordered logically into a master table. Within this stage, some of the sub-themes that did not connect with a super-ordinate theme, or those themes not represented by a rich source of data were removed. The table was used to revisit the initial transcript, and excerpts representing the theme were logged by their line number, and a key phrase from the excerpt. All instances occurring in the transcript were recorded against their respective theme in this way.

Smith (2003) highlights that, at this stage of the process, some themes may be governed by the interview questions, and some may be new themes emerging from interpretation of the data, or representing the participants' more generalised style of thinking. This stage enables the further consideration of meanings within the data, and can take the interpretation in a new direction, or can assist in the clarification of initial interpretations.

Stage 4: Nomothetic analysis: continuing analysis across cases

The master table of themes derived from the first transcript was used to analyse each transcript in turn. As new themes occurred, they were added to the appropriate super-ordinate theme, or where appropriate a new super-ordinate was generated. New themes were also tested back against the transcripts already analysed, to check if they had been missed. After each transcript was analysed, the table was reconsidered and modified, leading to a final master. Each transcript was then analysed against the master table and excerpts recorded as described in stage three.

Stage 5: Inductive and interrogative analysis: presenting the interpretation

Analysis continues during the presentation of the findings. As discussed in Section 4.1.2., the inductive characteristic of IPA occurs during both data collection and
analysis. Within the presentation of the findings, themes were translated into a
narrative to describe the participants' views. The master table formed the basis of the
account and further interpretation took place within the presentation. In order to
distinguish between interpretations on the part of the researcher and what was said by
participants, excerpts from the transcripts were used to illuminate the account.

Following completion of this stage, two colleagues who were unfamiliar with the data,
were asked to check the themes to ensure that they were consistent, and that the
interpretation represented the excerpts used to illustrate each theme. Although Smith
(1996 and 2003) does not suggest this in his guidance, using other professionals to
check for consistency aids the validation of the interpretation and reduces the
possibility of bias generated from the researcher (Willig, 2000).

A further level of interpretation takes place in the discussion of the findings (Chapter
7), wherein they are 'interrogated' against existing evidence in the field, with the aim of
either corroborating contemporary theories, or to present new considerations.

This chapter has described the methods and procedures for conducting the study, the
challenges and issues faced, and how these were addressed. The findings of the study
are presented in the next two chapters.
Chapter Five

Emerging Findings from the Parents’ and Carers’ Interviews

5.0 Introduction

This chapter will present the findings from the parent/carer participants. The data was analysed using the IPA framework presented in Chapter Four (Section 4.16). The data from parents/carers and children participants was analysed separately. The children’s findings will be presented in Chapter Six. The findings have been organised into super-ordinate, or main themes, and their clusters of sub-themes. A super-ordinate theme represents the main emerging subject category which describes the sub-themes that fall within it (Smith et al, 1999). A summary of the super-ordinate themes and related sub-themes is presented in Table 5.0. Each sub-theme heading has been illustrated with an excerpt from the participants’ dialogue. The excerpts have been selected in order to represent the nature of the related sub-theme. Using participants’ dialogue is an emerging practice within IPA, and in some studies the heading for each theme or sub-theme consists solely of an excerpt from data (Shaw, 2005). For the purposes of this thesis, each sub-theme has been given a heading which describes the theoretical content, and is illustrated by an excerpt from the findings in order to align the analysis more closely with the participants’ life-world. The dialogue selected for illustration of the sub-theme appears in italics beneath each sub-theme heading.

Nine super-ordinate themes emerged and included the following: defining mental health in adults and children; defining mental illness; causes of mental health
problems in children; experience of mental health problems; stigma – the meaning for
parents/carers; experiencing stigma; the impact of mental health problems; the
meaning of seeking help; and expectations of CAMHS. The emerging super-ordinate
themes are not presented in a particular order, and it must be acknowledged that
there are certain similarities and overlaps between a number of the themes. The
interplay within the themes, between the participant groups, and further interpretation
of the findings will be discussed in Chapter Seven.

Excerpts from the conversations with parents/carers have been used throughout this
chapter to illustrate each theme. In order to protect anonymity and confidentiality, the
participants have been given a pseudonym (presented in Table 5.1), and any
distinguishing names or references have been removed from the data.
Table 5.0: Summary of emerging super-ordinate themes and sub-themes from parent/carer interviews

<table>
<thead>
<tr>
<th>Main Theme</th>
<th>Sub-theme (with illustration from parents/carers dialogue in italics)</th>
</tr>
</thead>
</table>
| Theme One: Defining mental health in adults and children | 1a The challenge of defining and achieving mental health  
'I don’t think there is an absolute mentally healthy stable person' |
| | 1b The essential attributes for positive mental health  
'To cope with a variety of problems' |
| | 1c Sustaining mental health in children  
'Happy, healthy life... ...' |
| | 1d The paradox of meaning and mental health  
'The health of the child, or whatever, and deals with any problems they might have' |
| | 1e The extended meaning of mental health in children  
'Because children have to let off steam' |
| | 1f The meaning of difference: barriers to achievement and mental health in children with perceived problems  
'I’d like him to be able to be just like the other children' |
| Theme Two: Defining mental illness | 2a | The continuum of ‘mentally unhealthy’, from mental health problems to mental illness
'Somebody might just be feeling a little bit down, where others are depressed' |
| | 2b | Developing an immunity from stigma
'I suppose children do suffer, but you usually think more about adults' |
| | 2c | The ambiguous presentation of mental health problems in children and acceptance
'Much harder to spot and much easier to mistake for something else' |
| | 2d | Visibility versus invisibility - signs of mental illness and ‘madness’
'There is 'that kind' of outburst' |
| | 2e | Fear and safety
'Somebody who is mental living next door to me?' |

| Theme Three: Causes of mental health problems in children | 3a | Parents'/carers' impact on mental health problems of children and self-blame
'110% my fault' |
| | 3b | External factors which impact on child mental health problems
'Was something externally causing it...?' |
| | 3c | The need to find a cause and emancipation
'Has he got a syndrome?' |
Table 5.0: Summary of themes and sub-themes from parent/carer interviews (continued)

<table>
<thead>
<tr>
<th>Theme Four: Experience of mental health problems</th>
<th>4a. Personal perceptions and the understanding of mental illness</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>'Well, I’ve got a bit of an insight because I was actually ill'</td>
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<td></td>
<td>4b. Positive awareness, empathy and seeking information about mental health and illness</td>
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<tr>
<td></td>
<td>'I read it and thought, yes, I know how you feel'</td>
</tr>
<tr>
<td></td>
<td>4c. Learning and skills in mental health</td>
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<tr>
<td></td>
<td>'I've done my BTec [in child care]'</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Theme Five: Stigma – the meaning for parents/carers</th>
<th>5a. 'Mental' (health) is stigmatising/discriminatory</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>'I think the word is heavily loaded'</td>
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<tr>
<td></td>
<td>5b. Stigma and derogatory language</td>
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<tr>
<td></td>
<td>'We know you are a 'nutter''</td>
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<td></td>
<td>5c. Knowledge affects attitude</td>
</tr>
<tr>
<td></td>
<td>'It's the unknown that scares people'</td>
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<tr>
<td></td>
<td>5d. Society is stigmatising, not the individual</td>
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<tr>
<td></td>
<td>'There is still stigma about what is seen as socially acceptable'</td>
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<tr>
<td></td>
<td>5e. Myths and traditional views of mental health and services as institutions</td>
</tr>
<tr>
<td></td>
<td>'You think white walls padded doors, bars'</td>
</tr>
</tbody>
</table>
Table 5.0: Summary of themes and sub-themes from parent/carer interviews

(continued)

<table>
<thead>
<tr>
<th>Theme Six: Experiencing stigma</th>
<th>6a</th>
<th>Fear of accessing services and labelling</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>‘I don’t want my child to go on a database’</td>
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<tr>
<td></td>
<td>6b</td>
<td>Personal experiences of stigma and discrimination</td>
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<tr>
<td></td>
<td></td>
<td>‘They have made it blatantly clear, anyway, that is the sort of child they do not want at their school’</td>
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<tr>
<td></td>
<td>6c</td>
<td>The urgency to tackle stigma</td>
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<tr>
<td></td>
<td></td>
<td>‘Tackle it now’</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Theme 7: The impact of child mental health problems</th>
<th>7a</th>
<th>Frustration in getting help</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>‘It feels like for years I’ve been going through the system’</td>
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<td></td>
<td>7b</td>
<td>Desperation and struggle from within the family</td>
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<td></td>
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<td>‘I cannot cope with this, I need some help’</td>
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<td></td>
<td>7c</td>
<td>Effects of mental health problems on the family</td>
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<td></td>
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<td>‘It has been a long hard road’</td>
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<td></td>
<td>7d</td>
<td>Effects on the child’s quality of life</td>
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<td></td>
<td></td>
<td>‘Just have a normal quality of life’</td>
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<tr>
<td>Theme Eight: The meaning of seeking help</td>
<td>8a</td>
<td>Seeking help and the desire for a diagnosis</td>
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<tr>
<td></td>
<td></td>
<td>‘Offer some kind of diagnosis’</td>
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<tr>
<td></td>
<td>8b</td>
<td>Getting a service gives hope</td>
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<td></td>
<td></td>
<td>‘I felt that somebody was going to listen to me’</td>
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<td></td>
<td>8c</td>
<td>Knowing where and when to go for help</td>
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<td></td>
<td></td>
<td>‘We’ve got to get help for him’</td>
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<tr>
<td></td>
<td>8d</td>
<td>Resourcefulness and knowledge of what works with children</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘Trying all different ways’</td>
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<td></td>
<td>8e</td>
<td>Worries about going for help</td>
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<tr>
<td></td>
<td></td>
<td>‘I didn’t want to have him to have weeks and weeks worrying’</td>
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<tr>
<td>Theme Nine: Expectations of children’s mental health services</td>
<td>9a</td>
<td>Expectations of CAMHS approach to helping</td>
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<tr>
<td></td>
<td></td>
<td>‘I suppose they will ask a lot of questions’</td>
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<td></td>
<td>9b</td>
<td>The need for early intervention/ prevention of mental health problems</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘Get it right and nip it in the bud now’</td>
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<tr>
<td></td>
<td>9c</td>
<td>Developing knowledge of services</td>
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<td>/community CAMHS</td>
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<td></td>
<td></td>
<td>‘Somewhere for people to just pop in and get some information’</td>
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<tr>
<td></td>
<td>9d</td>
<td>Seeking help from others</td>
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<tr>
<td></td>
<td></td>
<td>‘We need a good network of people’</td>
</tr>
<tr>
<td></td>
<td>9e</td>
<td>Experiences of help from schools</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘They don’t have enough understanding’</td>
</tr>
</tbody>
</table>
5.1 The emerging super-ordinate themes from parent and carer interviews

5.1.1 Theme One: Defining mental health for adults and children

Sub-theme 1a: The challenge of defining and achieving mental health

(I don’t think there is an absolute mentally healthy, stable person)

Most of the parents/carers considered ‘mental health’ to represent an optimum state of mental wellbeing, or ‘happiness’. This perceived state of wellbeing was something to which they aspired and hoped for their children to achieve, in the long term.

However, when considering the concept further they suggested that no one would be able to remain at an optimum state of stability. In reference to this, they described the
term 'mental health' as a concept which can be in a state of continuous fluctuation. They went on to suggest that it was 'normal' to experience stress and challenges in their lives. They proposed that achieving the desired optimum state of wellbeing would not be the same for all individuals, but would be influenced by the individual's circumstances and their different abilities. The parents/carers proposed that their definition of mental health would apply to both adults and children, i.e. having good 'mental health' would mean that it contained a core set of components. However, they considered that when the definition was applied to children, it would also be influenced by their child's developmental level and functioning. Karen gives a definition of mental health which illustrates the concept suggested by the group:

KAREN: [Having 'Mental health' is] Someone who is happy with everything, and is doing the best that they can within their ability, and being happy with that. (Parent 15)

When defining the attributes required to achieve 'mental health', participants proposed that the key to accomplishing stability and happiness was to be able to overcome challenges and difficult life circumstances, and to be able to find solutions to everyday problems. Most of the parents/carers perceived that 'mental health' could be defined as having control over one's life, and that someone with good mental health would be switched on, alert, civil, polite, positive and motivated. However, Jane illustrated that no one was particularly mentally healthy and saw that good mental health was challenged when everyday worries went beyond the realms of being able to cope:

JANE: I don't think nobody's mentally healthy at the best of times, I just think its bits of worry that go over the extreme, so I don't think anyone is mentally stable or normal. (Parent 1)
Participants also advocated that the definition of 'mental health' should include a range of emotions and positive attributes. These included having self-confidence, positive self-esteem, self-worth and being able to act in a self-regulatory manner. In addition, they suggested that the range of components would include the experience of difficulties at different times in their life. In response to this, they expected that they would be able to develop resilience that would assist them to recover from their difficult experiences, and that they would be able to take consciously thought-out risks:

ANGELA: I don't think there is a perfect person as far as mental health is concerned, you know. I don't think there would be anybody on this planet who hasn't had some form of problem as far as death or emotional break-up, divorce, children whatever, you know. Everybody has gone through the same thing, so I don't think there is an absolute mentally healthy stable person. Really... (Parent 2)

Sub-theme 1b: Essential attributes for positive mental health

(To cope with a variety of problems)

Parents/carers suggested that positive mental health in children included a vital range of attributes and activities, which needed to be experienced in combination, for their child to obtain a state of positive mental health. They suggested a prescription of components which fitted into a number of categories, including promoting positive aspects of the self (i.e. self-confidence, self-esteem), having access to learning, experiencing a nurturing environment, developing strong relationships, having good personal experiences, and being able to enjoy a range of activities. Some parents/carers considered that in order to achieve the components of positive mental health, it was crucial to ensure that children were brought up in a stable family household. In relation to this, they suggested that the environment in which children lived should contain a relationship with at least one significant adult, where they were
able to receive stimulation, were able to rectify balance in difficult situations, and were praised for their achievements. The use of praise was seen as a positive approach which enabled their children to develop, and increased their capacity to participate in everyday activities. They advocated that all children should have access to praise and that this should be used regularly to reward achievements and effort, and not solely to reinforce expectations that the child should be functioning at a high level.

JANE: Stimulation as well, they like to be stimulated. I'm going to chuck you out in a minute [Child]. Stimulation and praise as well. Children like a lot of praise. (Parent 1)

ANGELA: Do well at school, you know I don't expect him to be an absolute superstar but to try and make a huge effort, whatever subject he does. Try to make that best effort. (Parent 2)

Parents/carers highlighted the need for children to be able to develop some sense of the world around them, to show some ability to control their own behaviours and actions, and to show empathy for other people. They wanted them to be mostly happy and contented, to have a network of friends and a range of skills that would help them to achieve positive mental health. These skills included a desire for their child to be good communicators, flexible, and have good coping skills to assist them in recovering from life's challenges. They also expressed an aspiration for their children to have emotional strength and motivation, suggesting that these attributes would enable them to accomplish an optimum state of mental wellbeing:

VANESSA: I suppose composure and being able to be quite composed, really. A sense of perspective, you know, not thinking everyone is against them or kind of having a distorted vision of everything... I guess. (Parent 3)
KATRINA: I suppose to have a good understanding, to be able to have acquired skills to cope with a variety of problems, some kind of diversity of being able to cope with problems. Also, some evidence of emotional stamina. (Parent 10)

Definitions of child mental health outlined by parents/carers were particularly astute and covered all dimensions of the child’s life, in a holistic way. This suggests that they had a good understanding of the fundamentals of promoting positive mental health in their children. In particular, elements such as being able to play and learn within their own abilities, being inquisitive, being able to spend time on their own and to use their imagination in play were seen as integral to attaining mental well-being:

ALISON: Well, like [child] if he is with other children he is very outgoing, he is straight in with other children. But if we are on our own here, he will play by himself, he has a brilliant imagination he’ll get his toys out and we will have Action Man all over the room, and he talks to them and he is making the noises. So, going by [child] he is quite capable of playing by himself, and it does stimulate his imagination because I have seen him play. (Parent 4)

Sub-theme 1c: Sustaining good mental health in children

(Happy, healthy life)

Parents/carers determined that aspects of good mental health in children could be promoted through a range of interventions. They concluded that a good family network, loving relationships, lasting friendships and being able to talk about issues when their child needed to, were all components that sustained a sense of emotional wellbeing. They highlighted that it was vital to ensure that their children knew that they were living in a safe and secure environment, and that simple things, such as
knowing that they would have a comfortable bed to sleep in, all contributed to the child maintaining a level of good mental health:

JANE: You need a lot of support.
FIONA: So, having people around you?
JANE: Yes, a good family network helps.
FIONA: Can you tell me more about that?
JANE: Just a loving relationship, people who you can sit down and talk to about anything, without feeling like you are burdening them. That causes a lot of problems as well when you don't talk and it piles up and up. (Parent 1)

A number of parents/carers identified that building confidence and self-esteem in their child would help to prolong mental health, whilst others outlined that physical aspects of health were also integral. The physical health characteristics, which were seen to be associated specifically to mental health, included being fit, having a good sleep pattern and paying attention to diet.

ALISON: Confidence building, trying to make them feel good about themselves and learn to cope with the situation that they are in. What has brought it about, what has changed in their lives? Try to point out the good that can come to help them cope with it. (Parent 4)

VANESSA: Yes, stability, healthy diet, routine, happy home life. If they get on at school and feel comfortable with that. (Parent 3)

JENNIFER: Happy family, that's important. Happy healthy life and fit, you know. (Parent 12)
The group also suggested that being able to play and socialise with peers and siblings, and being able to experience positive events in their life, all assisted in sustaining good mental health:

**ALISON:** If they socialise with other children and have plenty of opportunity to do so, and mix and do plenty of activities really. (Parent 4)

Many of the participants considered that interactions and quality of relationships could contribute to the development of good mental health. They emphasised that the importance of quality time, time to learn together, ensuring children knew they were loved and that they had physical love and attention, were essential. In addition, such principles required to be supported by a general environment of kindness, compassion and clear boundaries, all building on developmental needs and abilities. Kim offers her views about what is important for children’s mental health:

**KIM:** Ahm, you know, I often used to look at people on the street and think, ugh, look at that mother, she’s not even cleaned that child’s face, and then I’d think, well no, you know, whether or not they are wearing clean clothes, that they are not going to remember, but they will remember whether they were treated kindly or loved. I probably think they are the two most important things, and discipline within that, because I actually think they need boundaries…yeah, very much. (Parent 9)

**Sub-theme 1d: The paradox of meaning and mental health**

(The health of the child, or whatever, and deals with any problems they might have)

On occasion, some parents/carers struggled with defining the term ‘mental health’, using it interchangeably to mean ‘mental illness’. When asked directly to define ‘mental health’ they mostly focused on the positive health aspects, however, during conversation they tended to illustrate their thoughts about mental health with excerpts
from their experiences or knowledge of mental illness, by describing their children's needs or problems, or with descriptions of others whom they considered to have mental health problems. When engaged in free talk about mental health, some participants used the words to mean problems or illness. A common example of the use of 'mental health' to mean 'problems', occurred when participants were exploring the concept of mental health in children. Participants seemed to resist the notion of mental health and children being directly associated. This seemed to stem from their apparent confusion about 'mental health' and 'mental illness'. They appeared to be able to grasp the notion of mental health in relation to the general population, however, because of their acute awareness that they were accessing help, they seemed to associate the term to mean problems when thinking about their own children. In relation to this, they suggested that mental health was not the same for adults and children, whereas in an earlier sub-theme (1a), they had considered that the concept of mental health contained the same principles across the lifespan. Such contradictions amongst the findings challenge some of the earlier assumptions professed by parents/carers, implying that they are not always clear about the definition of mental health and that they find there to be a dichotomy of meaning. Two parents demonstrated the ambiguity of the terms:

JOYCE: I think it [mental health] is just the health of the child, or whatever, and deals with any problems they might have, whether it is due to illness or hyperactive or whatever. (Parent 7)

RITA: I think it's [mental health] down to behaviour and things like that and how you define the children. (Parent 19)

The findings seem to indicate that some parents/carers often infer a paradoxical view of mental health. In relation to prompts in the interview which asked them to elaborate
on their views of mental health, they tended to describe it in negative terms, i.e. they seemed to conceptualise 'mental health' as meaning difficult behaviours, mental illness or even 'madness'. Some of the parents/carers defined mental health as a state of instability, using scenarios that included people having mixed-up feelings or who had lost control. They often described it as observable and challenging behaviour, or used familiar or controversial mental health diagnoses to assist them, for example, ADHD or Schizophrenia. Some participants also included children with learning disability suggesting that learning disability was part of the continuum of mental health. Vanessa discusses her perceptions of the term 'mental health':

VANESSA: Where as other kinds of mental health...

FIONA: So you think there are different types of mental health problems?

VANESSA: I think they [mental health] are perceived in different ways, I don't know whether doctors see them as the same but I think when you are visibly acting irrationally, the word 'mental', people associate with madness, don't they? (Parent 3)

Sub-theme 1e:
The extended meaning of 'mental health' in children

(Because children have to let off steam)

Parents/carers seemed to find it difficult to explore the term 'mental health' in relation to children. They determined that maintenance of good mental health was important for children, if they are to have happy lives. This view included the need for children to be able to vent their feelings, where appropriate. In addition to their general description of the components of mental health, outlined in sub-themes 1a and 1b, the group considered it vital for children to be able to show empathy for others and to be able to reflect on the potential consequences and effects of their actions on others, before proceeding. Parents/carers determined that any child could experience mental health problems or 'breakdowns', which was similar to their views about
adults. However, the extremes of mental illness that were described in relation to adults when asked to define ‘mental health’ were not demonstrated in reference to children. Therefore, suggesting that children could not experience such severe mental health problems. In addition, some suggested that having mental health problems would not define the child as having a ‘disability’, nor would they solely be related to learning difficulties. Therefore, mental health problems could be experienced by any child regardless of intellectual ability. When formulating a picture of a child with a good state of mental health, parents/carers often described an ideal and expressed a wish for their own child to achieve this ideal:

ANGELA: What I would like him [child] to be doing is to be..., not all the time, because children have to let off steam, every now and again, you know but the majority of the time to be sensible, kind and think of others, and when any form of action he takes, to think twice before he takes that action. (Parent 2)

JANET: Whether [child] is bright or not and that shouldn't be brushed aside. I mean a lot of people who end up having breakdowns they class that as mental health. It doesn't mean that they have got learning difficulties.”(Parent 5)

Sub-theme 1 f: The meaning of ‘difference’: barriers to achievement and the mental health of children with perceived problems

(I’d like him to be able to be just like the other children)

When talking about their children, parents/carers projected a view that they were ‘different’ in some way to children in the general population. The regular reference to this view occurs within both expressed and implied suggestions that participants do identify their children as having mental health needs, and that this makes them different than the general child population. In conjunction with this, the entire group seemed to convey an implicit acceptance that their child required intervention. The
perceived difference that they recognised was expressed in certain phraseology. This was implied in their frequent assertion that they held an aspiration for their child to be like others, whom they considered to have good mental health. In relation to this, it seems that positive mental health is not wholly defined as something that their children would generally have, but something they would like them to achieve. However, despite the wish for their children to attain good mental health, the difference they appear to perceive seems to perpetuate a barrier to being mentally healthy:

JANET: I'd like him to be able to be just like the other children, all children can be naughty and do silly things like that, but [Child]'s is constant. He can't sit in the classroom and listen like other children, and the psychologist has told [Child] that he is different to other children. (Parent 5)

5.1.2 Theme Two: Defining mental health problems and mental illness

Sub-theme 2 a: The continuum of ‘mentally unhealthy’, from mental health problems to mental illness

(Somebody might just be feeling a little bit down, where others are depressed) When asked about the meaning of ‘mentally unhealthy’, parents/carers recognised a range of issues which they identified as relating to the term. These included the notion that ‘mentally unhealthy’ incorporated a variety of problems, which represented a continuum of severity. The continuum ranged from the more severe end of the spectrum, which they suggested would include self-harming behaviour, psychosis and clinical depression, to milder problem areas such as behavioural problems and friendship difficulties. Within this spectrum they expected to see some changes to the person’s internal perceptions and coping ability, however the presentation would be
dependant on the individual. Martin talked about his views of the term 'mentally unhealthy':

*MARTIN: ...no, I suppose the other thing is the internal perception, somebody might just be feeling a little bit down, where others are depressed. The feelings might be identical; it is just that some people are able to cope with natural mood fluctuations better than others...* (Parent 17)

Parents/carers seemed to struggle with their understanding of the term 'mentally unhealthy', and as a way of making sense of it, they tended to use 'depression' as a global term to describe any issue related to mental health or mental health problems. In this respect, 'depression' was highlighted as one of the main issues for children and adults alike. Parents/carers frequently used the term 'depression' to represent mentally unhealthy feelings or problems, and it appears on numerous occasions in the data in place of other words, which might be used to portray mental health needs. Use of the term 'depression' represents an all encompassing way of describing mental health problems or presentation, which seems familiar to the participants. Making frequent use of the term in this way suggests that it could be a more acceptable way of talking about a difficult or unknown subject area. Parents/carers determined that the definition of 'mentally unhealthy' would describe changes in behaviour, unpredictability, or problems with coping. As can be seen in sub-theme 1d, in which mental health is used paradoxically, such presentations are utilised to offer a definition.

In addition, some parents/carers determined that children who presented as withdrawn, had no self-confidence, or showed self-loathing, could also be included within the definition of 'mentally unhealthy'. Participants regularly seemed to be toying with the idea of a definition for mentally unhealthy. In some of the descriptions,
they tended to relate their definitions to experiences or observations, using such scenarios to assist them in constructing a meaning. The definitions offered were given in an uncertain manner, as participants tried to determine a definition they were comfortable with. In conjunction with this uncertainty, the participants often commented that a definition for the terms ‘mentally unhealthy’ was not something that readily occurred to them. This perhaps suggests that there are some difficult issues surrounding mental health and mental illness, which are not easily recognised or discussed. Two parents described their perception of ‘mentally unhealthy’ in relation to their observations:

JANE: I can’t think off hand. It’s not something that jumps out at me, it’s just things that children do like their actions, say like self-harming and depressed. I would say there was something wrong if a child is constantly crying or seems down all the time or withdrawn or even off food, things like that. (Parent 1)

SUSAN: The way I look at it [mentally unhealthy], there are borderlines and I’d say a normal average child, you’d give them 10/10. Then the really bad ones [mental illness] 0/10, then I’d say he’d [child of a friend] come in around 5-8, sort of thing. (Parent 14)

In contrast, some participants described ‘mentally unhealthy’ in relation to their experiences with their own child. As can be seen from the following examples, both parents tend to focus on the observable behaviours they have experienced, as a way of offering a definition:

JANET: Anger comes out as in hitting out at me, swearing at me, calling me all the names under the sun, and then an hour later it’s all forgotten, and he’ll say ‘sorry Mum’ and he thinks that’s it and everything is ok. (Parent 5)
DAVE: Sometimes it's like it never happened, isn't it with him, it's like it's completely wiped clear from his head. (Parent 6)

Some parents/carers expressed the view that it was important to differentiate between levels of seriousness. They considered that 'mentally healthy' would mean that problems are starting to emerge, whereas 'mental illness' would mean that the individual's mental health needs are severe. However, others in the group highlighted that the term 'mentally unhealthy' would usually represent a statement relating to an extreme presentation, rather than an everyday occurrence and consequently related directly to mental illness. Those who gave this definition thought of the problems as being diagnosable. In this respect, they suggested that individuals experiencing such severity of disturbance would definitely require help or treatment. They also suggested that problems would have a poor prognosis if they did not have access to intervention. Participants identified that people falling into this category would have serious mental illnesses, such as schizophrenia or psychosis, and would be confused or unbalanced. Some parents/carers suggested that children and adults with problems at the more severe end of the spectrum would have different thoughts and feelings to the norm:

ALISON: [mentally unhealthy]...probably to the extreme, whereas I say depressed, they would probably be more on the suicidal sort of level. (Parent 4)

KATRINA: I would see them in a different way. I would think mentally unhealthy would describe dysfunctional, and mentally ill would actually mean, for me, that someone had a diagnosable disorder and other illnesses that were recognisable. (Parent 10)
In addition to the two definitions of 'mentally unhealthy' outlined above, some participants offered a third dimension. They suggested that the term 'mentally unhealthy' meant that the person would be physically disabled, and could relate to individuals with genetic disorders. In these cases, distress would be seen through physical manifestations such as anger, hitting out and swearing. Janet offered the following definition in relation to the term 'mentally unhealthy':

_FIONA_: So, if I asked you what you thought a mentally unhealthy person would be like, what would you expect?

_JANET_: What do you mean by unhealthy?

_FIONA_: Because we just talked about 'mentally healthy' a minute ago, if I said someone was 'mentally unhealthy', what kind of things would you see?

_JANET_: What do you mean, physically handicapped?

_FIONA_: Whatever you think I mean when I say it.

_JANET_: People can't help how they are and they should be entitled to the help that they need. We have got a [relative] that's Downs Syndrome. (Parent 5)

**Sub-theme 2b: Developing immunity from stigma - mental health problems and mental illness are something that other people experience**

_(I suppose children do suffer, but you usually think more about adults)_

Throughout this theme, it is apparent that parents/carers expressed their thoughts about mental health problems and mental illness in a third person context. This suggests that they did not associate such a definition directly with their children. Almost all participants spoke about mental illness within this frame of reference, using words like 'they' and 'them', when talking about people with mental health problems. It was difficult to ascertain whether participants were talking about their perceptions of adults or their perceptions of children, as they often swapped from one perspective to another. Such jumbled portrayals of perception seemed to indicate that participants
found the terms difficult to relate to or define, especially where they had been applied to children. They often linked their descriptions to other people they knew of, or had heard about and seemed to portray that it was unusual to think about children in this context. A couple of parents were taken aback by the question in relation to children, and Jennifer reported that:

JENNIFER: I suppose children do suffer; but you usually think more about adults with mental health, than you do children. (Parent 12)

Parents/carers seemed to find it difficult to differentiate between mental health problems in adults and those experienced by children. They considered that mental health problems could be triggered by certain factors and also by the environment within which the individual found themselves, and their relationship with it. Although, when talking about these issues, they did not seem to convey that this was something which could happen to them:

ANGELA: Yeah, I think they could go that way anyway. Yeah. I think it triggers it [mental health problems] off anyway, yeah. Depends on…
FIONA: Yeah, so it could actually happen wherever you are?
ANGELA: Yeah. What situation you come to and the environment that you’re in. Yeah. (Parent 2)

When talking about mental health problems in children, the participants referred to their children as ‘naughty’ or as having problems with their behaviour. Sometimes they seemed to prefer to describe their children’s problems under the guise of a medical term, e.g. Autism or ADHD, rather than referring to them as mental health problems. When using these terms it seemed as though the problems their children were experiencing were more acceptable, if they were categorised in this way. This
approach suggested that they would be protected from the stigma they perceived others to have. Petra gave her thoughts on the uncertainty of how mental health problems in children might be classified:

PETRA: It usually means that they have mental health problems, doesn't it? I suppose that if he has ADHD, it might be considered that he has mental health problems? (Parent 23)

Sub-theme 2c: The ambiguous presentation of mental health problems in children and acceptance

(Much harder to spot, and much easier to mistake for something else)

When describing mental health problems that could be seen in children, parents/carers expected that they would present as withdrawn, depressed, worried or anxious, and would be exhibiting certain behavioural problems related to emotional upset. Descriptions included a range of emotions, such as anger, aggression and frustration, and these were seen to originate from the inability to participate in everyday activities. Parents/carers suggested that, from their own perspective, children would experience a good deal of unhappiness, upset and a certain amount of distress in their lives. Due to the multiplicity of presentation, parents/carers seemed to exhibit some confusion about what would constitute a mental health problem in children, therefore tended to give many and varied examples of what they would expect to see. This too, as in previous sub-themes, might suggest that acknowledging that mental health problems existed in children was a difficult issue to come to terms with. Some of these presentations were thought to have a major impact on the child's quality of life:

ALISON: Depressed, worried, certain behaviour problems, emotionally upset, sort of thing. (Parent 4)
KIM: Actually showing they can't cope with it or are upset about something. It comes out in different ways with children. So in lots of ways I think it's harder to spot. Much harder to spot, and much easier to mistake for something else. (Parent 9)

Some of the definitions were influenced by certain experiences that participants had with their own children. Such situations helped them define what they felt to be a presentation of mental health problems in children. In order to make sense of this, they tended to make observations which were individual to their circumstance, and then to apply it to other children. They even recognised that, until they had been able to understand more about the mental health needs of their child, they had perhaps responded in a discriminatory or negative manner towards others. Most participants offered a clear description of the presentation of mental health problems, and their ability to cope with the consequences within a positive frame. However, an exception to this was where an implied negative perception, exhibited by others, had been experienced by parents/carers. In these situations, parents/carers found it hard to comprehend the reason for the wider community’s negative responses. This might suggest that their difficulty in comprehending mental health problems was frequently highlighted in a harsh way.

Although these findings overlap with a later theme around stigma and discrimination, it is important to reflect them within this sub-theme, as they give a more global view of how mental health problems in children might be seen by the community around them. This aspect also heightens parents/carers awareness of society’s lack of understanding of mental health, which might be difficult to change. Parent/carers considered that children with problems were viewed by others, especially professionals, as naughty or badly behaved. This compounded their struggle to find an acceptable definition of child mental health that did not imply responsibility or
‘badness’. Paul describes his perceptions of child mental health problems, using his own experiences:

**PAUL:** You can see it in somebody’s behaviour, and how they are acting, and we have perhaps said it “look at that naughty little boy” or what have you. Not realising there is more to everybody than meets the eye, sort of thing… (Parent 18)

**PAUL:** …you know they have one or two problems, but to anybody else they are just naughty boys… (Parent 18)

Often parents/carers reported that it was only them who had recognised that their child had mental health difficulties. These suspicions were only confirmed to the parents/carers when professionals had also witnessed the situation. However, before such confirmations, the realities of the problems in the child were often seen as being embellished by the parents, or perceived by others to be the result of bad behaviour. From parents’/carers’ reports, it seems that the existence of mental health problems was only verified when it had been authorised by a professional. As a consequence, the problem areas had to be seen to become elevated, or to reach crisis point before help could be sought. Some parents/carers identified that mental health problems were only recognised when the child’s changes in behaviour affected others, or when they were seen to have gone too far. This was said with some underlying sadness, as parents/carers considered that this indicated that the child’s needs were disregarded as bad behaviour and that the child had some responsibility for their actions, often resulting in a delay in help:

**JANET:** She [teacher] has seen [Child] at school every year since he has been there, until this year and she saw him over there. Last summer, wasn’t it when they were putting the windows in, she saw him in his full flow. I’m glad, although I didn’t want
him to be like that. I was glad because she saw exactly what I was telling her and it was then that she came to the conclusion. Because he had been alright all the other times that she had seen, she thought there was nothing amiss, but that's wrong.

(Parent 5)

Sub-theme 2d: Visibility versus invisibility-signs of mental illness and 'madness'

(There is 'that kind' of outburst)

This sub-theme represents some of the dialogue used by parents/carers, which seemed to correspond to the end of the mental health/mental illness continuum which equates to the traditional definition of 'madness'. Instead of conceptualising problems along the length of the continuum, they only used descriptions which represented the more severe presentations. They indicated that 'mental illness' would signify displays of overtly aggressive and unpredictable behaviour. These presentations were suggested to include observable or 'visible' behaviours which would be extreme and would consist of violent acts, including damage to persons or property. Again, as with other themes, their descriptions fluctuated from being about adults to being about children, although most accounts used described adults' behaviour.

Participants suggested that they expected behaviours relating to this terminology would be in the extreme, and words such as 'maniacal', 'strange', 'erratic' and 'outburst' were used, indicating their belief that lack of control was displayed by people with 'mental illness'. Using such phraseology also seems to suggest that although behaviours can be observed, there is a sense of intangibility about them. Some of these descriptions were illustrated with scenarios that related to experiences that the group had encountered in their own lives, of people close to them:
JANE: People generally smashing things up. Then from extreme anger to sobbing. One minute they have been so angry and smashing things up and the next minute they will be crying and then when you go to love them. They will accept the love for a bit but then they will get angry because they have hurt you, upset you and they will say, why do you bother with me, I’m no good for you. (Parent 1)

VANESSA: A lot of mental health, unless they are, you know I suppose with media, that there is 'that kind' of outburst and scenes are particularly maniacal, aren’t they? (Parent 3)

When thinking about the term ‘mental illness’, parents’/carers’ responses were again related to other people, mostly adults. ‘Mental illness’ did not appear as a term they would apply to their own children. This was often used to describe a directly ‘visible’ set of behaviours or feelings. Discussions around the term ‘mental illness’ were somewhat deferred from the parents’ own particular family circle, except for where they had direct experience of a partner or family member who had suffered from a diagnosable mental illness. Using descriptions which implied such overt visibility seemed to suggest that mental illness was something that could be easily recognised, and so enhanced the ability for self-protection. Some of the group did not include people with a diagnosable mental illness within their definition of the spectrum of ‘normality’, but saw them as someone who was very different and separate to themselves. Using such a categorisation of ‘normality’ enabled the group to remove or distance the potential to experience mental illness from them or those close to them, offering them a form of immunity. This expressed view corroborates the findings in sub-theme 2b, as it seems to underpin the frequent use of the third person to describe mental illness, thus moving those with mental illness into a marginalised or ‘untouchable group’. Many illustrations related to scenarios of elderly people, or people who they would consider to be in mental health inpatient units, but did not
include children. One parent described her preconceived ideas of a work scenario that had made her feel nervous; however, she also recognised that mental illness was not always visible:

**JANE:** I was working for [Charity for the elderly] on a training course and I think I was there for about a year, and I was very nervous when I first went there; they had mild problems, but at the end of the day we treated them 'normal'. You can have people who have got mental illness and not look any different, or act any different but it is always there. (Parent 1)

Such realisations may represent the added concern that mental illness may not always be easy to detect. In this respect, the invisibility becomes as concerning as the visibility.

**Sub-theme 2e: Fear and safety**

( Somebody who is mental living next door to me?)

The findings demonstrate the perception that people with mental illness could be openly dangerous or a threat to others. Some participants identified that anyone who was seen as 'different' was someone to be afraid of. However, they made a point of determining that this was not their own belief, but a phenomenon they had witnessed in other members of their community when reacting to 'difference'. When examining responses further, it seems that although they thought themselves to be accepting of mental illness, they did hold some stigmatising or fear laden beliefs too:

**JANE:** It's not just mental illness, it's anything that is different, as people are scared of anything that is different. (Parent 1)
VANESSA: I suppose there is a difference, I suppose if there is visible signs because it's quite closeted, isn't it? (Parent 3)

CAROL: Yes, you know, because you do get people who can harm others and I think that could be what puts other people off. (Parent 11)

Sometimes the feelings of fear surrounding mental illness were expressed within a conflicting frame of reference, on the one hand feeling sympathy for them and on the other feeling afraid of what they were capable of, or what might happen to them if they were to come across a person with mental health problems. This could be related to fear of the unknown, unpredictability, or of not knowing how to deal with a person who may behave in an unexpected manner:

JENNIFER: I would be more scared if I met them, than if I sit here thinking about them. If I sit here thinking about them I feel sorry for them, because it must be horrible to not know where you are or what's going on. But if I had to be there, then I would be scared because I wouldn't know how to handle anyone. (Parent 12)

Other participants considered that there was a risk of being close to someone with a mental illness, in terms of safety of themselves or their family. The findings also suggest an underlying fear of contagion. Throughout the study, the cohort demonstrated a good understanding of mental health issues and how to cope with them. However, in this category they do not tend to reflect on the other sections of the continuum, as in previous themes, but rather focus on to those whom they would place in the extreme section. Even participants who have direct experience of mental health would avoid categorising them in this sub-theme, and would not report experiencing fear to this extent. This emerging phenomena seems to reflect that the participants in general, have a positive attitude toward mental health and mental
illness. However, when directly confronted with their thoughts on mental illness, they seem to develop a desire for distance, connected with the uncomfortable feelings derived from living near people with serious problems:

**CAROL:** Yes, the question is am I safe to leave my back door open, if I've got somebody who is mental living next door to me? But if I knew the person's problem I would be fine with it? (Parent 11)

### 5.1.3 Theme Three: Causes of mental health problems in children

**Sub-theme 3a: Parents/carers impact on mental health of children and 'self-blame'**

(110% my fault)

Parents/carers in the cohort reflected on a number of issues, which they thought could have an influence on the mental health of children, and could increase their risk of developing mental health problems. Many of the problems they experienced in their children were identified as being precipitated by themselves as parents, or by situations that had occurred within the family home. Of note is the perception that acrimonious parental separation could have a major impact on children. Within the group, most parents/carers reflected on the concern that their relationship problems had affected their child. As a result they indicated some amount of self-blame in relation to these life experiences, on occasions they also sought to blame others within the family for the child's problems. In addition, many parents/carers reported that they had experienced difficult life experiences themselves, such as domestic violence and mental health problems. They suggested that these issues had a direct impact on their children's mental health. Such beliefs that they were in some way to blame for what was happening with their child, were accompanied by expression of distress, guilt and disappointment. Angela articulates her views on the subject:
FIONA: Well out of the way, yeah. She [child's sister] is probably that little bit older, isn't she? She kind of maybe understands what was happening a bit more and things. But I mean, it's not your fault...

ANGELA: No, no, I know I am still blaming myself...

ANGELA: I mean it's quite hard. I also blamed him [Child's Father] for what [Child] has gone through, I mean if it could be something else or it could just be family circumstances or whatever. I class myself, 110% my fault anyway, regardless.

(Parent 2)

Parents/carers also reflected that some of their actions had an influence on their child's mental wellbeing. This was mainly in not being able to comprehend or cope with the problems themselves, or because they felt they had not spent enough time with their child trying to help them through their difficulties. This precipitated a certain amount of self-blame, feelings of guilt or a feeling that they were punishing their children for something because they didn't know how to help them:

PAUL: I was just worried that it was our fault. You know, we hadn't done what we should have done. I remember especially when he was younger and I regret some of it. How I spoke to him... (Parent 18)

VANESSA: But it's again the thought that I have not put as much in as I did with the others, and I feel guilty about that because there's not often the time, and ironically it's her more than any of those three, who need it. Which is why I am letting her go to this headmistress every two weeks, because I think she will get it there a little bit.

(Parent 3)

Some parents/carers highlighted that they thought their negative attitude towards their child had caused their poor behaviour, or unhappiness. They expressed a view
that sometimes their parenting gave mixed messages or caused confusion in the child. They occasionally felt that the impact of this was something that they could not undo, because it was too late. Such reflections were often accompanied by an air of resignation. Even though they had recognised some of their errors, they suggested there was nothing they could do to change the situations. Within the data, parents/carers showed a lot of regret for their past behaviour towards their children:

Kim: I know of one [a cause for problems] - having an understanding of [child] when he was small. The difficulties he was having in just walking. You know, I used to get cross with him for falling over. I used to say ‘walk properly, for God’s sake’. He used to be tripping me up, and now I know with Dyspraxia he was doing the best he can. But all of those negative messages would have done damage. (Parent 9)

Sub-theme 3b: External factors which impact on mental health problems –
(There was something externally causing it)
Parents/carers identified a number of issues external to the family environment, which they considered to impact on children’s mental health. They suggested that children’s mental health problems were not just caused by one factor, but had several complex factors which could interplay, and that it was the interaction between the factors which could cause the problems their children were experiencing. Some these, which they identified to be beyond their control, centred around the child’s social environment, such as the pressure that children can be under from peers to concur with fashions, or subsequent bullying that can take place as a result of looking different or being identified as having problems. Parents/carers considered there to be a significant risk related to this area, and many of their children had been subject to such discrimination, as a result. Jane talks of a situation she experienced with her child:
JANE: Off [local estate]. So all the kids have named stuff there and it's silly really because basically across the road there are two different schools.

FIONA: And that's the difference. Do you think that has an effect on children if they have to put up with that kind of pressure?

JANE: It's like games as well, you know computer games if they haven't got the latest games or consoles, they will get picked on at school and that will cause depression in the kids. (Parent 1)

Other causal factors related to life experiences such as bereavement or loss, or having high expectations placed upon children, especially within the school environment. Changes in life circumstances, such as the birth of a new baby, or having to move house or school, were also thought to have an impact. The difference in this sub-theme as opposed to sub-theme 3a, is that the parents/carers do not seem to hold the same self-blame or guilt feelings, about the impact on the child. However, within this sub-theme they seem to accept causal factors, but they do not offer any solutions to compensate for the problems. This view seems to portray a feeling of inability to change such pressures, or that individually they cannot have much impact on these situations, which they viewed as an ordinary part of life:

ALISON: Yes, because children are all different and it maybe something which is specific to them. The issues are all part of life, it's how they deal with them that makes a difference. (Parent 4)

Some parents/carers also considered that other issues, over which they had little influence, or sometimes were not always able to identify, could be a causal factor, e.g. chemical imbalances, congenital disorders, food intolerance and hidden drug misuse. Certain factors were beyond their control and these related to genetic disorders or the stresses of daily living in the present society:
SADIE: Like a chemical imbalance in the brain, or whatever. (Parent 13)

KATRINA: I suppose there would be a difference, whether there was something externally causing it or whether there were any congenital problems that were manifesting during their development. (Parent 10)

JOYCE: I know some children get hyperactive by what they eat. Diet can cause some problems. (Parent 7)

**Sub-theme 3c: The need to find a cause and emancipation**

*(Has he got a syndrome?)*

The parents/carers reported that their main objective was to find a cause for their child’s emerging mental health needs. Without exception, they suggested that they wished to know if there was a definable or diagnosable problem, and that if there was, then this would offer them some reassurance. The desire for reassurance seems to be related to the emancipation from self-blame, and reassurance in the knowledge that something can be done to help the child. The desire to find a cause focused on the belief that some of the problems their children were experiencing had been caused by external factors, on which they could have no influence. Whilst many of them believed that there was something unknown, ‘deep inside’ their children, that needed help to come out. Taking this view seems to show some incongruence with the self-blame reported in sub-theme 3a, and would also appear to help participants in being freed from responsibility for their children’s problems:

MATT: I’m a big believer in cases such as [child], where I think there is something in there and it needs unlocking. (Parent 16)
Some of the causes they identified related to the problems they had experienced in their own childhood and a perception that these problems had been passed on, or had contributed to the difficulties their child was now experiencing. Some parents/carers wanted to know if they were the cause and if it was related to their perceived negligence, or that in some way their own experiences had had some influence. Not having an understandable term that defined their child's behaviours or presentation seemed to imply that parents/carers were responsible for the problems. Having a recognised medical definition or cause seemed to help parents/carers make sense of their child's needs:

ANGELA: I've always thought because I read about it now, at the moment that is the MMR, because he was fine until he had that injection. (Parent 2)

The comments from some parents/carers indicated that the possibility of having a diagnosis would somehow give them reasons for or help them to make sense of their child's presentation, and this would assist them to find a cure, or enable them to follow the correct path to helping their child. Some of them identified that they had been making assumptions about what was wrong with their child, and that if they had a diagnosis they would then know how to help:

JANET: No, I'm not saying it's that and [Educational Psychologist] wasn't saying it was that. But what he did say was, he mentioned slight Autism to me and then he used the proper word and I just looked at him and said “thank you very much”. He said “why did you just say that?” I said it was because I had said this many years ago but I wasn't listened to. It really grips you because that's my child. Of course, I am going to want to know if there is something wrong. (Parent 5)
KIM: It’s not totally clear and relies on my sort of interpretation of how he behaves and that. And a lot of the time as a parent you’re guessing it. Well, you might think he might be thinking this, and if you have any preconceptions yourself, which some people might have, you steer information the wrong way. (Parent 9)

A couple of the parents were concerned that their child might have a ‘syndrome’ or ‘learning disability’, their major concern was to have these assumptions confirmed or refuted, so that they could try to make improvements:

CAROL: Has he got a syndrome? And with this syndrome, does he have learning disability? (Parent 11)

5.1.4 Theme Four: Experience of mental health problems

Sub-theme 4a: Positive perceptions and the understanding of illness

(Well, I’ve got a bit of an insight because I was actually ill)

A majority of parents/carers identified that they had experienced mental health problems themselves, or they had a close family member with mental illness. Their personal experiences related to depression, post-natal depression, panic attacks, eating disorders, having a partner with schizophrenia, or having experienced a period of in-patient care themselves. A number of participants reported that they had a relative whose children had some form of mental health problem; however, they tended to include children with learning disability in this category. Although they openly report these perceptions, they do not seem to tie in with earlier sub-themes, in which they express a conflicting and stigmatised view of mental illness. Many of the females within the cohort openly reported that they had been on medication or had treatment for a mental health problem at some point:
VANESSA: Well, I've got a bit of an insight because I was actually ill when I was younger, I had anorexia, so I was in, I suppose, what you would call a mental institution, but it's for adolescents. Although I don't think specifically that thing is more like an eating disorder. (Parent 3)

KAREN: I'm still on antidepressants at the minute and I've been to the Doctors for about six years. (Parent 15)

The group seemed to show a good understanding of the experience of caring for others with mental health problems and demonstrated empathy around some of the difficulties that a person may have. They felt that because of their experiences, they had developed a better attitude and understanding around mental health per se, and as a result often advocated against stigma. They considered the extent of people who had mental health problems to be on the increase, and that this could be because of them not being able to cope with difficult situations in their lives:

VANESSA: I think there is [a lot of mental illness], but I think today, like this article about the number of people on Prozac.

FIONA: Yes.

VANESSA: Was it five hundred thousand, and now it is five million, or something like that? I just think people aren't taught enough how to cope with ups and downs.

(Parent 3)

SADIE: Yes, it could, it could be certain things that have happened in the past and they come back and they just...I don't know. I've had a lot of friends go through psychosis or whatever. I have got quite a bit of understanding on it, breakdowns and so on. (Parent 13)
A couple of parents/carers had sought help for their own needs because of the problems they had encountered when trying to find help for their child, and many suggested that they had lived through difficult situations. They reported that these problems had occurred especially following periods of abuse within the home. Domestic violence was raised during the interviews on a number of occasions, and they believed that it had a direct impact on their own and their child’s mental health. These parents/carers reported that their understanding of mental health, and their reduced concerns about the effects of stigma, were a result of desperately wanting help, therefore they did not think in a protracted way about the meaning of going for help and the impact stigma may have. However, some parents reported that members of their family had some difficulty in accepting or understanding the mental health problems being experienced by their child, and this at times could cause certain problems within the family dynamics:

_ALISON:_ My partner at the time, he couldn’t accept that it was a problem, he thought it was [child] playing up. But I said I know my son, this is not him playing up, so it was just that everything was going wrong at the time. (Parent 4)

Whilst other participants suggested that having to deal with mental health difficulties within the family home had an impact on their quality of life:

_JANET:_ It’s not just that, I’m angry, I’m frustrated but I am upset for him. [partner] will tell you how I get, I’m actually seeing the doctor myself anyway, but it has taken me a long time to go and sort it. (Parent 5)

Although the participants demonstrated a more positive attitude toward mental health than in other themes, many of them expressed both notions within their interviews.
Sub-theme 4b: Positive awareness, empathy and seeking information about mental health problems and illness

(I read it and thought, yes, I know how you feel)

The parents/carers demonstrated an awareness and understanding of mental health problems and mental illness that related to their personal experiences, either directly or indirectly. They reported that their personal experience of mental health had prompted them to develop their knowledge further. All parents/carers had attempted to develop their knowledge through seeking more information, via a range of difference resources. This included either through reading books on the subject, picking up leaflets, watching TV, or through the internet. Some had developed their knowledge at work or through friends or family who had worked with children, or who had children whom they defined as having mental health problems. A few parents/carers commented on the way they had obtained information about mental health:

MATT: Our friend has been on everything [medication], so we have seen quite a range, and how different the behaviour is. We have seen from a distance how people like MIND [voluntary agency] and RE-THINK [voluntary agency] have all helped him come through. (Parent 16)

ANGELA: Oh yeah, I’ve seen it [mental health] on documentaries or things like that. If anything comes up like that, you know, if anything comes up on behaviour issues or anything like that, or the abuse I’ve been under as well, you know. (Parent 2)

KAREN: There is a lot really [information] and it [experiencing mental health problems] kind of brings it to the forefront, and it makes you realise that people might have a point and you go and find out. (Parent 15)
Some of the cohort explained that they had specifically sought to learn more about their child’s needs, using information or real life scenarios to prove or refute their concerns about their children. The desire to know more and understand the problems their children were facing was expressed regularly and accompanied with real passion to develop empathy for not only the child, but also for others who had been in similar situations. Alison explained how having more information helped her to connect with the problems her child was facing:

**ALISON:** Somebody left me a leaflet, a cutting out of The Times the other day about a young girl who is 10 and she goes into her mum’s room every night with fears of everything, from someone dying to someone breaking in. [Child] has gone through those as well, as much as his fears of ghosts, we have had the dying and his Grandma, Asperger’s syndrome and everything else. I read it and thought, yes, I know how you feel. (Parent 4)

Many of the participants stated that they were aware of other children with mental health problems. This recognition was mainly related to diagnosable disorders such as ADHD and Autistic Spectrum Disorders (ASD). However, some participants did not think they had come across children with mental health problems and had found out about problems by default. When parents/carers encountered children they defined as having mental health problems, they had used the observed presentations to compare against their own child’s problems, therefore acting as a self-assessment measure. Many parents/carers taking this approach did not feel their children had a comparable disorder:

**ALISON:** But you get used to that, and I do know that he is active and although he has got a bad temper, he doesn’t come over to me like some of the children you do see with ADHD. (Parent 4)
Some parents'/carers' desire to develop their knowledge about mental health was triggered by their experience of their child’s difficulties, particularly when they noticed significant changes in their child's behaviour. This also relates to an earlier sub-theme, where they discussed what had provided the catalyst for them to seek help. They demonstrated that they had tried to increase their knowledge as a consequence and they had sought knowledge from different sources to help them find solutions to their child’s problems:

JANET: We have learnt just as we have gone along. (Parent 5)

DAVE: [Teacher] went on the internet at school for us and we read the fact sheet and we went yes, yes, yes, to all the list of things. (Parent 6)

Sub-theme 4c: Formal learning and knowledge of mental health
(I've done my BTec [in child care])

A majority of parents/carers had actively developed their skills in coping with mental health problems. Their experiences and desperation to discover what was wrong with their children had prompted them to develop their awareness and understanding. Much of this desire to increase their own capacity, seems to have arisen from the frustration they had experienced in relation to seeking a solution to the problem. Although the desire to develop knowledge was illustrated in the sub-theme above (4b), many of the group had undertaken specific formal studies, and some were involved in work with a caring emphasis. Whilst a minority of remaining parents had not sought to develop their capacity further, those who had embarked on further studies had expressed their desire to learn more, with a distinct enthusiasm:
CAROL: I've done my Diploma in Child Care. I've done my BTec, which was very
good because that covered a little bit of psychology. (Parent 11)

FIONA: Sounds like you've studied it [mental health].

ANGELA: Well I am. I mean I want to pass my assistants’ course on Saturday.

(Parent 2)

5.1.5 Theme Five: Stigma – the meaning for parents/carers

Sub-theme 5a: ‘Mental’ is stigmatising and discriminatory

(I think the word is heavily loaded)

All parents/carers outlined that the words ‘mental health’ were stigmatising in some
way, although some of them did not specifically assign this perception to themselves
or their own beliefs, but to the wider community or society in general. Participants
suggested that those who considered ‘mental health’ to be a shameful or a potentially
embarrassing issue could act unwittingly in a stigmatising manner towards people
with mental health problems. Their view was that the stigma was generated and
maintained in society, because of the meaning and euphemisms associated to the
word ‘mental’, and the sensitivities and fears associated with mental health problems
and illness. A small number of parents/carers found the words shocking, upsetting
and even offensive, and suggested that they would deter people from seeking help:

MARTIN: ...much of it [language about mental health] is obviously negative. That’s
why there are so many colloquialisms around, which are to do with mental health.
Like, "he is crazy", or "she is looney", "thick", that sort of thing. That really is or how
people generally relate to others around them... (Parent 17)

MATT: I don't like the word 'mental'.
FIONA: What does it make you think about?

MATT: Being thick in the head, not knowing anything. (Parent 16)

ALISON: I think the word ‘mental’ could do [be stigmatising]. I don’t personally, but going by other people when it’s something new to them, if they haven’t dealt with anything to do with mental health before. People’s ideas of psychiatrists and things for children, they don’t want to admit that there is that sort of problem. They look at them as if... (Parent 4)

Some parents/carers suggested an alternative to using the term ‘mental health’ could make services more approachable, feeling that it might improve access. However, others considered that it was important to retain the words, and to challenge the stigma that surrounded them. Some participants reported that they were unperturbed by the name of the service, they just wanted to access help for their child:

FIONA: It [the words mental health] doesn’t put you off or anything?

JANET: No, no, because that’s like you are ashamed of your own child, how can I be ashamed of my own child? (Parent 5)

Despite the general demonstration of understanding about mental health, many of the parents/carers highlighted that the words ‘mental health’ still conjured up some stigmatising feelings in them, and made them challenge their thoughts about referral to a mental health service. The strength of the stigma still associated with the words left many participants feeling upset and worried about the effect that attending the service may have on their child. They often reported that their first thoughts about mental health were the images of severe, life-altering mental illness. They suggested that mental health was a powerful and stigmatising issue. In connection with this even the most aware reacted by experiencing fear, shame and distress. However, even
though they reported that they felt stigmatised by such words, they did question their own feelings, suggesting that the issues surrounding 'mental health' were deeply seated within society and held a form of legacy. Vanessa and Katrina described their reactions to receiving an appointment letter from CAMHS:

VANESSA: Yes, I do [think stigma exists], because when I got your letter it really upset me, not just the heading 'Mental Health'.

VANESSA: It was when I got it, it was just Child Mental Health Service, and I just burst into tears.

FIONA: Ah.

VANESSA: And that's me who knows it's not like that at all. But I suppose the legacy of it [mental illness] just carries it [stigma] on. (Parent 3)

KATRINA: I think that because of that stigma, there is a lot of denial...self-denial and there is a reluctance to go for help, and that is across a whole range of problems, that wouldn't actually mean mental illness? Serious mental illness? (Parent 10)

There was also discussion in many of the participants' dialogues, surrounding the image given to people with mental health problems by the media. They reflected that sometimes reporting in newspapers and on the news could be extreme, using negative attributes to describe mental health. This portrayal of mental health problems and mental illness was thought to contribute to the lasting stigma and discrimination associated with the term 'mental', and was suggested to contribute to the negative attitudes held by the general public. Jane reflected on the images in the media:

JANE: But if you see it in the media, if you see anything about mental illness, it's always all bad news.
FIONA: So you think it can go to the extreme?

JANE: Have you ever seen a clip in the newspaper about a mentally ill person who has done something good? It's always something that thousands of people do everyday but because they are seeing a psychiatrist or they are on medication, it's got into the papers. (Parent 1)

Some participants reflected that, in their view, society had accumulated a negative belief about the term 'mental', which resulted from a distinct lack of understanding. They considered that there was a certain amount of ignorance amongst people. They suggested that the general population would benefit from enhancing their awareness about mental health, especially around the words used in everyday conversation.

Parents/carers also considered that people whom they identified as being educated (for example, professionals), also held stigmatising beliefs. This notion demonstrated that the word 'mental', in some of its alternative forms were entrenched within common language. In conjunction with this, they suggested that 'mental' was generally perceived to be frightening and outside of the realms of personal experience. Alison and Vanessa offer some interesting insights:

ALISON: I think that if you are a little bit more ignorant to it, then I suppose you could do. I suppose it's scary to some people. They think "Oh, mental"! (Parent 4)

VANESSA: Yes I think they would, I think they know when they are educated, they know in their heart of hearts that that is not what it's about, and that's not what is going to happen to them, and they have not got to wear padded jackets. But I think the word is heavily loaded. (Parent 3)
One parent also highlighted that people with mental health problems, which were visible in presentation, were more likely to be perceived in a discriminatory way and be associated with 'madness':

VANESSA: I think they are perceived in different way. I don’t know whether doctors see them as the same, but I think when you are visibly acting irrationally the word ‘mental’, people associate with madness don’t they? (Parent 3)

Sub-theme 5b: Stigma and derogatory language
(We know you are a ‘nutter’)
Participants used a wide variety of words and phrases which seemed common to their general conversation when describing mental health problems. Some of the phrases used did not relate directly to problems, but used indirect descriptions of presenting behaviours; for example, phrases like 'on one', 'changes in the weather' and 'lost it'. This perhaps arises from the difficulty that parents/carers had in discussing mental health problems or mental illness directly, or suggests that words selected from familiar synonyms are used to describe mental illness:

JANE...But if he is ‘on one’, that’s what I call it; his school goes, he doesn’t look after his animals properly if he is ‘on one’. ‘Mental’, that’s another. ‘Lost it’...

JANE: ‘Schiz’, ‘loopy’, that’s one. I’m trying to think because I’ve said them all.
(Parent 1)

Many participants outlined that a range of stigmatising words were regularly used and, although they considered them to discriminatory in nature, they were used in an intentionally derogatory manner. Words such as ‘nutter’, ‘crazy’ and ‘mad’, were frequently used in descriptions. Some parents/carers used these words when describing people with mental health problems, or indeed their children’s issues.
However, the way in which they used them did not come across as deliberately offensive. Participants also observed that other children and the general public frequently used demeaning phraseology, and although they felt the phrases where not used in a directly disparaging way, the intonation sometimes appeared to be derogatory:

SUSAN: Kids could say to him, like we know you are a ‘nutter’, and stuff like that, and that could be off putting, couldn’t it? (Parent 14)

VANESSA: What you would call ‘nutters’ [describing a mental health hospital], I know I shouldn’t be saying that. For instance, they’d been there since they were children and they had been locked up for ages, and there was little old ladies pushing dolls prams and people shouting out and stuff. (Parent 3)

Some parents/carers recognised the demeaning quality of terms used in general conversation, and established that they actively ensured they did not use stigmatising language themselves. Instead they tended to use the words ‘mental illness’ and ‘difficulties’ to describe a person with mental health problems:

FIONA: What kind of words do you use to describe somebody who has a mental illness?

ANGELA: I would say it’s ‘difficulty’.

FIONA: Yeah.

ANGELA: I think ‘difficulty’ is a good word. (Parent 2)

FIONA: Ok, so do you use any other words to describe mental illness or do you use those two words?

ALISON: I probably use those two words to be honest. (Parent 4)
Sub-theme 5c: Knowledge affects attitudes

(‘It’s the unknown that scares people’)

Parents/carers expressed the view that it would be easier to access help from services if they knew what to expect. This also seemed to relate to their notion that being better informed about mental health and illness will result in more positive attitudes. One parent reflected that their concerns were mainly due to the stigma attached to services, and that mental health was an unknown field which conjured up fear in people. Whilst another parent reflected that concerns about mental health were not as great as they used to be and this could be accredited to general awareness raising. Some of the group suggested that their attitudes had improved because of their experiences at home, or within the work environment. However, there was still a feeling that people were frightened of mental health problems to some extent, and that although opinion has thought to have changed a little, parents/carers were still concerned about the adverse effects that stigma could have on children:

FIONA: They didn’t say anything about what to expect, do you think that would be useful?

JANE: Yes, because of the old stigma about it as well.

FIONA: So it would make you feel better? If we sent you a letter saying what would happen when you get here.

JANE: It’s the unknown that scares people as well. (Parent 1)

FIONA: How did you feel when you received the appointment letter from ‘Child and Adolescent Mental Health Services’?

SADIE: Just really worried, what it would mean for [child]. (Parent 13)
Those who had direct experience of mental health problems or had a friend who worked in the field, showed a greater understanding of mental health and a reduced concern about stigma:

**PETRA:** Well, I wasn't worried about the stigma, because of my previous awareness… (Parent 23)

**ALISON:** But then that's probably because I have friends that nurse, and a couple that I clean for actually work for mental health and the elderly dealing with problems like that. So, yes, I suppose I would use those words. (Parent 4)

**ANGELA:** No, I wouldn't [see ‘mental health’ as stigmatising]. Not personally but that is because I have known people and realise that it isn't. (Parent 2)

One parent reflected that it was important to separate her child's problems from others' perceptions of 'madness':

**ALISON:** My child is not a 'nutter', but it isn't that, it's getting over to them that it's help for other reasons not because the child is totally nuts or something. But it's quite common, I know with [child's] problem, it is a common thing just from people I have spoken to. (Parent 4)

Some of the older members of the cohort considered that there had been a fluctuation of levels of stigma and discrimination throughout the generations, and that those from the older generations were far more tolerant of people who had mental health problems or disabilities. They felt they had been brought up with a better attitude and were more inclined to help others:
JOYCE: Well, I think the older generations are used to things like that, as they were brought up to help people like that. You wouldn't stand there and take the mick out of anybody, but nowadays you see people that only have to walk funny or have something wrong with them, and you see kids taking the mick out of them. (Parent 7)

Some parents/carers reported that their experience adult mental health services increased their reluctance to access services for children. They demonstrated a pre-conception of services based on negative experience, and were concerned that their children might be hospitalised:

KIM: You know, in that they have been hospitalised or it was for rehabilitation. That’s the sort of norm view of services. (Parent 9)

A minority of parents/carers suggested that the words made them feel embarrassed, and that there was a definite stigma attached to them. They felt the words could generate bullying, were a frightening label, and could breed prejudice and contempt. They also considered these words to be extremely powerful and that it may take some time to eradicate the prejudice attached to them. Katrina and Kim reflected on their views of the terminology:

KATRINA: Absolutely, yes. They are very frightened [of the words ‘mental illness’] and it’s a label that people shy away from and people don’t want to be described like that and don’t want to be talked of in that way. (Parent 10)

KIM: But I am fully aware that a lot of parents, for instance, if their child was referred to [mental health service], they’d be like ‘Oh my God’ you know. Because of the ignorance and stigma and lots of misconceptions (Parent 9)
Sub-theme 5d: Society is stigmatising, not the individual

(There is still stigma about what is seen as socially acceptable)

A regular idea that emerged in relation to parents' and carers' experience of others' perceptions of mental health, was the belief that the majority of stigma originates from within society. Some had experienced stigma through discussion with others about their child, or in relation to observed behaviours of others toward people considered to be 'different'. These descriptions were often accompanied by the view that stigma did not originate them, but rather from societal attitudes. This seemed to be either compounded or reduced, according to the way that individuals had been raised to accept people of difference. In some cases, parents/carers identified that they saw their child as being different to other children. This idea was developed as a response to observing the way that others treated their child:

CAROL: I'm not [discriminatory], but you can see it around [Stigma] you, and there is still stigma about what is seen as socially acceptable. (Parent 11)

ANGELA: I think he [child] is aware, there are other children in his school that have problems as well, yeah. You know have things like that. I think he did [experience discrimination], when he first started at B[school], when he was at F[school] it was really hard for him because he, because it was such a small school, not many kids could adapt to what [Child] was like. But then when he went to B [school], he came across so many other children. (Parent 2)

One parent reported her personal experience of having a partner with mental illness, observing that he was stigmatised in the same way she had seen people with physical disability subjected to discrimination. She implied that society tended to group people together who were seen as different:
JANE: And you see people who are on say a bus, they do it with handicapped people as well, they move away like they can catch something, or if they go shopping and you see carers taking handicapped people out for their shopping, you see grown adults, I mean you would expect it off kids, you can see them staring and then you can see people getting agitated because they know people are staring at them. That's another cycle: they are agitated because people are staring at them, so people are going to stare at them more. (Parent 1)

There was a consensus amongst participants that the general public had, in general, difficulty in understanding and accepting mental illness. Although, as with other sub-themes, parents/carers reflected that they did not hold discriminatory attitudes, but rather considered society to categorise mental health in a stigmatising way. They suggested that society found the concept of mental health difficult to accept and that this was fuelled by ignorance:

ANGELA: I think there is a lot of people out there, you know, that see someone has a mental illness, you know, they'll go 'wow,' you know.

FIONA: Yeah.

ANGELA: And they step back and walk the other way. (Parent 2)

VANESSA: Because they see it as like, I mean I think it is perhaps a mental disorder because it's this idea of, me taking control and kind of mind over matter, I suppose a little bit.

FIONA: So you don't feel that they [people with mental illness] are like this?

VANESSA: Not so much me, but I don't think society does as much. (Parent 3)
Sub-theme 5e: Myths and traditional views of mental health services as institutions

(You think white walls padded doors, bars)

The majority of the cohort articulated a belief that 'mental illness' still produced an image of old-fashioned mental institutions. They described scenarios which included padded cells and secure provision. Some of the parents'/carers' ideas about child mental health services included this view. They reported that they expected staff to be wearing white coats and that children would be admitted to inpatient wards. When one parent received an appointment letter with mental health services written on it, this was her immediate reaction:

JANE: Another thing when you say that you are going to see someone about mental health, you think white walls padded doors, bars. (Parent 1)

Vanessa talked about her experiences of therapy and her notion that mental health services had not changed, whilst Janet highlighted her surprise about a school for children with special educational needs:

VANESSA: Well, yes [expectations were based on past experience] because although it was actually a separate unit attached to what was called "The Tower" [old psychiatric institution], so this great big gothic Victorian, you know how it used to be and for our therapy session we used to have to walk through. (Parent 3)

JANET: Yes, definitely. I mean Jody's mum took me up to [Special Needs] school and I had a chat with the Headmistress up there and it really opened my eyes quite a lot. As soon as I walked in and I saw the children, I thought this is not the place [Child] needs to be. (Parent 5)
Many parents/carers suggested that some of the historical stigma which still remained was because of fear and ignorance. They suggested that the word 'mental' conjured up fears of being institutionalised, and lack of knowledge about services bred fear in those seeking help. This supports the findings in the earlier themes, and corroborates the image that mental health is stigmatising, and that images held by participants are mostly grounded in the past. The idea that children might be taken away from parents or carers was still a predominant feature in some participants' thinking:

**SUSAN:** Then I thought like, when your heart beats mega, and 'oh I hope they don't put him a mental home' or something like that. It's a bit scary, sort of thing. (Parent 14)

### 5.1.6 Theme Six: Experiencing the stigma of child mental health problems

**Sub-theme 6a: Fear of accessing services and ‘labelling’**

(*I don't want my child to go on a database*)

Many of the group talked about their concerns related to asking for help. This was mostly in the context of a belief about the use of extreme treatment modalities for children in CAMHS, such as use of tranquilisers, in-patient care and the fear of being labelled. The discussion suggested that the stigma which surrounds seeking help for mental health problems was constructed through images of psychiatric labels that were conveyed in the media. Some parents/carers were concerned that children may be socially excluded as a result of attending mental health services, because of stigmatising perceptions held by organisations, such as schools, as well as the wider community. Some parents/carers also talked about their belief that their child would be labelled by going for help:
JANE: The labelling that we would get “Oh, he has to see a shrink” or “Her lad’s gone to see a psychiatrist”. So there is only a few close friends that I have told. If I had thought that taking him to the doctors would have given him, that kind of a label on him, I would not have gone. But at the doctors it’s all confidential. (Parent 1)

‘Labelling’ arose as an issue on a numerous occasions throughout the interviews. Comments relating to labelling were prompted through the experience of discussions with or opinions of others. Some parents/carers feared that their child may be bullied as a result of being labelled. Whilst others admitted that they had experienced denial about their child’s problems. They identified that being labelled would confirm their fears about stigma and would result in their child being shunned or marginalised.

A few participants suggested that their children could be embarrassed or feel shame because of the label they might acquire as a result of attending mental health services. One parent explained that her parents still considered there to be a stigma around going for help. In contrast, some parents/carers reported that being defined as having a mental health problem could be conducive to getting appropriate intervention. This reduced the fear of being labelled, so the issue was not a great as they had first interpreted. This dichotomy of perception appears in most of the interviews. Parents/carers seem to have an internal argument surrounding their own belief system about mental health and stigma, those beliefs influenced by external factors, such as friends or family, and the desire to gain appropriate assessment and intervention:

VANESSA: Yes, so it’s a kind of two-edge sword. On the one hand I think there is still the stigma. I don’t think it is as bad because people still see it as synonymous with help now, that you’ve got to have a diagnosis in order to get that help. So I think
JANE: The labelling that we would get “Oh, he has to see a shrink” or “Her lad’s gone to see a psychiatrist”. So there is only a few close friends that I have told. If I had thought that taking him to the doctors would have given him, that kind of a label on him, I would not have gone. But at the doctors it’s all confidential. (Parent 1)

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that's been eroded slightly. But I don't know what else you could do really, getting the schools more involved as well? (Parent 3)

Some parents/carers explained that the fear of being labelled had actually prevented them from seeking help at an early stage, reporting that they waited until the problems had escalated before requesting a referral to child mental health services. In this respect, they considered that being labelled could be a barrier to help. Such concerns were not solely related to the label of a diagnosis, but also fears of the long term effects of being placed on a mental health database:

KATRINA: I don't want my name to go on a database or I don't want my child to go on a database, so yes, it is frightening. (Parent 10)

Parents/carers expressed the perception that attending a mental health service resulted in a sense of shame. They explained that by attending a mental health service, it meant that they were putting their child into a specific category which indicated the child's problems were severe. The difficulty they had in relation to this aspect was firstly, the need to accept that there may be a problem and secondly, the fear that it may be worse than they first thought; thus admitting their inability to cope with the situation:

KATRINA: Yes, definitely, it's the degree of seriousness and again you are up against the labelling given to them. (Parent 10)

Sub-theme 6b: Personal experiences of stigma and challenging stigma
(They have made it blatantly clear, anyway, 'that' is the sort of child they do not want at their school)
The majority of the cohort reported that they had experienced some form of stigma or discrimination in relation to their children’s mental health needs. Their responses and reactions ranged from feeling uncomfortable when describing their child’s problems, to telling people they were going somewhere else for help rather than disclosing the true nature of their difficulties. Some parents/carers suggested that the discrimination experienced from the stigmatising effects of mental health was more covert and hidden than the prejudice that they had observed which they thought related to racism. On this count they found it hard to challenge. In some respects, as participants’ feeling of being stigmatised seemed to originate from with the ‘self’, the shame that emerged suggested that the hidden nature of the stigma could culminate in a ‘self-fulfilling prophecy’. The impact of this was thought to be two-fold, wherein there was a possibility that children may act out the expectations of others in relation to their label, or that parents/carers may avoid seeking help until they reach a crisis point. Thus, the severity of the problem would also be emphasised.

Some parents/carers explained that they felt that people where looking down on their child, or that they were ‘categorised’ in a negative way. A common message conveyed throughout the interviews was that children were excluded or shunned by others. This experience also served to magnify the problems. Angela describes the experience she had when asking someone for help with her child's problems:

ANGELA: Yeah. And I felt that, you know, like me and you are talking on our own now, but whatever problems I had with [Child], he was sitting there, so it felt like he was discriminating him slightly to actually sit there and gossip about my son who had to be sitting right next to this person [GP]. So you know, somehow, that might have made him feel humiliated or anything, like, that kind of way. (Parent 2)
Some parents/carers reported their tendency to define problems in more acceptable terms, e.g. that they had a learning disability, rather than a mental health problem, in an attempt to reduce the impact of stigma. However, their experience of pity from others contributed to the belief that their children were 'different' or tainted in some way. Vanessa described a situation where people treated her differently when talking about her child, especially in relation to the child mixing with others:

VANESSA: And it's like one of the mums, when she says "How's [child]?" She sort of tilts her head, you know like she is obviously aware that there is a problem, and "Will she be alright coming round and playing?" I said "she will be ok for an hour, just give me a ring, it will be fine". But, she means it nicely but it's all this, "And how's [child] doing?". (Parent 3)

Some parents/carers considered it necessary to challenge stigma when they encountered it. One parent stated that she would explain to people that mental health problems were relatively common, whilst another felt angry toward people with a stigmatising attitude:

JANET: What if they are talking in a horrible way about it [mental illness]? I think I would get very angry with them. I really would. (Parent 5)

Many parents/carers indicated that they had experienced discrimination from some of the organisations that work with children on a day to day basis. This seemed to arise from lack of understanding about the child's problems. They also had a fear that when they approached professionals for help, the problems they were encountering would not be understood:
DAVE: They have made it blatantly clear, anyway, that is the sort of child they do not want at their school. (Parent 6)

JANET: No, Mrs [Teacher] is good with him, she’s Deputy Head. The Headmaster has no tolerance with children such as [Child]. (Parent 5)

Parents/carers reflected that their children experienced stigma through bullying, or through their problems being misunderstood by professionals and peers. Occasionally this would result in their child being excluded from school or from social circles. They reported that they also suffered prejudice because their child had mental health problems, and that they were often branded and treated differently, as a result. As a consequence they reported that they were reluctant to ask for help, in case this escalated the repercussions of stigma:

KIM: Because [child] does have difficulties, and he’s been classed as a naughty child, before any problems were diagnosed. Can you imagine what a sense of injustice and harm that does to a child? (Parent 9)

KATRINA: What I know from work and my own understanding of my children’s needs and how I address it. It still makes me very reticent to go down that road. (Parent 10)

Sub-theme 6c: The urgency to tackle stigma

(Tackle it now)

A number of parents/carers in the cohort suggested that services do not do enough to reduce stigma. A way of challenging stigma was for child care agencies to promote mental health awareness, as a matter of urgency. In addition, they considered that education of the general population would contribute significantly to acceptance and reduction of stigma. Some participants suggested that it was important target
individuals who had the most entrenched beliefs, particularly adults. Others felt it was important to teach children about mental health from an early age. When participants talked about the need to tackle stigma, it was accompanied with a certain vitality and strength of conviction:

MARTIN: Tackle it [stigma] now. (Parent 17)

KATRINA: No, I don't think services do enough to explain about mental health. I think they could do a lot more to explain, a lot more awareness maybe even in the beginning, with some kind of definition to explain the spectrum. (Parent 10)

5.1.7 Theme Seven: The impact of child mental health problems

Sub-theme 7a: Frustration in getting help

(It feels like for years, I've been going through the system)

Parents/carers described their frustration in trying to get help and the subsequent relief they felt once a referral had been made to CAMHS. They identified that they had recognised their child's emerging problems from an early age. In response to this, they had encountered many dilemmas in trying to establish the origin and nature of the problems, both from a personal and service context. Many participants described the experience of asking for help as if they were 'going around in circles', suggesting that the care pathway was not clearly defined. The frustrations they described highlighted intense feelings of anguish and struggle, which had been precipitated by difficulties in receiving a service, or the feeling that their concerns had not been taken seriously:
ANGELA: Yes it is, it is really too long [the wait] because when he was being seen in October, we were just sort of like getting a ball rolling and strategies were sort of like working, and...(Parent 2)

Waiting times were described lengthy and considered to contribute to parents'/carers’ anxieties about their child’s problems. Much of their frustrations seemed to be heightened by the requirement to persevere and to pursue help, often being deferred or deterred from obtaining a referral to services. This was sometimes exacerbated by them having their own difficulties to contend with. As a result, they expressed concern for those who were perhaps less informed and less able to speak for themselves. They suggested that parents who fell into this category could experience a greater struggle in obtaining help and their children’s problems may become more severe:

KAREN: They didn’t really understand what I was trying to say to them. Because I was depressed, I couldn’t explain. Then I couldn’t be bothered going, and then you go down and down. That’s because you are not getting any help and you can’t do it on your own. (Parent 15)

SADIE: Oh, every time I rang them, they were like ‘come back in six months’. There is nothing for the foreseeable future. I have since found out that you can’t just ring up. You have to be referred by someone. (Parent 13)

Parents/carers highlighted that problems in organisational systems contributed to their difficulties in obtaining a service. This included poor communication between professionals; services frequently ceasing their support; or having to re-start the process because they had not been referred to the correct service. This indicated
their need for clear information about services, unambiguous criteria, easy access, and some co-ordination of the referrals:

BILL: Plus you have to wait for the Dr to write to someone, and then for them to write back. Just seems like a hell of a long process, you would think there would be a quicker way of doing things. (Parent 8)

SADIE: No, not just waiting, I had to go through so many different channels. It feels like for years I've been going through the system to get where I am. I just feel I've been pushed out. (Parent 13)

Sub-theme 7b: Desperation and struggle within the family
(I cannot cope with this, I need some help)

Parents/carers outlined their sense of desperation in trying to cope with their child's problems, at times. In these situations, some reflected that they would accept help from anywhere, regardless of appropriateness. Experiencing desperation was deemed to have an impact on the child, their family, and upon day to day family life. Such disquiet was sometimes accompanied by a feeling of not being able to cope, and having an inherent responsibility for the situation. In addition, parents/carers often talked of the consequences for their own mental health. Alison describes her inner struggle and her feelings of an inability to cope:

ALISON: But then it just reached a point where I thought no, I can't take this. Everything was falling apart around me and I thought I would go to the doctors, and as I say, he was really supportive and it did make me feel better when I had spoken to him. I didn't feel that it was all me and it wasn't just me who couldn't cope. (Parent 4)
Some parents/carers suggested that their desperation for support pushed them to the limit. This was often accompanied by feelings of uncertainty about services or fears about the context of their child’s problems:

VANESSA: I don't think there is, it was only because a friend of mine, her son has got learning difficulties and she had to fight for special needs and she was the one who said that you have to keep going, keep going for it. (Parent 3)

VIV: We really tried to cope and we really didn't know. (Parent 20)

ALISON: Yes, yes I said “Oh no, I can't keep going till then [being on waiting list].” (Parent 4)

Some of the cohort reflected on the struggle they felt from within, expressing that it required a large amount of energy, often leaving them with a sense of not being able to cope. This struggle and desperation was expressed in an emotional way, which portrayed a sense of disillusionment and distress:

KAREN: I went to the GP and I didn't get any help for a while and I started going down, and I just went in and I said “look, I cannot cope with this, I need some help, please get me somewhere where I can get some help for her. I don't know what I am doing anymore, I can't cope with it”. (Parent 15)

Sub-theme 7c: Effects of child mental health problems on the family
(It has been a long, hard road)

The cohort described their experience of caring for their child and how this impacted on them and on the rest of the family. One parent stated that caring for her child required her to be with him constantly in order to monitor and regulate his behaviour.
Whilst another described the difficulty she had in retaining her mental wellbeing. Some parents/carers described the restrictions their child’s behaviour had placed on the family, in terms of going on holiday, shopping and being able to work:

JANET: I’m on edge constantly, I’m waiting for my phone to ring. You know [Child], can you come and pick him up, he is being extremely naughty. [Mum’s Partner] had to come home from work and when he [child] has come home he has gone off on one, because I can’t calm him down. It’s been horrible. We have had some nice times when we have been together as a family but it has been a long, hard road. (Parent 5)

Some participants articulated their experience of isolation in dealing with the problems. Being isolated meant that they often experienced anxieties about knowing how and when to intervene, and how to access support for themselves:

CAROL: To have people around me that help, I would really benefit from that. (Parent 11)

Sub-theme 7d: Effects on the child’s quality of life

(Just have a normal quality of life)

All parents/carers identified major effects of mental health problems on their child’s quality of life. These included effects on school life and achievement, friendships, everyday activities, being able to make decisions, concentration, and happiness. There was also awareness that the child’s understanding of their problems caused an added amount of shame and stress, which in turn affected their daily functioning. Parents/carers were particularly concerned that, as a result, their child would not be able to develop and enjoy a normal quality of life:
JANET: I'd just want them to be happy, and to be able to open up to us more and all the frustration he has got, it's like he is frightened to try anything new, and just be a normal little boy, and just have a normal quality of life. (Parent 5)

Many of the group recognised that their child's insight reduced their self-esteem and increased their anxieties. This served to increase parents/carers concerns and added to the child's emerging problems:

KATRINA: They [the problems] have affected his quality of life, but more in the respect of how he feels about himself and his anxieties. I would describe him as a boy who is subject to very specific kinds of anxieties. (Parent 10)

5.1.8 Theme Eight: The meaning of seeking help

Sun-theme 8a: Seeking help and the desire for a diagnosis

(Offer some kind of diagnosis)

Parents/carers suggested that the principal outcome when accessing help for their children, mainly centred on getting a diagnosis for their child's problems. The consideration that there was something 'wrong' with their child, seemed to influence the pathways taken to obtain a diagnosis. Participants who approached their GP explained that they had wished to obtain verification that their child had a definable problem, which would require specific interventions. Obtaining a diagnosis seemed to enable parents/carers to be absolved of their feeling of self-blame (discussed in Theme Three), and often produced a sense of relief:

ANGELA: And they [GP] didn't help us much to find out what was wrong with him either. Because he'd be sitting there and he'd be fiddling with anything that was in the room, kick a radiator and things like that and I felt that… (Parent 2)
ANGELA: Yeah, well I worked with a teacher at F[school], where he was before at the school and we went, we come with all sorts of things like you saw triggers and signs, which was ADHD, as well, and he actually went for ADHD thing, but they said it wasn't. (Parent 2)

FIONA: So if you did get a diagnosis, how would you feel?

SADIE: Relieved I think. (Parent 13)

Some parents/carers considered the verification of a mental health diagnosis, or a form of official statement, as the key to accessing help. It seems that until they achieved this, it would be difficult to get the right kind of support for their child. Parents/carers expectations of CAMHS were also related to getting a diagnosis, which would be accompanied by support and interventions:

VANESSA: Well, I expect them to try and offer some kind of diagnosis like they would if you went to the GP. You know, they have been trained to spot certain things and to recommend the possible lines, tactics or treatment and for that to be continuous, not to suddenly leave it, but to monitor it and work with schools and families as well. (Parent 3)

Sub-theme 8b: Getting a service gives hope

(I felt that somebody was going to listen to me)

Some parents/carers highlighted that receiving an appointment at CAMHS gave them hope to find a solution to their current difficulties. They often reflected that they had encountered frustrations in trying to find solutions to their child’s problems or strategies that worked. Many described a deficit in their knowledge about what would help their child further. Their experience of the difficult pathway to care was often relieved when they knew that their referral to CAMHS had been successful:
CAROL: [I felt] relieved, because I felt that somebody was going to listen to me. Maybe give me some advice as to how to deal with [child] myself, because sometimes I wonder if I am handling him right. (Parent 11)

ALISON:...So we have pinned our hopes on the beginning that we will go and feel that we have some backup, whatever ideas that they give us, I can say to [child] “Right these people have said that and they know what they are talking about, we must try it”. (Parent 4)

There was also an emerging sense that being referred to or offered an appointment from CAMHS meant that the problems the parents/carers had been experiencing had been verified. It was reported to be a way of confirming that the suspicions that they had held were correct, and that they had been taken seriously:

MARTIN: It is a very good GP, and he agreed immediately that there was a problem, and that there was nothing physically wrong, which is unlikely to be true anyway. (Parent 17)

Sub-theme 8c: Knowing where to get help
(We've got to get help for him)
Some parents/carers described the complexity of the process they had to follow when asking for help. This was supported by their admission that they did not feel empowered or informed about what services were available. This was demonstrated by the range and number of services that they had approached for help. Some had approached their GP for help before being referred to CAMHS, whilst others had asked Health Visitors, School Nurses, Teachers and even friends to guide them. Many described the difficulties they experienced in establishing the appropriate
service to meet their child’s needs, showing a high degree of uncertainty and a lack of confidence about their help-seeking activities.

Some participants had received a response from CAMHS following their referral, which suggested that their child’s difficulties were not serious enough to receive help there. In response to such advice from CAMHS, many participants had tried alternative agencies in order to help their child, whilst others felt a sense of anxiety and dismay, and continued to try and cope with the problems themselves. These anxieties related to the initial struggle that parents/carers reported in finding the correct service for their child. Jane describes her experience of trying to get help:

**JANE:** No, I just said ‘oh thank you’, and she [the School Nurse] wrote a letter to my doctor saying that I had been in touch, I was worried about [Child]. I think she wrote one to my GP and one to [CAMHS] and one to me, then I went up to my Doctors and made an appointment, and he said that he had already referred him and then I got the letter through.

**FIONA:** So it was much better that time round then?

**JANE:** Pretty quick just from one phone call, after years of me banging my head against the wall. (Parent 1))

Most parents/carers had tried to deal with problems at home for relatively long periods of time, before seeking help. The desire to try to deal with problems without formal assistance came across strongly, and seemed to be related to the difficulty in admitting that the problem existed and that they could not cope alone. This was accompanied by the hope that problems might rectify themselves, which would eradicate the need for a referral to CAMHS. Although there was variation in the knowledge about services, most participants had tried some of the newly developed early intervention services:
ALISON: To start with I held back, because I was really hoping that things would settle down because it has always been a bit of a problem, and I was hoping it would ease down and we would get back to how we were. (Parent 4)

ANGELA: I think, I might have found it quite difficult [to ask for help]. When I was in first few weeks in [Voluntary agency parenting group] thing, things went really, really badly with [Child] and I went to try to make some changes… (Parent 2)

One parent described how resourceful she needed to be to get help for her child:

JENNIFER: Then if you didn’t know, then just widen the net and ask around and just check out what else is going on. Just to check that there aren’t things happening that you might not know about. (Parent 12)

On the whole, parents/carers did not find it difficult to ask for help once they had eventually decided they needed it; however, they did struggle to know where to access services. When they had reached this point, getting help was seen as important to enable them to cope with their situations:

JANET: No, every little thing we can get, it’s got to help, and we’ve got to get help for him.

FIONA: So you think that everybody should have the same access to help.

JANET: When you know that there is something definitely starting to happen, yes.  (Parent 5)
Sub-theme 8d: Resourcefulness and knowledge of what works with children

(Trying all different ways)

Parents/carers demonstrated some sound knowledge and resourcefulness, when trying to deal with their children’s difficulties. Approaches they had employed ranged from use of vitamins and nutritional supplements, in particular Omega 3 fish oils, to attempt to regulate their child’s mood, to asking for medication from their GP. They also used privilege strategies, behaviour management techniques, trying to talk to their child about their problems and approaches to build self-esteem. They reported that they tried to make use of community resources including: attending parenting courses, ensuring that their child accessed play groups and that they mixed with peers. Participants reported that they had tried to use these strategies before asking for a referral, as they wanted to try and resolve their child’s problems themselves.

Most of the time, parents/carers asked for the referral after they had tried a number of approaches and not seen any change. Alison reflects on the range of her interventions:

ALISON: Trying to be firm with him, and trying all different ways and trying to be all sympathetic. You know, I’ve gone round so many different things, I mean we have read for hours before bedtime, we have done things to calm down, it just doesn’t seem to happen, except for this medication. (Parent 4)

When asking for referral, some parents/carers explained that they had exhaustion their strategies and required advice on new approaches. They were concerned that they tended to punish their children, and sought support to implement strategies correctly. Parents/carers also expressed a desire for ongoing support, which would offer regulation of approach, and would assist them in maintaining a balanced role. They considered that being able to talk to a professional would enable them to
validate and review the approaches they were using, and would act as relief from stress:

JOYCE: I think you have got to try and get it right with the discipline as well, so you don't go over then top. And they do need some free time and that sort of thing. (Parent 7)

BILL: All we got is the areas that they thought would be good for him to do. But we didn't understand a lot of that. (Parent 8)

Sub-theme 8e: Worries about going for help
(I didn't want to have him to have weeks and weeks worrying)

Participants described having differing perceptions of help from specialist CAMHS. These ranged from a fear of their child being admitted to hospital, to a fear of their child being defined as 'mental'. Although they were not worried about attending CAMHS as such, the desire to receive help and lack of knowledge about the format of the service raised anxieties. A minority of parents/carers explained that significant members within the family had dissuaded them from asking for help, which resulted in them seeking support covertly. This also increased their anxiety, and combined with the concern that they may have a long wait for a service, they experienced increased feelings of guilt and shame. Within this sub-theme, parents/carers reported that their children were often worried about where they were going and what was going to happen to them. In addition, they described uncertainty about how and when to tell their children where they would be going:

CAROL: Support, to know that there is somebody there for them, if they need it. I think children, like you said yourself, they need to be told at some point. I left it to the
last minute to tell him because I didn’t want to have him to have weeks and weeks
worrying. They need to be told in a way they can understand. (Parent 11)

5.1.9 Theme Nine: Expectations of CAMHS

Sub-theme 9a: Understanding the process at the first appointment

(I suppose they will ask a lot of questions)

Parents/carers were generally uncertain about what to expect at their first CAMHS
appointment, and whether they would continue to receive intervention or support.
Most had not received information about the service, nor did they receive anything to
help them understand the process. This seemed to contribute to their worries about
the child, and to their anxiety about whether they would obtain the support they
desperately required. They also had concerns about explaining the process to their
child, and would have liked child-centred information to help engage their child in the
assessment. Jane explains her thoughts about how to involve her child in the
process:

JANE: Yes, because it [child-centred information]] makes them feel a part of what is
going on, not going somewhere about them, “Mummy’s going to see a doctor about
or to talk about me”, they then feel involved. I think that helps a lot. I was quite
surprised to see the letter for [Child]. (Parent 1)

The majority of parents/carers outlined that they were expecting to be able to talk
through the issues, and that they wanted an outcome at the end of the session to
help them understand their child’s problems. They expected that CAMHS
professionals would spend time talking to their child, as part of the process. They
hoped for confirmation that some of the strategies they were already using were
correct and that they would receive the support to continue with them. A couple of
parents/carers were concerned that they would be then sent away to implement strategies, without support or further communication:

*ANGELA:* Hope they'll say go with the strategies and question asking and all that stuff. And finding out what is wrong with my son... I don't know. (Parent 2)

*ALISON:* I suppose they will ask a lot of questions to start with to try and assess the situation, and see how bad it is, I suppose my only worries are that they will say go home and get on with it sort of thing, as though it will go away. (Parent 4)

The group suggested that they expected the professionals they saw to speak to them in a non-judgemental way, to have skills that would engage the child in the process and to use assessment and observations to draw conclusions. They hoped that professionals would have formal training in their field, and trusted that they would not use jargon when talking to them. They suggested that it was important for them to be given respect, and to be an active participant in the process.

Sub-theme 9b: The need for early intervention/prevention in mental health services

*(Get it right and nip it in the bud now)*

The importance of early intervention for children's problems was outlined by participants in relation to a number of areas, and was seen as a vital preventative strategy. The predominant view was that early intervention could improve their child's life chances in later years, and would reduce difficulties in receiving a responsive and appropriate service:
ANGELA: Yeah, primary age kids [intervening early], because it gives them that starting block. If they get it right and nip it in the bud, now, whatever form of behaviour it is. Should give him a good ride through to the second year. (Parent 2)

There was some suggestion that universal children’s (Tier 1) services might benefit from greater knowledge about children’s mental health, and that developing such knowledge might recompense the need for specialist services. Some participants suggested that investment in schools would be advantageous, and that early investment in services would reduce burden on specialist services:

KIM: The earlier the intervention, the less likely they need a psychiatrist, psychologist or intervention for self-esteem and mental health issues. (Parent 9)

Sub-theme 9c: Developing community CAMHS
(Somewhere for people to just pop in and get some information)
Participants suggested that it would be helpful if they had access to CAMHS in the community. They indicated that it would be easier to ask for help, less stigmatising, and could perhaps have an emphasis on changing the attitudes of the community:

JANE: It would be nice, as well, for somewhere for people to just pop in, and get some information.
FIONA: Yes, and it wouldn’t be maybe stigmatising?
JANE: I think it would be at first, and then people would just get used to it, it’s like anything new or different. (Parent 1)

Some suggestions around improving services related to the development of a screening gateway; access to advice; information and assessment; introduction of
helplines; outreach workers; and mainstreaming mental health services in the community to reduce stigma:

**KIM:** Services that can filter out, yeah, because other people might just have a child who is naughty, or other families who need parenting courses and various other things. I think there needs to be a) earlier intervention and b) something more prevalent as regards actual help for the parent to deal with their child, rather than just assessing the condition of that child. (Parent 9)

**Sub-theme 9d: Seeking help from others**

*(We need a good network of people)*

Participants tried a variety of sources of help, in the primary stages of trying to manage their children's problems. These ranged from accessing help from friends and family, to attendance at voluntary sector parenting groups, and behaviour management courses in the community. They had also approached Social Care and some of the multi-agency initiatives available locally. They highlighted that it was helpful to share some of their experiences with other families, and this assisted them in trying to make sense of what was happening to their child:

**RITA:** We need a good network of people. (Parent 19)

**ALISON:** We went through a phase where he was really pessimistic and he sobbed and sobbed every night and it's not going to work, and he would say in the day “it's going to be alright tonight Mum I'm going to do it.” My neighbour, her boy wasn't always very good with sleeping and she tried different things... (Parent 4)
Sub-theme 9e: Building knowledge in schools

(They don't have enough understanding)

Participants reported differing and variable perceptions of their child's experience in the school environment, and their support and understanding of children's mental health problems. They highlighted the need for schools to develop their knowledge of mental health, and to have better communication strategies and partnerships with families. One parent had tried to prepare for a move to a new school, taking with her all the information about her child's problems. However, she experienced barriers in getting the same help he was receiving from the previous school, consequently problems were exacerbated. Another parent described the school as having a good understanding of CAMHS, and teachers being very supportive to their child:

ANGELA: Yeah. I was well prepared for, I've took everything that they've had and it's the same for B[School], I was really, really cross with them, because I warned them, warned them and warned them, he has got learning difficulties, let alone behavioural difficulties. A[school] had one hell of a strategy going for him and targets, [Child] worked brilliant to targets. They need to set him a target, keep him on task. (Parent 2)

ALISON: Yes, he genuinely has got a problem there and his teacher has been very good. She has been very supportive and tried to help things in the class. (Parent 4)

Such evidence suggests that the experience of support from schools was undeniably inconsistent and parents/carers described the need for feedback from teachers about their child's progress, especially in terms of their problem areas. They described that they sometimes felt uncomfortable in school and recognised that teachers did not always know how to talk about mental health problems. Although on the whole, participants were satisfied with the support which individual teachers were trying to
give, they suggested that there was a flaw in organisational processes which needed to be tackled:

*Joyce: The teachers have been very supportive, but they don't have enough understanding. (Parent 7)*

This chapter has presented the findings from the parent/carer participants. The next chapter will present the findings from the children in the sample.
Chapter Six

Emerging Findings from the Child Interviews

6.0 Introduction

This chapter will present the emerging findings from the child participants. The data was analysed using IPA, as presented in Chapter Four. For the sake of clarity, the data from the parents/carers and the children participants was analysed separately. The emerging findings from the parents/carers were presented in Chapter Five. The findings have been organised into super-ordinate, or main themes, and their clusters of sub-themes. Each super-ordinate theme represents the main emerging subject category which describes the sub-themes that fall within it (Smith et al, 1999). A summary of the super-ordinate themes and related sub-themes is presented in Table 6.0. Each sub-theme heading has been illustrated with an excerpt from the findings, which is seen to represent the nature of that sub-theme. In IPA, using an excerpt from findings in this way is a developing practice. In some studies the excerpt will be solely used as a heading for the emerging themes, however, for the purpose of this thesis each sub-theme has been given a heading which describes the theoretical content, as well as an illustrative excerpt from the participants (Shaw, 2005).

Six super-ordinate themes emerged and included the following: understanding feelings and emotions; the meanings of health and mental health; perceptions of 'mental', mental illness and emerging stigma; understanding children's mental health problems; children's perceptions of seeking help for mental health problems; and empathy, understanding and the perception of other children's mental health.
The emerging super-ordinate themes are not presented in a particular hierarchical order, and it must be acknowledged that there are some similarities and overlaps between certain themes. The interplay within and further interpretation of the findings will be discussed in Chapter Seven.

Excerpts from the conversations with the children have been used throughout this chapter to illustrate each theme. In order to protect anonymity and confidentiality, the participants have been given a pseudonym (presented in Table 6.1), and any distinguishing names or references have been removed from the data. Table 6.1 also illustrates the age of each child participant.

Table 6.0: Summary of super-ordinate and sub-themes from the child interviews

<table>
<thead>
<tr>
<th>Main Theme</th>
<th>Sub-theme (with illustration from findings in italics)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Theme One:</strong></td>
<td></td>
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<tr>
<td>Understanding feelings and emotions</td>
<td></td>
</tr>
<tr>
<td><strong>1a</strong> Interpreting 'normal' feelings</td>
<td>'Feeling happy all the time, especially at school'</td>
</tr>
<tr>
<td><strong>1b</strong> The distress of noticing difference and difficult feelings</td>
<td>'Difficult feelings are hard to talk about'</td>
</tr>
</tbody>
</table>

| **Theme Two:**                           |                                                        |
| The meanings of health and mental health |                                                        |
| **2a** The importance of being healthy   | 'It means you are really strong'                       |
| **2b** Developing definitions of mental health | 'Is it about learning?'                           |
| **2c** Promoting positive mental health  | 'Enjoying myself'                                    |
Table 6.0: Summary of super-ordinate and sub-themes from child interviews (Continued)

<table>
<thead>
<tr>
<th>Theme Three: The perceptions of 'mental', mental illness and emerging stigma</th>
<th>3a Defining the extreme of 'mental'</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>'You might do something not very nice'</td>
</tr>
<tr>
<td>3b Unintentional stigma and the common language of 'mental'</td>
<td></td>
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<tr>
<td></td>
<td>'[Another word for] Mental is evil'</td>
</tr>
<tr>
<td>3c Mental illness, understanding behaviours and fear</td>
<td></td>
</tr>
<tr>
<td></td>
<td>'[They would be] Feeling angry and you would be afraid)'</td>
</tr>
<tr>
<td>3d Mental illness, and the concept of illness and disability</td>
<td></td>
</tr>
<tr>
<td></td>
<td>'Like you’ve lost a gene'</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Theme Four: Understanding children's mental health problems</th>
<th>4a Mental health problems in children as illness</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>'Children with mental health problems are ill'</td>
</tr>
<tr>
<td>4b Personal interpretations of problems and shame</td>
<td></td>
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<tr>
<td></td>
<td>'I have a dark secret…'</td>
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<tr>
<td>4c The impact of mental health problems on everyday lives</td>
<td></td>
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<tr>
<td></td>
<td>'It stops me from doing things…'</td>
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</tbody>
</table>
| Theme Five: | 5a Fears, the unknown and the process of going for help  
|            | 'It’s very scary'  
|            | 5b Components of help for mental health problems  
|            | 'People who help'  
|            | 5c Feeling better, relief and making changes for the future  
|            | 'I want to feel better and not worried'  
|            | 5b Developing services for children's mental health  
|            | ‘…make it less frightening’  
| Theme Six: | 6a Mental health problems in others – the continuum of understanding  
|            | 'Everyone calls him 'Crazy Boy’'  
|            | 6b Empathy and helping  
|            | 'I know what it is like…’ |
Table 6.1: Child participants, pseudonym and age

<table>
<thead>
<tr>
<th>Participant</th>
<th>Pseudonym</th>
<th>Child’s Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Researcher</td>
<td>Fiona</td>
<td></td>
</tr>
<tr>
<td>Child 1</td>
<td>Mary</td>
<td>5</td>
</tr>
<tr>
<td>Child 2</td>
<td>Scott</td>
<td>9</td>
</tr>
<tr>
<td>Child 3</td>
<td>John</td>
<td>9</td>
</tr>
<tr>
<td>Child 4</td>
<td>Mark</td>
<td>9</td>
</tr>
<tr>
<td>Child 5</td>
<td>Pete</td>
<td>10</td>
</tr>
<tr>
<td>Child 6</td>
<td>Colin</td>
<td>8</td>
</tr>
<tr>
<td>Child 7</td>
<td>Marcus</td>
<td>8</td>
</tr>
<tr>
<td>Child 8</td>
<td>Jacob</td>
<td>7</td>
</tr>
<tr>
<td>Child 9</td>
<td>Sienna</td>
<td>10</td>
</tr>
<tr>
<td>Child 10</td>
<td>Teddy</td>
<td>9</td>
</tr>
<tr>
<td>Child 11</td>
<td>Josiah</td>
<td>9</td>
</tr>
<tr>
<td>Child 12</td>
<td>Callum</td>
<td>8</td>
</tr>
<tr>
<td>Child 13</td>
<td>Emily</td>
<td>7</td>
</tr>
<tr>
<td>Child 14</td>
<td>Solomon</td>
<td>5</td>
</tr>
<tr>
<td>Child 15</td>
<td>Will</td>
<td>10</td>
</tr>
<tr>
<td>Child 16</td>
<td>Christian</td>
<td>9</td>
</tr>
<tr>
<td>Child 17</td>
<td>Saul</td>
<td>6</td>
</tr>
<tr>
<td>Child 18</td>
<td>Robyn</td>
<td>11</td>
</tr>
<tr>
<td>Child 19</td>
<td>Martin</td>
<td>7</td>
</tr>
<tr>
<td>Child 20</td>
<td>Harry</td>
<td>9</td>
</tr>
</tbody>
</table>

6.1 The main emerging themes from interviews with children

6.1.1 Theme One: Understanding feelings and emotions

Sub-theme 1a: Interpreting ‘normal’ feelings

(Feeling happy all the time, especially at school)

The children demonstrated a wide understanding of a range of feelings, which they considered to be ‘normal’. They seemed to define the term ‘normal’ as a combination of appropriate and acceptable feelings, emotions and activities which they mainly attributed to other children. They reported that they would expect to see such attributes on a day to day basis among children whom they considered to be within the ‘normal’ category. As well as being able to observe this range of feelings in others, they also indentified what they considered ‘normal’ for them, although this definition tended to contain less of the positive emotions. They selected feelings from
a set of cue cards which represented the suggested range of feelings and emotions reported to be understood by children aged five to fourteen (Appendix 10). In response to this approach, they showed understanding of the majority of feelings presented to them. Many children were able to articulate knowledge of some emotions, which were above their expected capacity for their chronological age, and to suggest additional emotions that were not available on the cue cards. When talking about feelings and emotions they expected to see on an everyday basis, children tended to use illustrations of other children they knew, who in their view, appeared to be happy and enjoying life. Seldom did they describe themselves in this way, or describe their everyday feelings, only focusing on themselves when prompted. A few of the younger children seemed to struggle with the concept of everyday feelings. On occasions the group demonstrated an underlying theme of feeling ‘different’ from other children. In relation to this concept, they seemed to find it difficult to describe appropriate emotions for themselves. When the conversation shifted to discussing other children, participants found it easier to illustrate a happy, ‘normal’ child.

Children offered definitions of the attributes of a ‘normal’ child. They identified that the most important aspects were for children to experience happiness, be able to enjoy things, and be able to have fun with family and friends. Although they initially described children using some of the more positive emotions, some participants thought that a certain amount of sadness, worry and anger were acceptable. These ‘normal’ emotions were mainly connected with worrying about friends and family, as well as arguing with siblings. However, they did suggest that feeling upset and sad should not be experienced for protracted periods of time, and if they were then this may indicate that there was a problem. John and Sienna explain their views about some of the less positive emotions:
JOHN: ...being sad and crying are ok, as long as they don't last long… (Child 3: Age 9)

FIONA: ...so you do get really, really cross?

SIENNA: Oh yeah, when he [brother] goes in my bedroom without asking! (Child 9: Age 10)

Some children demonstrated a sense of humour when thinking about feelings and emotions. Most of this was related to school, where not having lessons was thought to be good fun, and meeting with friends and having a laugh were an important part of the day:

FIONA: Ok, what sort of things would make you happy?

TEDDY: Feeling happy all the time, especially at school.

FIONA: Not having to do literature.

TEDDY: That's one of them [lessons to be cancelled], although I would probably be relieved! (Child 10: Age 9)

In addition, achieving at school was seen to contribute to positive emotions and general happiness. Some children considered that good feelings arise from positive achievements and from being able to successfully complete tasks. As well identifying that these aspects should be present in the school environment, some of the children suggested that it also applied to the family home, where receiving praise and rewards for their accomplishments or good behaviour was of high importance. Harry explains about the importance of praise:

FIONA: ...proud you said. When might you be proud?

HARRY: When you do good work and you get told so.
FIONA: I can't find proud now [on cue card], never mind I know you have said it now and it's on the tape. What kind of things might make you happy?

HARRY: When you do good work and you get free time, or when you have had a good day. (Child 20: Age 9)

Participants considered that, in contrast to the more positive emotions and feelings, which should be part of everyday life, there were certain issues or emotions that children should not experience, or should be protected from. These suggestions seemed to be related to being safe, free from fear, and not feeling worried or angry. Emily offers her thoughts on anger:

EMILY: Anger is not an everyday word… (Child 13: Age 7)

Sub-theme 1b: The distress of noticing difference and difficult problems

(Difficult feelings are hard to talk about)

Many children were able to identify difficult feelings which they considered to be common for them. In contrast to the findings in sub-theme 1a, where they seemed to have some difficulty in describing their own positive emotions, within this sub-theme they appeared extremely conversant with the more negative feelings, and often described these in relation to themselves, or their difficult experiences. When explaining some of the more difficult emotions they had experienced, the children often compared themselves to others whom they deemed to be 'normal'. The way that they portrayed such difficult feelings gave the impression that they considered themselves to be outside of the norm, both in comparison to other children, and also in terms of the severity of their emotions. Scott explains his experiences in comparison to others:
SCOTT: I'm crying... [describing an everyday feeling]

FIONA: And do people cry normally?

SCOTT: No, definitely not. That's my jealousy. (Child 2: Age 9)

Whilst John emphasises the severity of his worries:

JOHN: Hmm, yeah. Sometimes I cry...

FIONA: Do you?

JOHN: Yeah...

FIONA: Worried?

JOHN: Super duper worried. I always get worried... (Child 3: Age 9)

When considering their range of emotions, children identified that they felt different to other children they knew. When illustrating these differences, they used scenarios which included their descriptions of 'normal' children to help them determine their everyday feelings. The areas that they focused on when talking about themselves related to the anger and upset they had experienced, the sadness they felt as a result of being bullied for their problems, and worries from thinking about their problems. Marcus explains a scenario he experienced:

MARCUS: No, that is when I get sad [being bullied].

FIONA: When do you get sad?

MARCUS: When somebody injures me, sometimes really hard... (Child 7: Age 8)

In addition, children emphasised a range of emotions and feelings which may illustrate their distress as a result of their problems. Some children talked about being afraid and very tired. They explained that they had difficulty concentrating at school, and were irritated by the way their life seemed to be affected by their problems. Many cried frequently which made them feel embarrassed, angry or shy. Other
children explained that their worries made them feel out of control. Martin gives an example of how he feels as a result of his problems:

*MARTIN: I feel mean sometimes.*

*FIONA: Do you? Why is that?*

*MARTIN: When someone hurts me. (Child 19: Age 7)*

Children also depicted themselves as feeling more angry and unpredictable than their peers. This portrays a significant contrast from the 'normal' children they describe in sub-theme 1a. Being angry was often described as a common feeling. One child explained that he felt disappointed in himself because of his angry feelings, whilst another reported that anger, along with other problems, made making new relationships very difficult.

Children appeared to recognise the impact and intensity of living with difficult feelings. Recognising that they consider themselves to be 'different' resulted in a certain amount of distress, and made them feel socially excluded. This underlying theme comes across in much of what they report, and is implicit in their sadness and disappointment. Feeling different is perpetuated by the way they have been treated by peers at school, their families and through the impact of their problems across all realms of their life. The association that they make in relation to the way others describe their problems, makes them feel marginalised. Mark demonstrates the anguish he feels when he thinks about his problems:

*MARK: …like it's crying for help… (Child 4: Age 9)*
6.1.2 Theme Two: The meanings of health and mental health

Sub-theme 2a: The importance of being healthy

(It means you are really strong)

Children demonstrated a well formed knowledge of the word ‘healthy’. In response to the question on their views of ‘healthy’, all of the group were able to articulate a definition that focused on the physical aspects of health. Definitions included the need to have good nutrition, ensuring that they have sufficient vitamins and minerals, plenty of exercise, and being strong and free from illness. They tended not to directly associate the word ‘healthy’ with mental health. However, they did propose that participating in healthy activities could have an impact on learning, and would assist in the development of intelligence. Robyn and Pete give their definitions of healthy:

FIONA: Ok, so think about those words that we have picked. If I asked you what ‘healthy’ meant, what do you think healthy means to you?

ROBYN: Keep healthy like eat proper foods, and have regular exercise and everything like that.

FIONA: You do some of that already, don’t you?

ROBYN: Eat and be healthy and eat these medicine things, like vitamins or something, so that you can be brainier, or something. (Child 18: Age 11)

PETE: When your brains are strong, and you have lots of vitamins and minerals in you, and you do plenty of exercise. (Child 5: Age 10)

When prompted further about the source of their learning on the subject, children indicated that they had learnt most of the information at school, although they confirmed that they had been assisted at home as well. They explained that their learning about being healthy had taken place in specially assigned lessons, within an
initiative called 'healthy school week'. Children appeared to apportion an importance to the activities involved in achieving and sustaining good health; although a few of them did point out that they did not always put their learning into practice. This avoidance did not seem related to lack of encouragement at home, but could be attributed to their reluctance to eat certain fruits and vegetables or to participate in exercise, which is common to most children this age group. Although speaking of this reluctance in a humorous way, many of the group stressed the significance of looking after themselves, and in thinking about what can contribute to poor health. Will and Pete gave their thoughts on the subject:

**FIONA:** Yeah, so if I said 'healthy' to you and said what things do healthy people do. What would you say?

**WILL:** Healthy people, eat healthy food. Not junk food just like food and that lot...

(Child 15: Age 10)

**PETE:** Where you don't just sit around all day and watch TV, and eat veg and that...

(Child 5: Age 10)

Although children gave comprehensive definitions of 'healthy', aspects of mental health were noticeably absent. Most of the participants' descriptions related to the notion of physical health, in all but the one of the youngest children of the group. Mary, aged five, suggested healthy children are happy. All of the remaining participants only suggested emotions or feelings that could be associated with 'healthy' when they were prompted further during the interviews.

It is difficult to make assumptions regarding the absence of references to mental health in their definitions. Such exclusions of the concept of mental health could be related to a number of issues, including the absence of mental health from the
curriculum, or lack of cognitive capacity to make connections with the concept. What the responses from children seem to show, however, is that they have an ability to develop their knowledge about healthy concepts within the school programme.

Sub-theme 2b: Developing definitions of mental health
(Is it about learning?)

Some children initially seemed to struggle in defining the concept of mental health. From some of the responses, it seems that 'mental health' is not a concept that springs easily to mind, whereas in comparison with the findings in sub-theme 2a, 'healthy' can elicit immediate connection with physical health aspects. This could have been connected to children's developmental stage or the lack of mental health promotion at school. The difficulty in offering definitions seemed to be mainly associated with the younger children, however, with further prompting the entire group were able to present their thinking around the subject. Many of them had heard of the word 'mental', and by connecting the words 'mental' and 'healthy' together they were able to suggest their ideas about what they thought 'mental health' might mean.

In contrast to the definitions given by parents/carers (Chapter 6: sub-theme 1d), children tended to offer a positive description of mental health. There was no evidence of the use of negative aspects of the word 'mental', which are presented in Theme Three of this chapter.

Although the definitions were somewhat naïve, and based on a logical progression of thoughts in most cases, their descriptions were fairly complex and drew on a variety of aspects. Definitions included a range of categories which focused on positive feelings and emotions, mental agility or a range of intellectual activities, influence on relationships, and being able to participate in and enjoy new experiences. These definitions seemed to closely relate to the descriptions associated with children whom the group identified as being 'normal', presented in sub-theme 1a. The difference
within this sub-theme relates to the inclusion of the ability to achieve intellectually, and the ability to participate. Those who admitted they did not understand the concept suggested that they thought it might mean being happy within themselves and having fun.

Children suggested a smaller range of emotions in the definition than those they had presented in sub-theme 1a. These emotions were mostly related to being happy, contented, and receiving love and affection:

FIONA: What does mentally healthy mean?
MARY: It's like happy. (Child 1: Age 5)

JACOB: It's called happy...
FIONA: So when do you get happy...
JACOB: When mummy gives me a hug. (Child 8: Age 7)

Some children referred to a notion of mental agility or intellectual ability. These suggestions seemed to be related to a chain of reasoning which the children used when trying to work out the answer to a question they were not entirely familiar with. It was unclear as to whether they had used their definitions of physical health and applied them to a concept they thought was connected to the mind or the brain, or whether they had connected the use of the word 'mental' which they had encountered in a classroom situation. For example, they may have been talking about mental arithmetic at school. Such considerations have been prompted by suggestions from Pete, Teddy and Callum:

PETE... mental is the mind. (Child 5: Age 10)
TEDDY: ...it could mean that you think it out in your head without using a calculator or something.

FIONA: So you think mental is something to do with the head?

TEDDY: Yes... (Child 10: Age 9)

CALLUM: Your brain being healthy.

FIONA: Because a lot of the time we forget that we have a brain. It's being able to make sure that your brain is working properly and things like learning.

CALLUM: I'd have Einstein's brain if I was allowed.

FIONA: You might be able to, if you have a good brain now, just wait till you are older and then you can use it all over the place then. (Child 12: Age 8)

The final section of children's definitions of 'mentally healthy' included the need to participate in and enjoy activities. Although mentioned in sub-theme 1a, participation comes across in this sub-theme as an important contributor to mental wellbeing. In addition, enjoyment of activities was viewed as essential. However, they extended this comment and suggested that actually being able to participate and able to develop meaningful relationships was an integral part of achieving an optimum state of mental health. Josiah offers his thoughts:

JOSIAH: Having friends is important. (Child 11, Age 9)

Sub-theme 2c: Promoting positive mental health

(Enjoying myself)

This emerging sub-theme is closely aligned to a sub-theme which appeared in the parent/carer findings (Chapter 5: Sub-theme 1f). In addition to offering positive definitions of mental health, children seemed conversant with their needs, in terms of promoting their mental wellbeing. They expressed their views about a number of
activities which enable them to achieve mental health. As opposed to considering this issue in relation to other children, as they did in sub-theme 1a, within this sub-theme they tended to consider their own needs. Having fun and friends was high on every child’s agenda, and this was coupled with joining in and feeling involved. Other activities which were seen to contribute to good mental health included going to parties, enjoying school and Christmas, and participating in physical activities. Their selection emphasises the importance of mixing with other children. This thread runs throughout responses, and as was established in theme 1b, it indicates that children have heightened awareness of the difficult feelings they encounter. Based on this premise, it would be expected that being able to participate on a level with other children would be an essential component of promoting mental health. Teddy expresses his views on promoting mental health:

*TEDDY*: No, you wouldn’t be going “Oh no, I've got to do this again”, you would be all excited and glad to do it. (Child 10: Age 9)

Some children suggested that promoting mental health meant that there was an element of responsibility for oneself, and that it was only possible to achieve mental health if you look after your health and take care of your personal wellbeing. Preventative approaches mainly consisted of participating in stress-relieving activities, such as reading or listening to music. Pete, however, takes his thinking a step further:

*FIONA:*…so what do you think mentally healthy people would be doing?

*PETE:* Focusing, meditating…

*FIONA:* Just being able to focus, meditate, be calm do you mean?

*PETE:* Yes. (Child 5: Age 10)
6.1.3 Theme Three: Perceptions of 'mental', mental illness and emerging stigma

Sub-theme 3a: Defining the extreme of 'mental'

(You might do something not very nice)

In the main, responses to questions on defining the word ‘mental’ produced descriptions of behaviours which were extreme and emotive. Children's reflections appeared to be describing a concept of mental illness which related solely to adults, and would not be applied to children, or indeed to people that they knew. When giving their views about the word ‘mental’, children described a person who was out of control, frightening, aggressive, and unpredictable. They also expected to see a person with bizarre behaviour, which would include hitting out, running into walls and being ‘crazy’. A few of the group were not able to offer a suggestion on the meaning of ‘mental’, and in contrast to the extreme descriptions above, one child said his mother was mental, and another said that he thought ‘mental’ was someone with problems like he had:

FIONA: What do you think the word mental means?

COLIN: Someone with problems like me... (Child 6: Age 8)

Other perceptions offered by the children related to the notion that the word ‘mental’ represented instability, being unable to control feelings, or being stupid. Some children thought that it meant a range of conflicting emotions. Pete and Scott offered some interesting thoughts on the word:

PETE: Sorrowful, smiley. (Child 5, age 10)
SCOTT: Is it like being in love?

SCOTT: Like being in love and being dumped? (Child 2: Age 9)

Some children saw the word 'mental' as having a demeaning quality, suggesting that people to whom it applied were dangerous or horrible. They also considered that 'mental' might suggest a degree of criminal activity and that possibly the police might be involved at some stage:

MARTIN: People who are mental are horrible… (Child 19: Age 7)

FIONA: Yes, OK, what do you think the word 'mental' means?

HARRY: Maybe if you have got things wrong with you, or maybe you go sometimes a bit crazy…

HARRY: They could go a bit annoying, and maybe go and do things that are illegal?

(Child 20: Age 9)

Sub-theme 3b: Unintentional stigma and the common language of 'mental'

(Another word for] Mental is evil)

Although children found some initial difficulties in defining the word 'mental' and being able to locate it in their everyday language, what became strikingly apparent was the range of alterative words that they were aware of. They drew on an array of synonyms in order to describe 'mental'. Some of the alternative words they used were derogatory, while others represented an air of mistrust in those to whom they may be attributed. There are some overlaps between this and the previous sub-theme (3a). The difference in this sub-theme is in the exploration of the substituted words and the implications behind their use, rather than looking at the meaning of the word 'mental' per se. The alternative words offered by children fell into four areas. These areas could be divided into substitute words for 'mental' which: a) implied
'madness'; b) indicated that 'mental' meant danger or angry behaviour; c) indicated that people had some flaw in their intelligence; and finally d) that people were sick or ill. Despite using alternative words in place of 'mental', one child did express his concerns around the stigmatising connotations of the word:

**CALLUM:** I don't like the word. I don't like the way it is used. (Child 12: Age 8)

In the first category relating to alternative words meaning 'madness', most children substituted 'crazy' and 'mad' for 'mental'. However, although these words did not seem to be used in an intentionally degrading manner, they did imply that those people who they defined as 'crazy' were experiencing extreme behaviours and were out of control. In addition, children tended to use words like 'weird', 'odd' or 'strange' to try and make sense of the word 'mental'. When considering the use of these synonyms in relation to the children's contexts and descriptions, it seems that although they were not used in an intentionally stigmatising way, the manner in which they were used did express an integral discriminatory characteristic:

**TEDDY:** Well, it could mean that you are crazy, or... (Child 10: Age 9)

**SCOTT:** Someone who is 'mental' means they are crazy.

**FIONA:** Would you pick any words out to describe that word [Mental]?

**SCOTT:** Crazy, crazy, crazy. (Child 2: Age 9)

In the second area that emerged within this sub-theme, children implied a sense of fear and danger, and a certain amount of anger and aggression could be attributed to the word 'mental'. They suggested alternative words which included 'evil', 'horrible' and 'angry'. As well as descriptions in this vane, children gave demonstrations of
what they thought 'mental' might be. These acted scenarios included children pulling frightening faces, pretending to punch and kick out, and rocking and pulling their hair:

JACOB: Yeah, when you going crazy...

JACOB: Let me demonstrate... [pulls faces, runs around the room]

FIONA: We can see you are running up and down.

JACOB: That's like crazy... (Child 8: Age 7)

The third area within this sub-theme represents words that children used in place of 'mental' which meant that people lacked intelligence or were stupid. What was unclear was whether children used the word ‘mental’ to describe people at school whom they considered to be intellectually deficient, or whether they thought that ‘mental’ means that people have some learning problems. With further prompting in the interviews, it did seem that children used the terms interchangeably:

CALLUM: [mental] means stupid. (Child 12, Age 8)

In the fourth emerging area, children used alternative words for ‘mental’ which implied illness. They used words like ‘poorly’, ‘sick’ and ‘ill’. The use of such words came across in a less stigmatising way than in the previous three areas, and seemed to be associated with a certain amount of empathy and concern. Only a few of the children proposed these alternative words, with the remainder falling into the other three areas. Martin explains his thoughts about the word ‘mental’:

MARTIN: [Mental is] Very poorly.

FIONA: What kind of poorly would you be?

MARTIN: Don’t know...

FIONA: No? So, just any kind of very poorly?
Sub-theme 3c: Mental illness, understanding behaviours and fear

(They would be] Feeling angry and you would be afraid)

When thinking about mental illness, children provided a clear perception of the term and the people with whom it might be associated with. They appeared to make some firm distinctions about mental illness, which separated it from the definitions they had offered in relation to the word 'mental' and the term 'mental health'. The difference in their views about mental illness was that they were in no doubt about what it meant, whereas in the other two subject areas there seemed to be some blurring of ideas. Even though some children had suggested they did not understand 'mental health', when presented with the term 'mental illness', they seemed confident in proffering an answer. The term 'mental illness' thus seemed to conjure up some extreme pictures of people suffering from a distressed state of mental disturbance.

All of the children, with the exception of one, talked about mental illness in the third person, using words like 'they' and 'them'. This association with the third person echoes the findings from the parent/carer participants (Chapter 5, Sub-theme 2b). One child who presented a more positive definition of 'mental illness' had direct experience of mental illness, in that his mother was diagnosed with psychosis, and had been an in-patient at a mental health unit on a number of occasions. In relation to this definition, he identified and explained about mental illness from his experiences with his mother. Most of the other children did not identify any direct experiences of mental illness, and so did not make any judgements based on knowledge. However, some did recognise that their parents may have received some help for their problems, which suggested that they might consider them to fall into this category.
Children depicted a grave and frightening description of mental illness, where they described violent, uncontrollable images. In their view, people with mental illness were seen to be different to everyone else, were invariably sad and likely to be bullied. Even the younger children gave a description of people displaying overt behaviours. Solomon gives his views on mental illness:

*FIONA: What do you think 'mental' means?*

*SOLOMON: Crazy!*

*FIONA: Does it? So, if you saw somebody that was mental, what do you think they would be doing?*

*SOLOMON: Smashing bottles. (Child 14: Age 5)*

The emerging findings in this sub-theme illustrate some differences to the behaviours described within sub-theme 3a, which were proposed in connection with the word 'mental'. Within this sub-theme, children described their ideas about the extremes of mental illness, and alongside this description they suggested that they should remain on their guard, or be fearful of people with mental illness. A number of them considered that people with mental illness were definitely someone to be afraid of. When this was explored further, some children suggested that they were afraid because they were not sure what people with mental illness might do, considering that they were weird, or that they may harm them in some way. Harry and Sienna describe the unpredictable nature of mental illness and their associated fears:

*HARRY: They could maybe come up to you and hurt you, or they could perhaps say silly words. (Child 20: Age 9)*

*SIENNA: You would sometimes be scared; either you’re only a little bit crazy. You’re in the middle crazy, or you’re very, very crazy. So you don’t know… (Child 9: Age 10)*
As well as feeling frightened, some children suggested other reactions to seeing a person with mental illness. These reactions ranged from ignoring them and staying away from them, or protecting themselves by hitting back or hurting them. The latter responses did not seem to be backed up by thinking around the possible outcome to such a situation, but were more a result of feeling worried for their personal safety, and tying to deal with these feelings:

FIONA: Would you be scared [if you saw someone with mental illness]?
JOHN: No, if they'd touch me, I'd just kick them. (Child 3: Age 9)

Sub-theme 3d: Mental illness, and the concept of illness and disability
(Like you've lost a gene)
Children described a further dimension of mental illness, which related to the concept of mental illness as physical disease or physical disability. Similarities in this sub-theme can be drawn with the ideas that emerged from the parents/carers’ group. Again, as with the other sub-themes in this super-ordinate theme, children predominantly related their examples and ideas to adults. There were only a few comments which were linked to views about other children. In this sub-theme, some children seemed to make strong associations with the illness/disability model, linking mental illness with a genetic deficiency, or physical disability. Connections with physical disability appeared to have developed through watching television programmes on disability. Scott and Pete offer their ideas on mental illness as a disability:

SCOTT: …because [child at school] who used to be in our school. What’s he got again?
MUM: Down’s syndrome.
SCOTT: Down’s syndrome, and this kid lost a gene, but not [at the school] anymore. I don’t know where he has gone?

FIONA: How did you find out about that, did someone tell you?

SCOTT: Yes, and I’ve seen it on Blue Peter [television programme] as well. (Child 2: Age 9)

PETE: It means someone is disabled or in a wheelchair. (Child 5: Age 10)

A small number of children associated mental illness with the generic concept of illness, perhaps picking up on the ‘illness’ part of the term. These ideas ranged from physical diagnoses such as diabetes to general physical illness.

COLIN: Is it like diabetes? (Child 6: Age 8)

6.1.4 Theme Four: Understanding children’s mental health problems

Sub-theme 4a: Mental health problems in children as illness

(Children with mental health problems are ill)

In this sub-theme, children in the sample group suggested that those with mental health problems were generally ill. This idea seems to differ from the views expressed in the previous theme (sub-theme 3d), in that when specifically asked about children they thought had a mental health problem, participants thought that they were ill or ‘poorly’. Whereas, in the previous sub-theme, when asked to comment on their perceptions of mental illness, children seemed to only associate their views with adults. This suggests that they did not appear to relate the concept of mental illness to something that children could suffer from. When trying to explore the concept in relation to children, they tended to present scenarios which seemed more familiar and comfortable within their realm of knowledge and experience. Some of the
group expressed the definitive view that mental illness was not possible in children, whilst others saw them as sick or injured in some way.

Many of the group were able to identify children whom they thought might fall into the category, and some expressed a distinct empathy and concern for those who they thought might have problems:

SCOTT: I know a boy at school who has [mental health] problems, he is ill. (Child 2: Age 9)

MARTIN: They [children with mental health problems] are very poorly…(Child 19: Age 7)

HARRY: I would be very worried about them… [children with mental health problems]. (Child 20: Age 9)

Sub-theme 4b: Personal interpretations of problems and shame
(I have a dark secret…)

Many children appeared acutely aware of their personal problems. Although they did not directly identify themselves as having mental health problems, they were able to recognise the components of their difficulties, and in tandem with this, the intensity of the shame and embarrassment they had experienced as a result. The feelings of shame, which accompany the responses in this sub-theme, overlap with the feelings of being ‘different’ reported by the children in sub-theme 1b. The apparent inability to classify their problems within the realms of mental health, seems to stem from their difficulty in conceptualising the notion of mental health among children, and their association of the word ‘mental’ with the adult population. In essence, they seem to struggle to connect the words ‘child’ and ‘mental’ as being two words which could be
used in conjunction with one another. In addition, the tendency to define the word ‘mental’ as a term which encompasses sets of extreme and unpredictable behaviours, seems to add some confusion to their recognition of mental health problems in the self. In order to describe their problems within a category, children seem to identify themselves as falling into three related areas. The first of these areas represents a view that their problems relate to difficulties with their behaviour, using terms like ‘naughty’, having tantrums, having ‘moods’, or presenting with bad behaviour. Josiah and John give their views of their problems:

**JOSIAH:** [I need help] because I am naughty… *(Child 11: Age 9)*

**JOHN:** [My problems are]…behaviour, behaviour, behaviour. *(Child 3: Age 9)*

In the second area, children tend to categorise their problems into feelings of anxiety and worry. Many children describe experiences of being frightened or feeling that they are losing control of their emotions. They use a variety of expressions to describe the interplay between their problems, and the resultant fear about their emotions. Many statements appear to suggest that there is an added concern about feeling different, or not being able to understand what is happening to them. Robyn and Harry describe their worries:

**ROBYN:** I am very scared…there is something wrong with me. I think I am ill… *(Child 18, Age 11)*

**HARRY:** I know that it [my problem] makes me frightened… *(Child 20: Age 9)*

The final area emerging within this sub-theme is particularly centred on the shame that children attach to their mental health problems. Two facets can be connected to
the feeling of shame; firstly, that problems are something to be ashamed of, and secondly, the identification of a covert fear that there could be a connection with becoming more severely mentally ill. Will talks about his worries:

**WILL:** I feel ashamed and I can't talk about it... I have a dark secret...

**WILL:** Being mad... if you are mental you can't control yourself. (Child 15: Age 10)

**Sub-theme 4c: The impact of mental health problems on everyday lives**

(It stops me from doing things...)

The impact of experiencing mental health problems seems to have diverse consequences on children. They reported a range of issues which occurred as a result of their experiences. The reported impact of their problems falls into three distinct areas; firstly, impact on the self; secondly, impact on the family and social environment; and thirdly, as a result of external consequences, on the child and their everyday life.

Children reported that, in their view, there was some cost to their general wellbeing and persona resulting from the manifestation of their problems. They appeared to experience a reduction in daily functioning, which emerged from worry, anxiety, and inability to control moods and temper. Issues like difficulty in concentrating, or being upset and worried, made children feel frustrated, marginalised and embarrassed. These were consequently reported to impact on school work, relationships, and being able to participate fully across all realms of life. Solomon, Colin and Callum explain the impact of their problems:

**CALLUM:** I am worn out... (Child 12: Age 8)

**SOLOMON:** I don't like being this way... (Child 14: Age 5)
FIONA: That one [feelings card] is concentrating...do you ever have trouble concentrating? Are you not very good at that?

COLIN: No.

COLIN: I get like an itch, or something, on both sides...

FIONA: So, you get that. Guilty [child picked feelings card], do you know what that means?

COLIN: Yes, I have it if I hit my mum sometimes. (Child 6: Age 8)

In the second area within this sub-theme, children identified that their problems affected their family environment, and social relationships. These findings reflect those of parent/carers participants in sub-themes 7b, c and d of Chapter Five.

Children reflected that their problems prevented them from joining in with family activities, which ranged from simple activities such as shopping, to activities that required greater organisation such as family holidays. A few children reported that their problems frequently caused arguments and regularly culminated in punishment:

JOHN: It [My problem] gets me in trouble...

JOHN: Dad made me do thousands of jobs as well.

FIONA: And do you get things at home, if your behaviour is not very good?

JOHN: Yeah, I get things taken off me. (Child 3: Age 9)

In the final area within this sub-theme, children described the intensity of bullying they suffered as a consequence of their problems. This overlaps with sub-theme 1b in this chapter, where children started to identify the feelings of difference and the distress this caused for them. In this sub-theme, the impact serves to exclude children from their peers, and also causes them to retaliate on occasions. The need to retaliate seems to add to the volume and intensity of their problems, and forms the beginning of a cyclical process, which increases the likelihood of children being socially
excluded or singled out. On many occasions, children reported that their reaction or retaliation to bullying, whether covert or overt, frequently culminated in them being punished, rather than the agitator. Marcus and John explain:

MARCUS: …yes, someone at school [bullies me], don’t know…

FIONA: What do they do when they get angry? [with you]

MARCUS: Beat me up… (Child 7: Age 8)

JOHN: Last week, Friday. You don’t really know what it [my problems] did to me.

FIONA: Yeah I do, I do understand these things…

JOHN: I walked through the dining hall, yeah, dining room hall door, bumped into this year six kid, he grabbed me and put me up against the wall, and I punched him right in the nose…

JOHN: Yeah, yeah. That kid lashed out as well and it was only a year four, he lashed out on me as well, got me back on the nose and chucked me onto the floor.

FIONA: Gosh!

JOHN: I felt embarrassed then… (Child 3: Age 9)

6.1.5 Theme Five: Children’s perception of seeking help for mental health problems

Sub-theme 5a: Fears, the unknown and the process of seeking help

(It’s very scary)

The predominant features within this sub-theme, derived from children’s comments about seeking help for their mental health problems, are related to the apparent lack of understanding around the process, their idea about the format of the help they might receive, and their difficulty in comprehending the concept of receiving help for their problems. Most children felt frightened of going for help. This partly related to
their preconceived ideas about where they were going and what might happen to them. Some children had not received a full explanation about where they were going, whereas others seemed to have no understanding about the association of going for an ‘appointment’ and their identified difficulties. Some children identified that they were not concerned about going for help. However, this seemed to be rather connected to general lack of understanding about their situation, or their expectations of their forthcoming appointment. The apparent lack of information and comprehension about the appointment and the place they were going to visit, seemed related to a number of influences. These included not having the process explained by parents/carers; parents/carers’ lack of understanding about the process (Chapter 5, Theme 8); not being given appropriate information; and possible communication of outdated or traditional views of mental health services. Some children thought that they were going to a hospital, whilst others thought it might be a service for adults with mental health problems. In general, children seemed to think that attending the appointment was quite a daunting and frightening prospect, which came across clearly in some of their comments:

MARTIN: It's not going to be a nice place… (Child 19: Age 7)

ROBYN: They should say it's a child's place… (Child 18: Age 11)

JOHN: Yeah, well. I might have to spend a million hours there! (Child 3: Age 9)

In addition to worries and concerns about their mental health problems, portrayed within other themes in this chapter, children described the act of going for help as a mysterious entity which heightened the fear and anxiety they were already experiencing. Some children thought that they might be punished for their behaviour, whilst others reflected that their lack of knowledge exacerbated their worries and the
extent of their problems. The supposition they seemed to be making was that because they needed help, they had done something wrong. As a consequence children portrayed feelings of guilt and inadequacy, which seemed to arise from shame about their problems. A few of the children gave examples of how they felt:

ROBYN: I'm scared. My brother went there because he was naughty (Child 18: Age 11)

SCOTT: I feel nervous. (Child 2: Age 9)

Sub-theme 5b: Components of help for mental health problems

(People who help)
From the range of responses there was evidence to suggest that children hold no firm conception of what CAMHS might offer, or what help might comprise of. What can be deduced from the interviews is that, where the children had a deficit in knowledge about the service, they attempted to create a picture that would assist them in understanding what they were to encounter. The risk of developing such a notion was that children either produced a negative or positive image; however, what did not emerge within either category was a true description of what the service would actually provide. Some children talked about the person they might see, whereas others talked about what they thought might happen. In addition, a third group of children were able to project that the service was there to help them with their problems, and although they were not able to give a definitive description, they were able to make connections with anecdotal ideas of receiving help for problems which seemed related to aspects of mental health.

The group of children who described the help they thought they might receive in terms of the professional they might see, gave descriptions derived from a
medicalised stance. Although they seemed to be uncertain about what might happen when they attended the appointment, they seemed to be sure that the person would have some sort of profession, and be either a doctor or a nurse. A few of the children suggested that the person might be female and wearing a uniform, whilst a couple of others thought they would be a male and possibly be Asian in origin. It is difficult to pinpoint the origins of these ideas; however, they could be based on stereotypical ideas about healthcare professionals, or created from previous experiences. Of interest, however, is the absence of ideas about other professionals whom they may come across, for example psychologists or therapists. Overall, children expressed the hope that the people they would see would be nice and considerate towards them:

WILL: Will it be a Doctor? (Child 15: Age 10)

TEDDY: I'm not sure what is going to happen. Will it be a hospital? (Child 10: Age 9)

Children who described their ideas of the service in terms of what might happen at their appointment, fell mainly into two camps. One set of children described their ideas in much the same way as children in the above paragraphs, in that they expected a set of medical investigations or treatments, or that they might be prescribed medication. The other set of children described a process which could be connected with the stereotypical idea of a ‘therapist’. In these descriptions, children thought that the professional would talk and listen to them, as well as ask their parents questions. Harry, Robyn and Emily give examples to support these two sets of ideas:

FIONA: Do you have any idea about how they might help you, or what they might be like?
HARRY: I got worried because I thought they might give me an injection. (Child 20: Age 9)

ROBYN: They will take my blood. (Child 18: Age 11)

EMILY: They would listen to me and talk to me. I would want them to be nice… (Child 13: Age 7)

Finally, the group of children who had developed the notion that the service would be specifically there to help with their mental health problems described a service which would give time to listen to them, assist them with finding solutions to their problems and help them in improving their situation. In particular, some children expected that staff would demonstrate empathy:

CALLUM: They will try to understand me, what it’s like to be in my shoes. (Child 12: Age 8)

Sub-theme 5c: Feeling better, relief and making changes for the future
(I want to feel better and not worried)

A consistently emerging view within this theme related to the hope that there would be significant changes for the better in the future. For many children, the desire for changes in their behaviours or mental health problems was a priority. The link between understanding of their problems and wishing for improvement was demonstrated with enthusiasm, and a seemingly high degree of motivation to implement change. Most of the ideals they expressed seemed to be tangible and appropriate. What came across in this sub-theme was that the children’s underlying sadness and distress served as a baseline measure to determine goals for an improved quality of life. When they talked about improvements in their lives, they
immediately focused on the mental health issues they had, rather than presenting other wants or needs that might make a better life, for example, toys, games or money.

HARRY: They [Children's mental health services] will talk to me and say how I can get all my problems away...

FIONA: ...How do you think you will be feeling once they have done that?

HARRY: Relieved that it has gone. (Child 20: Age 9)

Many of the comments included a reference to 'feeling better' or eradicating problems. The desire to 'get better' seems to relate to the illness model, which children described when trying to conceptualise or categorise mental health problems (presented in sub-theme 4a). Additionally, children frequently alluded to a desire to 'be normal', or to participate in 'normal' activities. Both these issues have been raised in other themes, in particular the cross over with sub-themes 1b and 4c, where children discuss the intense feelings of 'being different', and the resounding impact that their problems can have on their daily lives. Colin explains his hopes for the future:

COLIN: Just be like the other children really.

FIONA: What do they do? That's different to you?

COLIN: My cousin, I'd like to be like him... Jamie.

FIONA: What's Jamie like?

COLIN: He's very good. (Child 6: Age 8)

WILL: I would like to be like everyone else... (Child 15: Age 10)
Children's aspirations for the future included wanting to be happier, more successful at school, having friends and be problem free. Views which related to being problem free, referred to a desire to eliminate problems and to return to a position of normality. Some children suggested that having medication might help them. Some of these views overlap with an earlier theme (Theme 4), where children presented their thoughts on the impact of the problems on their quality of life. Scott, Josiah and Jacob explain:

**SCOTT:** ... *[I want] something that will calm me down...* (Child 2: Age 9)

**JOSIAH:** I hope someone will be my friend. (Child 11: Age 9)

**JACOB:** ... *[I hope] they are going to destroy my problems.* (Child 8: Age 7)

**Sub-theme 5d: Interventions which might help with mental health problems**

(…*make it less frightening*)

Children showed some insight into what they thought might help them with their problems. This mainly related to interventions which they considered might help and support them. Although there is overlap with the previous sub-theme, within this sub-theme children talk about the format of the support and how services might expand to help them more effectively. Some children spoke about needing advice and guidance, whilst others thought someone who was a friend might be able to support them in a more responsive way. They also expressed ideas about how services could be more accessible and less frightening. Children suggested helplines, better information about services, and some reassurance that nothing bad would happen as a result of attending the service could improve their experience. Robyn and Callum offer their suggestions:
FIONA: Maybe do a leaflet or something to explain where you are going, something different?

ROBYN: Yes. It would make sure that children aren’t scared or anything? (Child 18: Age 11)

FIONA: So that’s it, unless there is anything else that you want to say about how we can make things easier for people to ask for help and things like that, any last comments from you or last ideas?

CALLUM: Something that tells you what number to call if you are feeling really depressed or something like that? (Child 12: Age 8)

6.1.6 Theme Six: Empathy, understanding and the perception of other children’s mental health

Sub-theme 6a: Mental health problems in others – the continuum of understanding

(Everyone calls him ‘Crazy Boy’)

In response to questions on knowledge of others with mental health problems, participants were able to recognise a range of children, and also some adults, whom they considered to be experiencing mental health problems. The degree to which children determined whether or not others they knew had mental health problems, appeared to be related to a number of criteria, which they used as a benchmark. These criteria were based upon certain factors, which ranged from making a comparison against their own problems, identifying children whom they thought represented their definition of ‘difference’, the selection of children whom they considered to fit into the category of ‘mental’, and also making judgements based on personal experience of either friends or family.
Children who tended to identify others with mental health problems by comparing them to their own, represented two distinct factions. One group reported that they had not met anyone else with similar problems to theirs, or indeed other children who they thought might have some form of problem, whilst the other group reflected that they had met others with mental health problems. Children who had not met others with mental health problems, reflected this with an air of sadness. Their disappointment can be detected within their responses in the form of seeming to feel alone, indicating that they were isolated in someway or that they were experiencing an obscure difficulty. The group who identified that they had met others with mental health problems, defined them as being 'sad' or 'upset'. They also saw these children as being 'different' or 'noticed', which again concurs with how they perceived themselves and their own problems, in comparison to others. An interesting aspect of being able to identify others with problems, was that it seemed to be accompanied by an element of surprise, and had the role of offering the children some relief from their feelings of exclusion. Teddy and Will's views demonstrate the views of the two groups:

FIONA: Have you ever met any child with similar problems to you?
TEDDY: I have, yes; I went to this thing called ‘Cubs’ and it was in a hall that had two sides. The side I was in, there were three people and all three of us had the same problem. I was sat in group of them and it was really weird. (Child 10: Age 9)

FIONA: ...Ok, do you know any other children who have had a similar problem?
WILL: No.
FIONA: Do you think there are any?
WILL: Don't know.
FIONA: There are. So you are not on your own.
WILL: Have you met anyone else like this?
FIONA: Have I? Yes. It's my job to speak to children who have had similar problems. So does that make you feel a little bit better to know that there are other people around?

WILL: Yeah. (Child 15: Age 10)

The tendency to identify others with mental health problems based on children's perceptions of 'difference' or definitions of 'mental' was fairly common. The decision to categorise others in this way seemed to be multi-factorial and was derived in a plethora of ways. Children tended to include others whom they identified as being stigmatised, discriminated against or whom they perceived to be having difficulty in participating. Although the association was ostensibly naïve, the children who fell into this group used social stereotypes, which could be considered to be stigmatising, to describe individuals with mental health problems. They often referred to children who were 'struggling', were 'weird', or who were treated differently. The message that such interpretations convey is that children in this group would tend not to identify themselves as being in the same group as children they deemed to have mental health problems:

FIONA: What I want to know is, do you know any children at school who have got similar problems to you or any problems that you have noticed? Do you know anyone in your class?

EMILY: Jade, she is a different girl from the whole class. (Child 13: Age 7)

FIONA: Sometimes you might see children in school who get upset or angry. Have you ever seen anybody like that?

TEDDY: There is one boy in our school who has a mental problem or something.

FIONA: Ok…
TEDDY: Everyone calls him 'Crazy Boy', which I think makes it worse for him, because it makes him angry. (Child 10: Age 9)

PETE: Yes [other children who have mental health problems]. At first you might think they are weird to start with, and then, after a while, you might notice things what they are doing and you might not see them playing with anybody, just sitting there and you might just think .. I'll be friends with them.

FIONA: Do you know anyone in particular?
PETE: Yes, his name is Jake. He keeps saying that he wants to blow himself up.

FIONA: Where do you know Jake from?
PETE: In school. (Child 5: Age 10)

A small group of the children made judgements about the mental health of others based on their personal experience. These children demonstrated an extended understanding of the term 'mental health', in that they were able to recognise that their parents, siblings or friends had mental health problems. They were also aware that, in some cases, their parents had taken medication. One particular child reported that his knowledge of others with mental health problems was derived from his mother, who was diagnosed with schizophrenia, although after further prompting he did not believe that children could experience mental health problems:

WILL: Just that, my mum she is mentally ill. She sometimes thinks she is Jesus. She's like being weird and...

FIONA: Ok, that's how you know about mentally ill is it? Do you know of any children that have had a mental illness?
WILL: No, I don't know any children...
FIONA: No, any children you might think had some problems?
WILL: No. (Child 15: Age 10)
Sub-theme 6b: Empathy and helping

(I know what it is like...)

The desire to help and the innate expression of empathy was implicit in children's reactions toward other children with mental health problems. Although in earlier themes children expressed fears and concerns about people with mental illness, this appeared to be mainly related to adults. The difference within this sub-theme is that they did not express fear, concerns or desire to reject children with mental health problems. Their wish to provide help and support was strongly implied, and they offered a range of suggestions about how they might achieve this. They suggested that they might ask a teacher to help them, give them comfort, try to calm them down, befriend them, or stop them from being bullied. In addition, they reflected upon the difficulties children might have, and expressed insight and concern about the way they might be treated by others. The ability to show compassion for children with mental health problems could be related to the goals that they hold for themselves and how they would like to be treated by others. When considering the extent to which children are able to empathise, it is necessary to refer to other themes which may have an influence on this response. In particular in Themes One, Four and Five, where children talk about their intense feelings, the discrimination and bullying they have suffered and their hopes for the future. Sienna, Pete and Marcus demonstrate their empathy:

FIONA: What would you do [to help]?

SIENNA: I'd help them and take them to the teacher...

FIONA: Would you?

SIENNA: And try and calm them down… (Child 9: Age 10)

FIONA: So, if you saw a mentally ill child like before what would you think about them?
PETE: Try to help them with stuff…

FIONA: That’s very good.

PETE: Try and get them some friends, and get on with them myself. (Child 5: Age 10)

FIONA: So, if you did see any other children who had problems like yours, what would you think about them?

MARCUS: Help them keep out of trouble. (Child 7: Age 8)

This chapter presented the key findings from the children participants. The next chapter will discuss the findings and key concepts emerging from both the parents/carers and children, and will explore the convergent and divergent views which emerged between the two groups. It will also propose a conceptual framework for communicated stigma between parents/carers and children. A discussion of the implications of the findings for policy, service provision and tackling stigma, will be presented. The chapter will conclude with a presentation of the methodological implications and will make suggestions for future directions of research in the field.
Chapter Seven

Summary of the Main Findings and Discussion

7.0 Introduction

The purpose of this study was to develop an understanding of the perceptions held amongst children of primary school age, who have emerging mental health needs, and those of their parents/carers, in relation to mental health and mental illness, children's mental health services and stigma attached. This chapter will discuss the key emerging findings, for both the parents/carers and children in relation to the purpose of the study.

Within Interpretative Phenomenological Analysis (IPA) (Smith et al, 1999), the final stage of data analysis involves interrogation of the findings against existing literature within the field of study, and also the development of new theories and concepts emerging from the findings. This chapter will approach the discussion of the findings on this basis for each group within the sample, and will also present the interplay between convergent and divergent themes which emerged from the data. A conceptual framework, which explains the dimensions of stigma and child mental health, will be proposed. The chapter will then present the possible implications of the findings for policy and service provision. The methodological benefits and implications will be explored, and the chapter will close with recommendations for the direction of future research in the field.
7.1 Summary and discussion of emerging findings from the parent/carer interviews

This section will explore the key findings from the parents and carers who participated in this study. These significant points of emphasis, related to the findings presented in Chapter Five, focus on seven specific concepts, which will be discussed below. The specific concepts, highlighted in the discussion that follows, communicate the perceptions and experiences of parents and carers of children who have been identified as having mental health needs for the first time. They range from issues which are particular to the definition of mental health to the pervasive experiences of the associated stigma on an individual, familial and societal level.

7.1.1 The paradox of mental health in children: Aspirations versus barriers to achievement

The understanding of mental health and mental illness, portrayed by parents and carers, presents as a form of enigma. The positive concept of mental health in children is represented clearly by most of the participants, and the definitions of mental health presented are closely aligned to those outlined in recent literature (HAS, 1995; Mental Health Foundation, 1999). This suggests that parents/carers are able to formulate the concept of mental health and to present a logical discussion around it. Such findings are supported by research undertaken by Crisp et al (2000). In their study, which explored the stigmatisation of people with mental illness in the British adult population, they found that general opinions about mental health and illness indicated that the population had a reasonable knowledge. However, Crisp et al (2000) also found that, although their sample had well developed knowledge, this was not reflected in their attitudes, which were still predominantly negative. In addition, they found that knowing someone with mental health problems did not make any difference to attitudes. Such findings can offer some supporting explanation to
the difficulty that parents/carers had in retaining positive attitudes towards mental health. When given the freedom to explore their ideas further, parents/carers tended to juxtapose the concept of positive mental health for mental illness. Such a phenomenon is discussed by Giorgianni (2004), who suggests that primarily, when thinking about health and illness, people tend to focus on the illness and its manifestation, rather than the people who have that illness. When considering this further, it seems to suggest that the predominately stigmatised word ‘mental’ has been entrenched in thinking and in common language, so when the focus of discussion becomes wider, the raconteur reverts to their preconceived notions of the word ‘mental’ and its intrinsic link to ‘illness’. This frequent substitution of terms presents parents/carers with a difficult dilemma, or puzzle, to solve. On the one hand, their desire to assist their children in attaining good mental health, and their desire to overcome the repercussions that stigma has for their children and themselves, is at the forefront of their aspirations. On the other hand, their inadvertent use of discriminatory language, the underlying demonstration of prejudice toward people with mental illness and the act of distancing themselves and their children from the contagion of mental illness, means that they have inevitably presented themselves with some barriers to achieving their aspirations.

Although it is apparent that parents and carers experience the effects of stigma and openly demonstrate this throughout the findings, it also seems that they find themselves in a difficult position which arises from the complexity of their perceptions about children’s mental health and mental illness. In this respect, their potential to define mental health in paradoxical terms results in the description of the two extremes of the spectrum, with no apparent regulation. As a consequence, it seems that parents/carers experience three aspects of the stigmatising process at the same time (presented in Chapter Two). Firstly, this complex scenario means that they adopt the role of the general public, described as public stigma (Corrigan, 2000),
wherein they seem to have and communicate stigmatising beliefs about mental health and illness. Secondly, they also experience *courtesy stigma* (Goffman, 1963), which originates through association with the person who has mental health problems, in this case through their relationship with their child. Finally, because of their role as protector, guardian and decision-maker for their child, parents/carers seem to experience *self-stigma* (Corrigan, 2000) by proxy. The third dimension of *self-stigma* is usually attributed to the person with a mental health problem, and is defined as such in the literature (Corrigan, 2000). However, the added concept of *self-stigma by proxy*, which seems to emanate from the findings of this research, means that parents/carers appear to take on the stigma that would be ordinarily experienced by the person with the mental health problem, in this case their child. This phenomenon could be due to the young age of the children and the position of responsibility parents/carers find themselves in.

Although, such a concept is rarely mentioned in the literature, Gray (1993) describes a similar situation in his study of perceptions of stigma in the parents of children with autism. Gray suggests that parents of children under the age of twelve seemed more likely to perceive themselves as stigmatised. Although, he does not identify that parents experience self-stigma to the extent that the parents in this study seem to, Gray suggests that it is difficult for parents to distance themselves from their child, and their responsibility for their child’s difficulties. Ordinarily, a person experiencing *courtesy stigma* would be able to remove themselves from potentially stigmatising situations connected to their family member with mental health problems, however, as Gray points out, dissociation from younger children is not quite so easy. This phenomenon, coupled with the feelings of shame and guilt, which seem to emanate from the parents and carers in this study, and the developmental age of their children, means that they appear to experience the stigma on their child’s behalf.
Being immersed in this ambiguous situation seems to create difficulties for parents/carers in enabling them to develop a salient understanding of mental health. As the findings demonstrate, they have a good understanding of the continuum of mental health, factors that promote mental health, and interventions that are effective where there are emerging mental health problems. However, the barrier to firmly embedding this in their understanding appears to result from the prejudice and discrimination they experience as a result of their self-stigma, and the stereotypical concepts they have of mental illness. As a response to this predicament, they often demonstrate an unwillingness to acknowledge that children can have mental health problems, and tend to describe their children in terms of their behaviours, or their difference to the 'norm'. By way of avoiding the perceived attribution that stereotypes of mental health and mental illness may have on their child, parents and carers actively avoid talking about mental illness and children in the same sense, therefore avoiding the potential of prejudice and discriminating behaviour (Corrigan, 2000).

In addition, when comparing parents/carers' perceptions against research on Labelling theory (Scheff, 1974; Link, 1987), wherein people who are identified as mentally ill are known to be subjected to stigma and discrimination, their avoidance of this label may be seen to reduce the potential effects of the stigma associated with it. However, what also seems to happen is that as a result of finding it difficult to categorise their children's problems, parents/carers tend to cast about for reasons or causes, which often results in frustration, and in emphasising the perceived difference of their child from others. Although this process may seem to avoid the label of 'mental' or 'mental illness', it still serves to bestow a form of label on the child, often that of 'badly behaved', and can present as a 'self-fulfilling prophecy' (Rosenthal, 1995) presented in Chapter Two (Section 2.1.3).
7.1.2 The cycle of shame/blame and absolution/emancipation: Breaking the effects of stigma on parents/carers

Throughout the findings, parents/carers speak of an overt sense of shame and guilt which they experience in relation to their child's emerging problems, their perceived responsibility for them, and other possible causes which they identify as originating from negative experiences within the family home. In tandem with this, they frequently demonstrate an inherent or 'internal' shame, which is not always apparent to them, is pervasive, and by which they regularly appraise themselves and their abilities as an effective parent. In addition to these insidious feelings of shame, parents/carers seem to experience an increased stigma as a result of the connections they make, which place their child's problems within in the realm of mental health.

Gilbert (2004) discusses the serious effects that stigma can have on the individual and their family, which often culminate in a devalued self-identity, feelings of inferiority or feeling worthy of rejection. He describes a number of processes that take place as a response to shame and stigma, which produce an avoidance of possible appraisers, or concealment of the problem. Much of this behaviour originates from the perceived awareness that others may disapprove of or judge the individual, and thus when applying such perceptions to the 'self', can result in the individual being devalued (Gilbert, 1998; Lewis, 1998). These theories about the relationship between stigma and shame begin to explain the process that occurs for the participants in this study. Parents/carers often report that they feel responsible for their child's problems, and they identify many aspects which they feel could have contributed to the situation. However, despite having an awareness of the possible effects of some of their actions towards their children, they report that they feel powerless to change the situation, and often unable to cope. The product of this cycle of shame and
consequential powerlessness seems to originate from the view that 'others', namely family, but also professionals they may have encountered, will make judgements about their ability to parent and the genesis of their child’s problems. This effect seems to produce a feeling of humiliation in parents/carers, which appears to have two conflicting consequences: firstly, the parent/carer feels the need to tackle the problems head on, through the employment of a variety of tactics, and secondly, when these tactics fail, parents/carers seem to submit, which enhances their feelings of powerlessness.

This shame-powerlessness cycle seems to produce an outcome, in most cases, which parents/carers describe as reaching crisis point. In effect, what ensues through the experience of shame and powerlessness is a reduction in the ability to act, or to seek help before reaching crisis point. Some parents/carers described that acknowledging their inability to cope and accessing help, was tantamount to admitting that they had failed. The implications of this scenario could contribute to the child’s problem. If the parents/carers had not been immersed in the cycle of shame, then they may have been empowered to access help at an earlier stage. Bryne (2000) suggests that experiencing shame can result in a denial of symptoms or the existence of a problem in order to maintain social distance, therefore avoiding situations which could contribute to being judged. The consequence of this process can result in poor or delayed access to services, and reduced support networks.

The added impact of parental shame in this case could be the communication of stigma to the child. As was discussed in the section above (Section 7.1), parents/carers tend to seek reasons for their child’s presentation. Often this is communicated through a definition of ‘difference’, which is then applied to the child. This situation could have the effect of exacerbating problems, which in turn can cause the child to self-evaluate, and as a result they may experience social exclusion.
or isolate themselves. This process of communicated stigma within families is presented by Fossum and Mason (1986), who examined the inter-generation of family shame. They suggested that where a family cycle of shame and shaming exists, there can be an impact on the child's self-esteem. In addition, Schock and Gavazzi (2005) explored the burden of mental illness on families and suggested that family stress and subjective burden could impact not only on the person with the mental health problem, but on the family as a whole. Such a response to the stress of shame in the family could, in turn, influence the way in which the child perceives themselves, and result in heightened self-stigma; hence, the cycle of shame and stigma gathers force.

Within the findings, parents/carers demonstrated an attempt at absolution from being blamed or responsible for their child's problems, as a way of achieving emancipation from the stigma, guilt and shame they were experiencing. They frequently described that their main objective was to find a cause for their child's problems, and that gaining a diagnosis or an underlying medical explanation, would assist them in freedom from shame. Klasen (2000) found that parents of children with ADHD considered their diagnosis to be empowering, as it reduced parental blame and helped them to access services. However, whereas these parents found that the effects of the diagnostic label were not pejorative, the extent to which parents/carers in this study sought freedom from blame, through the identification of a formal cause, could result in stigma from the application of inappropriate labels. In addition, unnecessary referral to specialist services, could paradoxically contribute to the extent of stigma.
7.1.3 The denial of the existence of mental health problems in children: Protecting children and families from the harm of stigma

Besides the difficulty in developing a salient definition for mental health and the possible reasons for this (discussed in Section 7.1.1), parents and carers constantly grapple with the extent to which they accept that mental health problems and mental illness exist in children. This apparent lack of acceptance and the denial of the existence of mental health problems in children is demonstrated through the constant battle they seem to have in finding suitable words to describe mental health and mental illness. As parents/carers perceive that mental health problems and mental illness are associated with isolation, discrimination, engrained stigma and poor chances of recovery, they display a tendency to medicalise them, or associate them solely with the adult population. What seems to happen within the findings is that, when considering mental health problems in children, it is more acceptable for parents/carers to view them as a physical problem or 'disability'. From research with both children and adults, it has been found that the most negative qualities are applied to people with mental illness, in comparison to people with a physical disability or illness (Adler and Wahl, 1998; Green et al, 2003). In combination with this, parents/carers also tend to diminish the severity of problems. This, again, appears to be influenced by denial on two counts; firstly, the perception that children cannot experience severe mental health problems and secondly, admitting that the children's mental health needs are severe enough to require help, means that parents/carers may believe themselves to be responsible.

Whilst denial could be attributed to the shame which parents/carers experience in respect of their child's mental health problems (discussed in Section 7.1.2), there seem to be two additional forces at play. Similar examples of denial have been recognised in the stressful chain of events which occurs when children are initially
identified as having, or are diagnosed with serious or chronic physical illnesses (Robinson, 1987; Burke et al, 1991; Coyne, 1997). Although the problems of the children in this study may not seem to be equivalent with serious or chronic diseases, such as childhood cancer or cystic fibrosis, the process that parents/carers experience is relatively comparable. Burton (1975) suggests the discovery of a serious illness in a child can represent an attack on the integrity and well-being of most parents. Such reactions can be seen from the parents/carers in this study, as the desperation and struggle they experience as a result is represented throughout the findings. Following this realisation, parents go through a sequence of emotions which are similar to a bereavement process, wherein they are seen to mourn the loss of their 'perfect' child (Eiser, 1990; Coyne, 1997). Evidence to support the occurrence of such a process in the research findings can be seen in the anxiety, sadness and impact that children's mental health needs have on their parents/carers' mental wellbeing. In addition, the second strand of the process of denial in this study seems to originate from the severe impact that stigma can have on the individual, and the deficits and fluctuations in knowledge that the parents/carers seem to have about their children's mental health. McCubbin (1984) suggests that one of the most effective ways of assisting families is to enable them to understand the child's problem, through information and communication with healthcare teams.

When considering the underlying processes in this study, it seems that parents/carers operate within a framework of protection. Their role of protection is influenced by a number of conflicting dilemmas; the need to protect their young child from the labels of mental illness, which they mainly attribute to the adult population; the desire to protect themselves and the rest of their family from the stigma and shame of parenting a child with a mental health problem, and the need to act accordingly to gain appropriate help for their children, without stigmatising them in the process.
7.1.4 Unintentional and referred stigma, and potential discrimination

Although parents and carers in this study seem to demonstrate a motivation and a desire to make changes to the process by which people with mental health problems are stigmatised, the way in which they talk about mental health and mental illness is punctuated by unintentional, or unconsciously 'referred' stigma. In addition to the apparent confusion displayed when they attempt to define their concepts of mental health, one of the most striking findings to emerge from the data is the consistent tendency to refer to people with mental health problems or mental illness, in the third person. In conjunction with this is the tendency to describe people's mental health problems as extremes, i.e. representing bizarre or dangerous behaviours.

Although the parents/carers lean towards the possession of a positive attitude towards mental health and mental illness, in that they recognised that they had perhaps experienced mental health problems, and that they were close to others who had also experienced them, they still demonstrated perceptions which would corroborate the effects of stereotyping and prejudice. The way in which they talk about mental health could be seen as having the effect of 'social distancing' (Hayward and Bright, 1997). The function of social distancing is to ensure that one is not associated directly with people whom are considered to be dangerous, who instigate fear, or whose behaviour is hard to comprehend. Hayward and Bright (1997) also suggest that there is an expectation that those who are more directly associated with mental health problems or have a mental illness would be less stigmatising, however, evidence has suggested the contrary and has not changed over time (Swanson and Spitzer, 1970; Alexander and Link, 2003).

On a few occasions, throughout the findings, parents/carers also display an inadvertent discrimination towards people with mental health problems. The
engrained idea of a ‘mental patient’, coupled with images from the media and the belief that mental illness is associated with violence and criminality, seems to have prompted parents/carers to feel the underlying need to marginalise people with mental illness. This was demonstrated subtly on most occasions, but on a few occasions, parents/carers openly suggested they may have felt differently if they were in close proximity to someone with a mental health problem. Such findings are supported by research on the community’s attitudes towards people with mental illness, wherein many of the participants indicated they would not mix with them in many social circumstances (Brunton, 1997). The Social Exclusion Unit (2004) highlighted that people experiencing mental health problems were often marginalised. Reasons for this included ignorance, lack of understanding and fear in the general population.

In addition, most parents and carers used certain derogatory words and language which seemed to be part of their common vocabulary. Although they recognised that words like ‘crazy’, ‘loony’, ‘schizo’, were stigmatising and discriminatory, they did inadvertently use them in conversation, implying that the effects of the stereotypical images of mental illness are omnipresent. Page and Day (1990) suggest that people with mental illness are victimised by the generalised effects of depreciatory labels, and Hayward and Bright (1997) comment that the use of references to mental illness in this way helps to reinforce and sustain a negative attitude. However, a small group of participants did express a blatant desire to avoid the use of prejudicial language and were taking to steps to change it, which supports the suggestion from Bryne (2000) that challenging the language surrounding mental health would contribute to the reduction of stigma.
7.1.5 The effects of the legacy of mental illness and societal stigma

The resounding legacy and myths around mental health problems and mental illness are insidious and permeate the findings of this study. Parents and carers speak openly of the views that pervade beliefs about mental health and mental illness, which they perceive to exist to some extent within themselves, but to a greater degree within society. Their discussion frequently highlights the perception that mental illness is still categorised in historical terms, and is represented by society in the form of images of old institutions, less than modern or unconventional treatments, continuation of the metaphors of 'madness', derogatory language, and shunning of those with mental illnesses. As with any issue that is not understood, parents and carers seem to consider that, because of the continued legacy that surrounds mental health and illness, perceptions of society breed contempt and maintain the taboo that is associated with it. Hinshaw (2005) discusses the historical perspectives of mental illness and stigma, and highlights that even though there were radical reforms of the way mental illness was approached in the 20th century; stigmatised views of mental illness remain. In addition, Hinshaw comments that the reform of child and adolescent mental health services has tended to lag behind adult services, therefore has created an increased challenge to educate the general public about children's mental health and their respective needs.

Parents and carers suggested that the myths they have encountered are perpetuated by the media, not only through films and television, but also through computer games and comic books. Whilst they seem to believe that their overall attitude towards mental health is fairly positive, they suggest that the biggest challenge is to tackle views in society. The consideration that the media assists the process of stigmatisation in continuing to convey such messages, presents an even greater challenge. Seiff (2003) explored the effects of negative media frames on mental
illness and found that the media did contribute to the development and persistence of negative attitudes held by the general public.

Experiencing such overt signs of prejudice prompted parents and carers to suggest that their perceived attitudes of society force them to hide any associations they may have with mental health problems. The suggestion that mental health becomes hidden, could also imply that stigma becomes hidden, therefore making it harder to challenge. Bryne (2000) comments that it is more difficult to tackle prejudice, when it is not immediately apparent where it is being directed. The feeling of ‘being different’, which is often used to describe children with mental health needs, perpetuates the hidden nature of the stigma that both parents/carers and their children experience. As a way of avoiding the label of mental illness and the ‘branding’ that they feel society attributes to it, identifying children as ‘different’ creates the potential for them to take on a new stereotype. However, it may then become harder for them to associate with any particular group and consequently remain on the periphery and excluded from different social settings. In turn, this makes it harder to identify and access appropriate services.

7.1.6 The effects of organisational systems and services on the mental health of children: Contributions to the stigmatisation process

The attempt to find help for their child’s mental health needs appears to have left parents and carers with a sense of disillusionment and despair. Throughout many of the interviews, parents/carers recounted the struggle they had encountered on their journey into CAMHS. In order to tackle this struggle, they displayed a unique resourcefulness, and invested heavily in developing their knowledge about mental health and interventions that work with children. Whilst some parents and carers had identified that their child had mental health needs at an early age, others reported
that they had tried all the strategies they could, before asking for help. Regardless of
which path they took into gaining help from CAMHS, their overall experiences appear
to be similar. The characteristics of their struggle are related to poor referral systems,
professionals’ lack of knowledge on what help is available, inadequate
communication between organisations, and poor information about services and their
child’s problem. These, coupled with long waiting times, being inappropriately
referred and the frustration at having to start the process of referral again, were
all reported to contribute to the stress, shame and disenchantment of parents/carers.
Many of these issues were highlighted in the HAS thematic review of CAMHS (HAS,
1995) and again in the National Service Framework for children, young people and
maternity services, almost a decade later (Department of Health, 2004a), as priority
areas for improvement within CAMHS.

Such difficulties in initiating the process of obtaining help could contribute to the
experience of shame, and an increased reluctance to approach mental health
services. This in turn could increase the severity of the child’s problems (Leaf et al.,
1986; Corrigan, 2004). As parents and carers experience a great deal of self-stigma
in relation to their child’s mental health problems, then it would follow that a difficult
journey to help would substantiate the reduced likelihood of seeking help earlier in
the emergence of these problems.

In addition to their experiences of the complicated pathway into care, parents and
carers reported that their sense of self-blame and their child’s experiences of
marginalisation and exclusion, were often perpetuated by the attitude and the
apparent lack of knowledge of professionals and within organisations. These
examples of poor understanding tended to be located within professionals they
encountered on a day to day basis in the child’s life, most particularly within schools.
Crisp et al (2000) suggested that these deficits within organisations and professionals

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are likely to account for some of the social distancing and isolation that those with mental health needs experience, and are a good starting point on which to base professional competency development (Crisp, 1999).

7.1.7 Changing attitudes toward mental health

Parents and carers presented their views on how the stigma associated with mental health might be challenged. Although some of them reported feelings of sadness and shock when receiving an appointment letter, which was headed 'Child and Adolescent Mental Health Services', and others recognised the stigma that was associated with mental health and illness, they recommended that stigma should be challenged, and that this could not be achieved by changing the words. They recommended a large-scale educative programme to help develop understanding and challenge ignorance, was a priority. This should target children and adults, including professionals. Such a programme should involve the media, which was perceived to be a highly influential means for change. Programmes such as these have been highlighted as necessary in recent literature, if the current extent of stigma around mental health is to be tackled (Corrigan, 2000; Social Exclusion Unit, 2004; Stuart, 2005). In addition, the findings suggest that awareness raising should also be aimed at all parents/carers, if there is to be reduction in the severity of mental health problems, and more efficient access to help.

If the stigma of mental health in children is to be tackled, then it would perhaps follow that services need to be provided in a different way, and that pathways to care need to be less complex and easier for parents to understand. The concepts discussed in Section 7.1.6, outline the impact that the struggle of accessing help has on parents/carers and children. The findings also outline several ways of changing the shape of CAMHS, which have been found to be effective, yet have not been
mainstreamed (HAS, 1995; Department of Health, 2004a). Much of the changing shape of services suggested by parents/carers relates to the provision of CAMHS in the community, easier pathways to help, early intervention and prevention, building on knowledge and capacity in universal services, and the development of skilled, trained, non-judgemental professionals. These firm ideas of what would improve the experiences, and life chances of their children, have been only recently prioritised in children's policy in England (Department of Health, 2004b; DfES, 2004b).

This section (7.1) has presented a discussion around the findings from parent and carer participants. The following section (7.2) will present a discussion around the findings from children.

7.2 Summary and discussion of the emerging findings from the children's interviews

This section will explore the key findings from the children who participated in this study. The discussion will follow a similar approach to the format used in Section 7.1, and will highlight significant points of emphasis emerging from the findings presented in Chapter Six. The discussion will focus on six specific concepts, which communicate the perceptions and experiences of children who have been identified as having mental health needs. They range from concepts which relate to the definition of health and mental health to the impact that children's problems and the associated stigma have on them.

7.2.1 Concepts of mental health and mental illness in young children

The understanding and perceptions of mental health demonstrated by the children in this study seem to be sophisticated, especially with regard to the young age of the participants. Although they displayed an initial difficulty in recognising the concept of
'mental health', many were able to apply logic and other existing knowledge to their thinking around the subject, which enabled them to elucidate positive definitions of mental health. Roose and John (2003) found similar levels of sophistication in their study, which investigated the understanding of mental health in ten and eleven-year-olds, within the general population. In addition, some of the findings from this study are echoed by the findings of research with much older subjects (Armstrong et al., 2000). When comparing the findings from the younger children in this sample with studies of older children, they show an understanding and ability to develop positive definitions of mental health, which is on a par with young adolescents' perceptions (Bailey, 1999; Armstrong et al., 2000).

The term 'mental health' does not appear to be in the forefront of the children's thinking. This was demonstrated by children's tendency to focus on one or the other of the words, when initially trying to explain their meaning. Many children focused on the 'health' aspect of the term, and were able to offer a very succinct definition and explanation of the activities required to promote a healthy lifestyle, such as physical exercise or nutrition. What children seemed able to demonstrate was their ability to learn about health concepts and to retain this knowledge. Armstrong et al. (2000) encountered a similar phenomenon in their research with adolescents. Children's apparent capacity to learn about health could provide a rationale for the inclusion of learning about mental health in the school curriculum. Bedelow et al. (1996) studied primary school aged children's capacity to understand health concepts, and their capacity to learn about cancer prevention. They found that children, as young as six years of age had a considerable knowledge about health, and also some knowledge about cancer. In their study they taught children about health and cancer related terms, and found that they were able to retain a good knowledge of what they had learnt. Rebok et al. (2001), in a study of elementary school children's learning about health, found that they were also able to report on the activities which were vital to
well-being. The findings from these two studies would support the detailed knowledge about health and the capacity to retain information, demonstrated by children in this study.

Children who focused on the word 'mental' and its relationship to 'health' did not tend to immediately explain it by framing it in a 'mental illness' category, but rather to explain it in the literal sense of the word, i.e. the way in which one might use one's brain or mind to achieve certain objectives. This differs from other research studies, where older children (i.e. ten years old and upwards) and adolescents tended to define 'mental' in terms of mental illness or mental health problems (Armstrong et al., 2000; Gale and Holling, 2000; Roose and John, 2003).

In this study, the children seemed to develop a more positive definition of 'mental health', and the activities required to achieve good mental health, with some prompting from the interviewer. However, it is difficult to draw conclusions about why this might have occurred, in the absence of research in this age group, on the underlying mechanisms. It could be that because children seem to have developed a more definite understanding of 'health', they were able to apply their knowledge to their understanding of 'mental'. However, what seems to stand out is the difference of children's views from those of their parents and carers, whose apparent struggle in defining 'mental health' demonstrates a tendency to associate the term with mental illness.

Quite a different picture emerged, however, when children were asked about their understanding of the word 'mental' and 'mental illness'. In response to these questions, they immediately described extreme presentations of a person with mental illness, and many of their reflections on mental illness seemed to imply connotations of danger and violence. Their descriptions showed a considerable capacity to
differentiate between physical problems and mental health problems. These findings are comparable with some of the studies undertaken with similar age groups (Weiss, 1986; Alder and Wahl, 1998). What is particularly apparent in this study is the tendency for children to suggest that mental illness can only affect adults, with only one child considering that he may have mental health problems.

Hinshaw (2005), in his review of the small number of studies in this field, suggests that children seem to have more difficulty in attributing mental illness to youth, than they do to adults. This suggests that the existence of mental illness among children is an ambiguous concept for young children to comprehend. Such a tendency to categorise mental health problems and mental illness as an extreme presentation and to relate it to adults could be an indicator that the effects of the stigmatising attitudes of the adult population (including parents, professionals and the general population) have begun to have an impact on children’s views at an early age. This potential impact of stigma on the way children develop negative stereotypes about mental illness has been found in some of the few studies which examined younger children’s perceptions of mental health (Weiss, 1994; Adler and Wahl, 1998; Wahl, 2002). In addition to this, a small group of children within the study tended to focus on the concept of illness, especially when thinking about children who may have mental health problems. This suggests that illness in children is perhaps an easier concept to grasp. What also emerges is the tendency for the children to identify with other children whom they perceive to have similar problems to their own, which will be discussed further in Section 7.2.5.

7.2.2 The role of experiencing ‘difference’ in children’s mental health

Two major concepts, which emerged in the findings, relate to the children’s distinct feelings of being ‘different’ to their counterparts, and the intense feelings of shame
and guilt that they seem to experience as a result of their problems. Children appear to have a heightened perception of what is attributed to 'normal' children of their age, and their apparent marginalisation from this group as a consequence of their problems. One of the few studies on the perceptions of stigma in young life involved adolescents (Armstrong et al., 2000). It shows that older children seem to be less likely to talk about their negative feelings related to mental health. However, within the children in this study, there is an inclination to talk openly about experiences of shame and difference in this respect. This contrasts with findings in older age groups, and suggests that younger children have not developed more sophisticated ways of protecting themselves against the invasive effects of stigma. Another explanation is that they have not or do not assign themselves to specific labels which categorise their problems more distinctly.

The existence of shame, which was explored in detail in relation to parents/carers (Section 7.1.2), also seems to be evident within the child participants. The children communicated their feelings of shame, by describing their acute understanding of their problems and the way they are treated by others. Although for most of the group this seemed to be as a result of being treated differently, or talked about by others as a result of their problems, a small group of children displayed a suspicion that their problems might be related to mental illness. As a result of such a concern they described a fear that they may experience some of the adult presentations they had described. Such feelings of shame, difference and marginalisation are not uncommon amongst both children and adults who have been identified as having mental health needs. The negative effects of a label on children and young people was the subject of some recent studies (Adams et al., 2003; Holguin and Hansen, 2003; Kelly and Norwich, 2004), which were related to anti-social behaviour, sexual abuse, and learning disabilities. Kelly and Norwich (2004), in their study of the perceptions of young people aged 10-14 years with learning difficulties, found that most were aware
of their difficulties, and their negative feelings about them. They also found that children who were in a special school had a more positive self-perception than those in mainstream education. Although the children in this sample were not given a specific label, the way that they perceived themselves as being different to the norm, especially given that they attended a mainstream school, could be interpreted as contributing to the overall feelings of stigma that they were experiencing.

When comparing these findings against the concepts of stigma, two issues seem to apply to the children's experiences of having been identified with mental health needs. Firstly, children in this study do experience self-stigma (Corrigan, 2000) as a result of their perceived difference from others, and secondly, they experience the effects of public stigma (Corrigan, 2002), i.e., the prejudicial and possibly discriminatory effects of public stigma, emanating from their peers, family, the community, and professionals around them. Although their mental health needs are not overtly stated, children tend to pick up on the communication of cues and messages about their difference from others (Corrigan, 2004). In addition, parents/carers do not appear to openly recognise the effect that stigma has on their children. In this respect, it is not that parents/carers are ignorant of their child's experiences of their problems, but rather that they are more determined to resolve their child's problems or to protect them from potential exclusion, which they consider to be a possible by-product of their child's presentation. However, it seems that the children do recognise that others perceive them as being 'different', or as having problems, which has a direct effect on the way they interact in social settings.

In relation to their perceptions of being different, children also identified that they are shunned by their peers, and within a variety of social environments such as school. Although there is a dearth of research on younger children's perceptions of stigma, some studies have explored children's perceptions of mental illness or disorders in
their peers (Roberts et al, 1981; Spitzer and Cameron, 1995). These studies identified that children tend to have negative reactions towards other children who have been identified as having emotional or mental health problems. Therefore, such findings would support the postulate that children’s perceptions of being different could potentially be confirmed by their peers’ ability to recognise their problems, and their tendency to categorise them negatively.

7.2.3 The communicated fear and stigma of mental illness

Children seem to demonstrate a considerable amount of fear and some stigmatising views towards people, mainly adults, whom they identify as having mental illness. Their reasoning is similar to that demonstrated by their parents/carers, and replicates findings from studies undertaken with the general population (Crisp et al, 2000; Social Exclusion Unit, 2004). Children’s perceived fears about people with mental illness seemed to leave them feeling unsafe and believing that they might be harmed, either deliberately or inadvertently. In addition, they perceive people with mental illness as evil or as engaged in criminal activity. The origins of such perceptions seem to be derived from a number of quarters, all of which could be identified as having an overt influence on the development of children’s views. Most apparent is the similarity to views which are communicated to them by adults, especially those who are significant in their day to day lives. Studies on the origins and development of fears in childhood have identified that these usually arise from three distinct pathways, i.e. through direct observation, modelling (e.g. from a parent, peer or siblings), or through information/learning (e.g. stories on the news or films) (King et al, 1997; Ollendick et al, 2001).

Further research on the effects of negative information on children’s fears (Muris et al, 2003), provides some supporting evidence on the way that negative and
stigmatised images of mental illness are communicated from adults to younger children. Muris et al (2003) examined the effects of negative information which they gave to children aged four to twelve years old about an unknown animal character called ‘the beast’. They found that the information increased children’s levels of fear, which then became generalised over time to a wider group of characters. They also found that positive information had the effect of decreasing levels of fear. Such findings could suggest the possible process by which children develop their fearful images of mental illness, especially given their parents/carers’ responses, discussed in Sections 7.1.4 and 7.1.5. In conjunction with theories of communicated fear in children, is the contribution by the media (Wahl, 2003).

In relation to the inadvertent relationship that children’s heightened fear of people with mental illness seems to have on their tendency to stigmatise and discriminate against mental illness, is their added propensity to socially distance themselves from those whom they identify as fitting within this category. The inclination to refer to people with mental health problems or mental illness in the third person, echoes the findings from the parent/carer participants, as does the proclivity to consider that mental health problems are something that other people have, and that they are less apparent in children. From these findings, it seems reasonable to suggest that, although children can recognise that they have some form of emotional or behavioural problem, in general they do not consider their problems would ever be related to mental illness. Most research around younger children’s perceptions of mental health problems shows that they are able to recognise them, especially in others. However, they seem more able to differentiate between those people that show extreme psychopathology, than those that are less obvious (Weiss, 1985; Spitzer and Cameron, 1995). On this basis, it would seem that children in this sample can recognise mental health, but would not associate themselves with mental illness, or feel comfortable in the company of someone whom they consider to have a severe
presentation. This scenario is probable confirmation that the initial development of fears and stigma of mental illness originates from an early age. Children's familiarity with stigmatising words commonly used in conversation, could suggest that they have a significant knowledge of prejudicial language at a level which would enable them to engage in the stigmatisation process (Scheff, 1966; Weiss, 1985 and 1994).

7.2.4 The developing empathy for those with mental health problems
A concept that comes across throughout the findings is children's ability to demonstrate empathy for peers, whom they consider to have some form of mental health problem. This is particularly striking, given children's fears about mental illness and the inadvertent stigma that is derived from their views. As discussed in the section above, it seems that most of these fears are related to the extremes of behaviours and presentations, and more directly to adults than children. Such subtleties are corroborated by findings from research which explored children's attitudes toward severity of presentation (Weiss, 1983 and 1994; Poster et al, 1986; Spitzer and Cameron, 1995). These studies demonstrated that younger children showed more understanding for those with less severe presentations. The difference in this study seems to be that, in addition to being more understanding of children's mental health needs, there is a desire to help other children with mental health problems, which is a similar finding to those from studies with older children and adolescents (Armstrong et al, 1998; Roose and John, 2003). However, this display of the desire to help and compassion for others seemed to wane a little, where there was a consideration that the other children might be aggressive or were seen to be 'acting out'.

Clarke (1984) suggests that empathy can be developed in children through encouraging the sharing of thoughts and feelings. Such qualities are communicated
by children in the sample, as they demonstrate an awareness of their problems and
the effects on others, and at the same time they demonstrate an ability to consider
how one might help those whom they regard as to having similar problems to
themselves. In addition, Aboud (2003) proposes that children have a strong proclivity
to form and identify with \textit{in-groups} and \textit{out-groups}. In-groups are persons linked by
heritage, community or shared values. They tend to differentiate themselves from
out-groups, i.e. those persons existing outside of the boundaries. These tendencies
are believed to form within the preschool years, and could possibly explain why
children in the sample have a tendency to empathise for others whom they would
identify as being 'different' from the norm, and similar to themselves.

7.2.5 Children's mental health services and the contribution to changes
in attitudes towards and experiences of stigma

Considering the young age of the children in the sample group, they were able to
offer a wide range of ideas about what might help to tackle the stigma and
discrimination of having mental health problems, and to change the shape of services
for children across all tiers. The main emerging concepts related to their desire to be
active participants in both their care and the way future services were planned. In
addition, they suggested the need for services to be accessible, the importance of
schools in the helping process, the need to improve their knowledge and attitudes
toward mental health, and the notion that professionals who work with children with
mental health needs should possess specific attributes.

The desire for children to be active participants in their care and in future changes in
children's services has been subject of many recent policy and guidance reports
(Department of Health, 2004a; DfES, 2004b; Street and Herts, 2005). What children
seemed to be advocating was that professionals need to engage them at a
participatory level, i.e. that they should have an active part in projects or processes, not just as consumers, but also as key contributors, thus affording them empowerment in the healthcare system (Kirby et al., 2003). This was also seen to be an important way to combat some of the feelings of shame, difference and exclusion which they experienced in school and in the community. Being given opportunities and the ability to take part seems to convey the ability to achieve ‘wealth’ in relation to the attainment of good mental health (Ridge, 2002). Studies related to children's perceptions of childhood poverty highlight similar processes in the effects of social exclusion on the child and their reduced ability to take part (Ridge, 2002 and 2003). These studies suggest that citizenship rights (Hine, 2004) and the development of participatory approaches for children will help reduce exclusion and stigmatisation.

Children strongly conveyed that there was a lack of appropriate information on mental health services available to them. In this respect, they used symbolism which portrayed the image of old psychiatric institutions, and a medicalised idea of the treatment that they would receive. Such images seemed to instil a sense of fear and foreboding about what might happen to them, and this apparent lack of information could possibly contribute to their sense of stigma and reluctance to attend services. These findings are similar to those of parents and carers discussed in Section 7.1.7. In addition to having age-appropriate information to help develop confidence about services and knowledge about mental health, children suggested that making services more accessible in the community and consideration of helplines could enhance the range of support. Such suggestions for service improvement were also highlighted in a recent study by Roose and John (2003).

The final areas that were considered to be beneficial for the improvement of understanding of children's mental health, and that may have a positive impact on the reduction of stigma and social exclusion, were the improvement of the knowledge
and attributes of professionals. Children considered that a difference could be made through the education of schools about mental health, and communicating with children. Roose and John (2003) found that children aged ten and eleven years old did not have much confidence in school teachers, and their capacity to help with mental health issues. In addition, their study found that the qualities of professionals who were available to specifically help with mental health needs were seen to be particularly important. This aspect is also confirmed within this study, with children suggesting that specialist professionals should have appropriate knowledge and skills, be trained, be able to listen and show a non-judgemental approach and attitude toward helping. Such qualities are particularly important in changing attitudes toward mental health, as many professionals have been found to hold stigmatising attitudes toward those they work with. This can be one of the primary sources of stigmatisation perceived by persons with mental health needs and their families (Wahl and Harman, 1989). Both of these issues can accentuate the propensity for the self-stigma of those who go for help (Hayward, 2005), therefore are fundamental to consider in bringing about long term change in the way services are delivered to children.

7.3 The interconnectedness of the emerging findings from children and parents/carers

Children and parents/carers in the study shared many perceptions related to mental health and stigma, which will be discussed in this section. In addition, they held some divergent views, which will also be explored. The convergent and divergent themes are presented in Figure 7.0. To assist in the explanation of the interconnectedness and interface of these shared and divergent views, a conceptual framework of the stigmatisation process and the communicated stigma of mental health between parents/carers and their children, will be proposed.
7.3.1 Shared perceptions of parents/carers and their children

Both parents/carers and children seem to demonstrate that they experience the pervasive effects stigma, in a number of forms. Both groups experience a high degree of self-stigma, although the interconnectedness of the effects of self-stigma does not seem to be acknowledged by either party. This convergence of perception appears to have an implicit relationship to the way that stigma is felt, enacted and communicated within the two groups. The experience of stigma appears be a catalyst for the feelings of shame experienced by the participants. This is then outwardly enacted by both parties, but seems to be communicated to children from parents/carers, which possibly culminates in children feeling marginalised or
shunned. Inversely, the parental feeling of shame seems to be responsible for heightened sensitivity in the parents/carers which serves to increase their feelings of guilt and failure, and prompts the desire for the liberation from responsibility for their child's problems.

The communication of feelings of failure and shame in parents and carers has a number of direct and indirect consequences for children. Firstly, parents/carers tend to experience an enhanced cycle of shame and powerlessness, which is almost mirrored by their children. Secondly, the communicated stigma associated with this has the effect of making children perceive that they are different to others. Finally, the contradictory position that parents find themselves in, through their own stigmatisation, delays their inclination to seek help. Gray (2002) suggests that a similar situation occurs between parents and their autistic children, i.e. they are stigmatised by their children's condition, but would probably be condemned if they rejected the association. As a result of the intimacy in the parent-child relationship, it seems reasonable to suggest that the stigma and shame experienced by both groups could be inter-related. However, although both groups experience shame, the extent to which this is externalised differs, with children appearing more able to talk openly about their problems and the impact they have on their daily living. This difference could be related to the stage that the children are at in their development and the absence of sophisticated ideas about the direct consequences of stigma and mental health.

Another converging theme occurring within the findings relates to the contribution to public stigma from both groups. It seems that although both parents and carers, and to some extent children, recognise the discriminatory effect of stigma on individuals with mental health problems, they would not primarily categorise themselves being associated with this group. Although mostly inadvertent, the effect of this perception
is that both parties participate in prejudicial and stigmatising behaviour towards people with mental health problems. This phenomenon was demonstrated in both groups through the use of prejudicial language in common conversation, and more clearly through the desire to keep a distance from those whom they considered to have more serious mental health needs. Participants possess a desire to reduce stigma and to develop a positive attitude towards people with mental health. However, negative opinions appear to be pervasive and have been communicated to the participants on a societal level, and through the continuation of the myths and legacy that surround mental health and mental illness. In addition, as was discussed in Section 7.2, children are able to form attitudes about mental health and mental illness at an early age, therefore the views they hold, which are similar to those of their parents, could be a result of the communications and interactions of these beliefs and attitudes within the dyad.

Although Wolff et al (1996) suggested that knowing someone with mental health problems does not assure a more enlightened attitude, there is a dearth of exploration in the literature of the stigmatising attitudes of those with mental health problems or mental illness, towards others with the same diagnosis. What seems to be occurring within the findings, is that both parents/carers and children are unknowingly discriminating within their own group. This appears to be related to a preference for more acceptable groups of people who could be classed as having mild to moderate mental health needs, as opposed to the rejection of less favourable groups of people with more severe presentations. This is demonstrated in both children and their parents/carers within the extent and the levels of compassion or empathy they show for people with mental health needs. Similar scenarios can be seen in research on inter-group discrimination related to racism, where a preference is shown for one particular racial group over another (Dovidio et al, 2001; Nicholson et al, 2005). Equally, studies of in-groups within youth culture show that certain
stigmatised or out-groups, which convey a perceived threat, can serve to intensify stigmatisation (Stangor and Crandall, 2000). This would perhaps suggest that the ambivalence towards people with mental health problems is instigated by the uncertainty of parents/carers and children in respect of the distinct group they fall within. Hence, the tendency would be to identify with those people who are seen to have less severe mental health needs or who are seen by society to be less threatening. Additionally, this scenario could also occur as an attempt at self-protection or survival, as being associated with a more accepted group could serve to reduce the effects of stigma and discrimination. Although both groups showed the propensity to relate more to people with mild to moderate mental health needs, children demonstrated heightened ability to show empathy towards other children whom they perceived to have mental health needs similar to their own. This differed from parents/carers' perceptions, and perhaps indicates that children's negative views were not as strongly developed as those of their parents.

Although parents and carers demonstrated some difficulties in developing a positive definition of mental health, there was some agreement with their children on what constituted mental illness. Both groups demonstrated the ability to describe severe presentations of mental illness, but attached to these definitions was the inclination to deny the existence of more severe mental health problems or mental illness in children. Both groups displayed a tendency to describe mental illness as being attributed entirely to adults, and demonstrated though extreme symptomatology. In conjunction with these perceptions, both groups displayed similar levels of fear about people with mental illness. Such shared perceptions suggest the existence of a further dimension of communicated stigma within families. The inclination of parents/carers and children to stigmatise more extreme presentations of mental illness could be explained by literature which relates to the stereotypical signals that may lead to stigma, resulting from the way that people act (Corrigan, 2000).
Research has shown that more stigmatising reactions are often a result of behaviours which are seen to be inappropriate or bizarre (Socall and Holtgraves, 1992; Penn et al, 1994). The response to fear originating from stigma linked to more extreme presentations of mental illness, was for both parties to socially distance themselves from such associations. However, this seemed to have the perceived benefit of increasing the likelihood of immunity from the escalation of child mental health problems to such a level of severity.

Finally, parents/carers and children expressed similar views on the contribution of children's services to the shame and struggle experienced when attempting to gain help. Both parties identified that services demonstrated a deficit of knowledge about children's mental health needs, poor communication strategies (both with families and across agencies), and lack of clarity around referral criteria. In addition, these issues were seen to complicate the pathway to help, and to contribute to the levels of stigma experienced in relation to children's mental health needs. Bryne (2000) suggests that one of the ways to combat stigma is to provide education about mental health and to instigate health service changes that promote social inclusion and reduce discrimination. He suggests that the current practices of assessment can contribute to the stigmatising process, and recommends that mental health services and other organisations must collaborate to reduce this effect. In order to find solutions to problems in systems of care, it is imperative that the interconnected aspects of stigma are translated into interventions to tackle the consuming effects experienced by families.
7.3.2 Dimensions of stigma in children with mental health needs and their parents/carers: A conceptual framework

In order to understand the complexity of the many dimensions of stigma, it was deemed necessary to locate the inter-relationship between the stigmatising process and the experiences of parents/carers and their children, within a conceptual framework. Many studies of stigma in adults with mental health needs have explored dimensions of stigma and their functional role (Corrigan, 2000; Sieff, 2003; Corrigan, 2004). However, there has been little exploration of the role of stigma within families with a child with mental health needs. The emerging findings from both groups and their shared themes demonstrate an interconnected relationship between all aspects of the stigmatisation process, and the impact and effects of stigma on the child and their parents/carers, as well as on a societal level.

As in research that examined this process in the adult field, the problems and effects of stigma are severe, diverse and complex, and can contribute to the overall consequences and experience of having a mental health problem or illness (Corrigan, 2000; Link et al, 2001; Stuart, 2005). The paradoxical role of both parents/carers and children, within the stigmatisation process, has been demonstrated by the part they play in inadvertently contributing to the continuation of public stigma in the general population. In turn, they seem to experience the effects of public stigma, as they begin to realise that having mental health problems involves being caught up in a cycle of shame, self-stigma, lowered self-esteem and powerlessness. In conjunction with the cycle of stigma and shame, which seems to be communicated from parents to children, is the possibility of social exclusion and increased severity of mental health needs. Figure 7.1 presents a framework to explain the relationships occurring within the stigmatisation process, and will be used to identify points for intervention in the following section (7.4).
Figure 7.1: Communicated stigma: The effects of stigma on parents/carers and their children

- PARENTS
  - Self-stigma by proxy
  - Shame
  - Powerlessness
  - Failure
  - Blame
  - Courtesy Stigma
  - Struggle to access help

PUBLIC STIGMA

- Increased stigma and social exclusion

CHILDREN

- Self-stigma
  - Difference
  - Withdrawal
  - Blame
  - Shame
  - Lowered self-esteem

- Lack of knowledge about services

- Increased mental health needs leading to crisis
7.4 The implications of the findings on tackling stigma, policies and child mental health services

The interconnectedness of children's and parents'/carers' perceptions of mental health and stigma, discussed in this chapter and outlined within the conceptual framework presented in Section 7.3.2, illustrates the complexity and impact of the stigmatisation process. The exploration of the relationship that the stigmatisation process has on parents/carers and their children, and the way in which stigma is communicated between the family, services and society, and within the family itself, produce key points for intervention.

This section will consider the implications of the key findings for child mental health services and for the policy agenda. It will present a framework, interventions and actions for tackling stigma, improving the understanding of mental health and the experience of mental health services for children and their parents/carers.

7.4.1 A multi-dimensional framework for tackling stigma, improving understanding of mental health and the experience of mental health services for children and parents/carers

The key findings from children and parents/carers have a number of implications which should be applied by services, and which could enhance policy guidance in relation to children, their mental health and anti-stigma campaigns. When considering the key concepts discussed earlier in this chapter (7.1 and 7.2), nine areas for action emerged. These critical areas for intervention (presented in Figure 7.2) can be applied on a number of levels, and within a range of settings and scenarios. This model would include work between families and professionals, challenging beliefs and attitudes about mental health in society, and the mainstreaming of anti-stigma policies that specifically focus on children and their families.
In order to improve the understanding of and attitudes toward mental health, and the experience for parents/carers and children with mental health needs, the nine critical areas for intervention should be implemented concurrently. The following two sections (7.4.2 and 7.4.3) will consider these areas for intervention and the possible actions necessary for their successful implementation within policy and service provision.
7.4.2 The implications of the findings on children’s and anti-stigma policy

Developing a shared understanding of child mental health and mental health problems and reducing stigma, presents a unique challenge to policy. Action around the nine crucial interventions presented in Figure 7.2 may not be without difficulty, and should be addressed strategically. Whilst there is a need to mainstream mental health promotion, education and anti-stigma programmes so that they are embedded with policy, strategy and delivery of services; tackling stigma also needs to become an integral aspect of every organisation’s value base. In order to achieve this, some fundamental aspects need to be considered. Bryne (2000) suggests that the approach to overcoming stigma, regardless of the means, should have an outcome which aims to promote social inclusion and to reduce discrimination. As suggested in the previous section (7.4.1), achieving such an outcome would rely on concurrent implementation of the key interventions across all policy dimensions relevant to children and to mental health. The essential aspects of change range from achieving a clarity of mental health definitions and challenging commonly used stigmatising language, to the integration of tackling mental health discrimination within social justice models (Myers et al, 2005) and legal frameworks (NIMHE, 2004).

One fundamental aspect which emerged for both groups of participants was around the common use of stigmatising language and the lack of clarity about definitions of mental health, and mental health problems in children. Although it is difficult to determine the precursors to this, a phenomenon which has occurred within recent children’s policy and guidance, is the variety of terms and phrases used to describe mental health (Department of Health, 2004a; 2004b; 2004c and 2004d; DfES, 2004a and 2004b). In this respect, some misunderstanding seems to originate from the way in which terms are used. Such terms range from ‘emotional wellbeing’ or ‘emotional literacy’, which are commonly used as a substitute for ‘mental health’, to using the
term 'mental health' to mean 'mental illness'. It seems that this new range of terms attempts to reduce stigma. However, this variation could contribute to confusion amongst organisations, which could also be communicated to children and families. Within the findings, the emphasis centred on the need to have a clear understanding of mental health, not on changing the terms. Embedding an agreed and clear definition of children's mental health within policy and ensuring that the term 'mental health' is the commonly accepted term, could help limit the discriminatory aspects of stigma, and empower children and their families to recognise their mental health needs.

A positive aspect of recent children's policies is the recognition of the need for mental health promotion and education programmes to target children, parents and professionals (Department of Health, 2004b, 2004c and 2004d; DfES, 2004a and 2004b). The overarching children's policy framework – Every Child Matters (DfES, 2004b) recognises that children and parents need to be listened to, included in the planning and review of services, and be able to make healthy choices and a positive contribution. In addition, both Every Child Matters and the National Service Framework (NSF) for children (Department of Health, 2004a and 2004b), emphasise the importance of providing accessible services in non-stigmatising settings. However, they do not recognise of the impact of stigma, nor do they firmly embed actions to tackle it in their guidance. The findings of this study suggest the need for policies to be explicit about the impact of stigma and the interrelationship of the stigmatisation process between children and parents. Based on the emerging concepts from this study, it would seem reasonable to suggest that understanding of the stigmatising process that occurs within families, and the interventions to tackle it, should be explicitly stated. Additionally, the current reform of children's services should include the mainstreaming of anti-stigma interventions. The combined approach to tackling stigma from an early age, as well as within the parent-child dyad, could reduce the
chances of developing negative attitudes in later life. As the parents/carers demonstrate a sense of powerlessness and failure, ensuring that policy considers the cycle of shame/blame and powerlessness, and the relationship this has on children's perceptions about mental health, could serve to redress the power imbalance and reduce the negative emphasis of the cycle of shame within the family.

Both parents/carers and children highlighted a perceived deficit in their understanding of mental health, especially in relation to children. This was seen to be global and included services and organisations. They outlined the need for education programmes to challenge attitudes and beliefs, and to improve understanding of mental health. However, the provision of information and education on a small scale may not assist in the reduction of stigmatising attitudes. Hinshaw (2005) suggests that public educational programmes to tackle stigma and improve understanding of mental health cannot solve the problem of stigma on their own. Parents/carers' and children's views about improving knowledge of mental health, especially within schools, should be highlighted within policy and coupled with programmes to help public and professionals understand the debilitating and severe effects of stigma. As parents/carers and children wish to be helped by skilled and competent professionals, such programmes would also need to be embedded in professional training programmes.

Being able to disseminate the effects of stigma described by the participants, and understanding individual and organisational contributions to the stigmatising process could enhance the recognition of the problem. The crux of the matter does not seem to be entirely located in developing mental health awareness, but also in developing stigma awareness. The Social Exclusion Unit (2004) recommended that challenging stigma and discrimination of mental health should be the responsibility of all organisations. In addition to this, the delivery of mental health awareness or anti-
stigma programmes to children, especially in schools, could consider the involvement of parents/carers in the learning process.

*From Here to Equality* (NIMHE, 2004) suggests a comprehensive plan for overcoming the stigma of mental health across a number of individual, service and policy dimensions. The effects of stigma on families of adults with mental health problems are often mentioned in the literature (Crisp *et al.*, 1999; Social Exclusion Unit, 2004; Hinshaw, 2005). However, the key role that children and their families could play in overcoming stigma is often omitted from plans. As parents/carers and children in this study suggest, effective communication with them, not only about their child's mental health problems but also about organisational structures, processes and planning, could serve to reduce the discrimination and exclusion experienced along the care pathway. Where there has been a move to develop strategic approaches which include children, policies seldom recognise effects of stigma within the family. The benefit of including both the child and their parents in anti-stigma strategies could assist in breaking the cycle of stigma at critical points, which have been highlighted in Figure 7.1.

Policies suggest that less stigmatising child mental health services could be achieved through provision in local environments, such as schools (Department of Health, 2004a). However, the findings from this study indicate that child mental health carries a great deal of stigma, as do services associated with it. In addition, parents/carers and children identified that schools contributed to the stigmatisation process. Based on these assumptions, it is imperative that policy considers the dynamics of stigma before developing services in the community. In order to ensure that new service developments are responsive to the needs of children, it is vital for policy makers to consult across all age groups in contact with CAMHS.
The highly influential role of the media in communicating an ongoing culture of fear and stigma around mental health was highlighted by parents/carers and children. Many studies highlight the negative impact of the media on the way that mental health and mental illness is perceived in the general population (Philo et al., 1993; Wahl, 1995 and 2000; Sieff, 2003). Current policies and guidance suggest that recruiting the media as allies in tackling stigma and discrimination may be beneficial (NIMHE, 2004; Hinshaw, 2005). If such collaboration is to be effective, then central government bodies and policies need to ensure that the media takes account of children's mental health, and that they are assisted to recognise the importance of conveying positive messages. Hinshaw (2005) suggests that a blend of approaches which include giving clear definitions of mental health, information about mental health problems, and realistic portrayals of mental health problems in children, could assist in the development of positive attitudes. In addition, media information that is age-appropriate and empowering may help to reduce the discriminatory effects of stigma and mental health highlighted in this study.

Children's policy suggests that service planning should take account of users' views in the future development of more effective systems of care. However, methods to ensure that younger children and their parents are active participants in this process are not usually outlined, and effective methods of user participation tend to focus on young people and adults. Recent policies and guidance introduce the concept of participation (Department of Health 2004a and 2004b; DfES, 2004b; NIMHE, 2004), however, this tends to focus on the elucidation of users' views, or service evaluation. The findings in this study indicate that younger children also have a great deal to offer, as do their parents/carers. Both groups speak about wishing to be active participants in the design, development and delivery of their care. Acknowledging their unique contribution to the understanding of stigma, children's mental health and services, could assist in the development of protocols for active participation.
In addition, the development of approaches to eliciting the views of younger children, such as the method used in this study, would enable children to contribute to the development of anti-stigma programmes and inclusive child mental health services. Street and Herts (2005) describe a participatory citizenship model for children (Arstein, 1969; Hart, 1992). This model suggests a ‘ladder of participation’ for partnerships between children and adults, and then moves towards child-initiated decision-making which is shared with adults. Endorsing such approaches within policy would be beneficial in providing insights to assist better planning and provision of services. Such approaches would enable the request for active participation, highlighted in the findings, to be achieved and to be integral to child mental health service development and provision. In addition, the inclusion of parents/carers in such a model would also enable the capture of the shared and communicated perceptions of mental health.

Moving towards the integration of children and parents as ‘citizens’ within policy guidance would enhance programmes to tackle stigma, and improve the overall experience of asking for and receiving help. Teaching citizenship skills has been recently been outlined as beneficial for children, in relation to recent policy on tackling on youth crime (Hine, 2004). Children’s citizenship models are deemed to be pro-active in enabling children to recognise and report unfairness and discrimination, develop moral and social responsibility, be involved in their communities, and in developing social capital and political literacy (Hine, 2004). All these aspects could help improve the experience of mental health services and reduce stigma.

Given the complexity of perceptions surrounding mental health, a sustainable programme to combat stigma and to raise awareness would need to be supported by a framework that promulgates rights and social justice. If the basic principles of overcoming stigma and discrimination, discussed in this section, are to be effective,
then locating the stigma of mental health within a social justice and legal framework may be supportive in challenging these issues (Corrigan, 2004). As Bryne (2000) points out, the stigma of mental health and mental illness has had a long existence. Although there have been campaigns to tackle stigma and discrimination, there has not been a vast reduction in discriminatory practices (Crisp, 2004).

Studies undertaken in Scotland found that mental health inequalities have been overlooked within social justice frameworks (Myers et al, 2005). The involvement of children and their families, as a tangible group, could assist in the overall achievement of an inclusive social justice model. Myers et al (2005) suggest three levels of intervention within social justice. The first level would be within the population, where economic well-being and life chances are improved across generations and pay attention to mental health. The second level focuses on social identities and recognises the specific inequalities experienced by particular groups, in this case children with mental health needs and their families. The recognition of the experiences of 'difference', isolation and exclusion, within an equality-based framework would support the development of accessible and appropriate services to meet child mental health needs. Finally, the third level recognises diversity between individuals. This would bring together the concepts of citizenship and participation discussed earlier, thus enabling the production of a culture and practices which recognise and value difference among children, their parents, families and professionals, as well as on an organisational basis.

Plans to tackle the discrimination of people with mental health problems may benefit from being located within a legal framework (NIMHE, 2004b; Social Inclusion Unit, 2004). The Disability Discrimination Act, 1995 (DDA) (1995) (HM Government, 1995) was a milestone in reducing the discrimination against people with disabilities and mental illness. However, whilst this legislation challenges the discrimination against
individuals with mental health needs, many would not view themselves as ‘disabled’. This is even more likely in parents/carers, in light of their difficulty in recognising child mental health problems, and the severity of the stigma they experience. Steps to move towards this approach would require careful consideration regarding the possible effects on children and families, and how they perceive themselves. However, the DDA can offer protection, as can other legal frameworks such as the Human Rights Act (HM Government, 1998) and the Children Act (HM Government, 2004). NIMHE (2004b) and the Social Exclusion Unit (2004) both suggest that working together with the Disability Rights Commission and raising awareness of individuals’ rights is crucial. In conjunction with this, it is fundamental to ensure that children with mental health needs and their parents/carers are advocated for within such a programme, thus ensuring that they have a voice and their opinions are listened to.

7.4.3 The implications of the findings on services for children with mental health needs

Promoting understanding of the mental health of children and challenging stigma must be firmly embedded within policy frameworks, as discussed in Section 7.4.2. However, there are also implications for local implementation within child mental health services across the four tiers of service provision (Appendix 1). The nine interventions for tackling stigma in children and their parents/carers presented in Figure 7.2, can be implemented locally, but will have different actions to those described in relation to policy. Practical actions for the implementation of the multi-dimensional intervention framework (Figure 7.2) within local CAMHS provision are discussed in this section.

The mainstreaming of approaches to tackling stigma and raising awareness of child mental health should be recognised and implemented across all children’s agencies. Parents/carers and children in this study described the difficulties they experienced in
gaining access to help and in receiving a responsive service. Although raising awareness of mental health and stigma has been the focus of campaigns which included children and young people (Bailey, 1999; Crisp, 2004; NIMHE, 2004a), such initiatives seem to have had limited influence on the awareness, values and beliefs of professionals and services. The integration of anti-stigma programmes, stigma awareness and education about children’s mental health needs to become the business of all service providers and to be integrated within each individual professional’s value base. Practical strategies for the mainstreaming of such approaches could include the development of action plans for services, which incorporate the principles of tackling stigma outlined in the NIMHE strategic plan (NIMHE, 2004b). Plans should also develop activities and interventions suggested in Figure 7.2, and through the integration of the ten essential shared capabilities for the mental health workforce developed by the Sainsbury’s Centre for Mental Health and NIMHE (Hope, 2004). These ten essential shared capabilities include tackling inequalities and stigma, therefore would be a vital component to raising stigma awareness in the CAMHS workforce. Raising awareness of the effects of stigma on children and parents/carers, as outlined in the findings of this study, and previous research (Armstrong et al, 1998; Bailey, 1999; Roose and John, 2003) could increase the likelihood of changing beliefs and attitudes about mental health.

The previous section (7.4.2) addresses the importance of developing a salient definition of mental health. Local services could tackle this by considering their language and terminology, and also through development of standard explanations of mental health, which are age-appropriate and do not inadvertently stigmatise. Children and parents/carers in this study have demonstrated that they were able to hold articulate and sophisticated discussions about mental health. This suggests that both parties would be able to contribute to such discussions with professionals. In this respect they could usefully contribute to developing definitions and terminology, which
promote equality and inclusivity within CAMHS. Roose and John (2003) found that older primary school children were able to have valuable discussions about mental health. Therefore, developing a shared understanding of mental health between professionals, and with children and their parents/carers, would be a sound base from which to launch programmes to promote mental health awareness and to challenge stigma.

Both parents/carers and children highlighted their concerns about seeking help and attending CAMHS. They determined that they were uncertain about what would happen when they attended their first appointment, as they had been given limited information in their appointment letters. When seeking help, parents and carers explained that they were not sure where to go or which was the right service for their child’s mental health needs. These issues appeared to contribute to the mystique and fear which surrounded CAMHS, and the adverse effects of stigma experienced by the child and their parent/carer. Both groups indicated that these views were corroborated by the apparent lack of available information about services in the public domain. In addition, parents and carers identified that frontline professionals were not always well informed about services, and did not show a comprehensive awareness of children’s mental health.

Day et al (2006) found that children who had attended specialist CAMHS had little understanding about what would happen at their first appointment. This was seen to contribute to concerns about asking for help and meant that children were ill prepared for their assessment. The authors thus highlighted the importance of pre-appointment preparation. The findings of this study are similar and indicate that useful interventions might include the development and dissemination of age-appropriate and user friendly information about child mental health and CAMHS. In addition, such information could be used by parents to help them reduce their children’s potential anxieties. Information
for children could employ methods such as the tool developed for this research, which seemed an effective way of enabling children talk about mental health and their concerns. Developing a storybook approach could assist in the explanation of mental health to children, and engage parents in the process. If CAMHS are to tackle stigma and raise mental health awareness in a strategic way, then it is imperative that all services consider how they impart information. Developing material and protocols to ensure that parents and children are informed about their care could be an easily achieved outcome, with few resource implications.

As the reform of children's services and CAMHS has indicated the need for the early recognition of child mental health problems, and for increased capacity and knowledge about children's mental health across services, it is necessary to develop robust, local education programmes (Department of Health, 2004a and 2004b; DfES, 2004b). The key findings from parents/carers and children indicate that such education programmes should be delivered in multiple contexts, and include a curriculum on children's mental health and stigma. Although most of the current policy which relates to CAMHS suggests that education programmes should target frontline (Tier 1) professionals, the findings indicate that programmes should be implemented across the tiers. In addition, the inclusion of knowledge about child mental health and the stigmatisation process could be included in training courses available for professionals at a pre-registration and post-graduate level. Sebuliba and Vostanis (2001) described an interagency training and education model for tier one staff around children's mental health, which could be implemented at a local level and which could include training about the effects of stigma. Local services would also need to consider how parents and children can best contribute to education programmes and how they might benefit from them. The citizenship model discussed in Section 7.4.2 (Hart, 1992) would be a useful framework for the appropriate involvement of parents and children in the design and delivery of training. Such involvement would be beneficial in empowering parents.
and children to promote their own mental health, to recognise their mental health needs, and to challenge the negative impact of stigma.

The need to develop communication protocols with parents/carers and children was communicated in many aspects of the findings. Their desire to be informed and active participants in their care was clearly articulated. Parents/carers were often left feeling uncertain about the process for referral and the outcomes of discussions with professionals. In addition, poor communication with them and between agencies resulted in loss of faith in the systems and left them feeling unsupported. They also reported that they were made to feel inadequate, or that they were to blame for their children's mental health problems. Children perceived that they were not listened to and indicated that they wished to be part of the decision-making process about their problems. Such concerns would suggest that services need to consider their relationship with users. Inclusive models of working should be developed to ensure that children and parents are active partners in determining the care process. Within clinical services, agreements or contracts can be developed in partnership with the child and their family to ensure that all parties are clear, and have a vehicle to ask questions or challenge assumptions. Such approaches are used in therapeutic relationships, often in family therapy (McDowell, 1999), and can assist parents and children in feeling they are an active partner in the process.

The findings indicate the importance of the therapeutic alliance, not only with the parent and clinician, but in particular between the clinician and child. Children possessed clear ideas about how they would like to participate in this alliance. These ideas included being seen separately from their parents and being listened to. Children formulated views on the clinician's qualities, i.e. that they should be kind, have empathy and be qualified to undertake their job. These key findings indicate the importance of considering how clinicians communicate with children. In addition,
regular evaluation of the therapeutic relationship with the child and within clinical supervision would ensure that clinicians remain responsive to the child’s needs. Within the therapeutic alliance it would also be beneficial for clinicians develop their awareness of the possible effects of stigma on the child and their family, thus ensuring they take steps to consider the impact within their practice.

The relevance of current policy recommendations for more accessible, responsive, timely and comprehensive CAMHS provision (Department of Health, 2004b) is echoed by the findings, which point to the requirement for the revision of some local organisational structures. The findings indicate that there is lack of clarity in referral routes and criteria for services across the tiers, uncertainty about their remit, lack of knowledge about community services, and ambiguity about joint agency working. Many of these views appeared to impact on both parents/carers’ and children’s experiences of self-stigma, shame and powerlessness, as indicated in the conceptual framework outlined in Section 7.3.1 and Figure 7.1. Consequently, these offer specific points for intervention in challenging stigma and breaking the cycle of stigma communicated between parents and their children. The development of transparent referral protocols and criteria would contribute to the reduction of stress, confusion and reluctance associated with seeking help. In conjunction with this, the apparent gap between specialist CAMHS and Tier one services could be closed by the further development of the new Primary Mental Health Worker (PMHW) role, which is located at the interface between specialist and Tier one services, to support Tier one staff by building their knowledge, confidence and capacity to work with children with emerging mental health needs (Health Advisory Service, 1995; Gale, 2003; Gale and Vostanis, 2003). The impact of the PMHW role on parents/carers’ and children’s experiences of care pathways has not yet been evaluated.
Although partnerships with the mass media appear to be more relevant within the policy context, parents/carers’ reflections on the role of media in the transmission of negative stereotypes of people with mental health problems were strongly portrayed within the findings. Wahl (2003) suggests that the mass media contributes to children’s negative attitudes about mental health, therefore adults should actively guard children from being subjected to negative media influences, through rigorous regulation of films, computer games and other materials. In addition, it may be beneficial for CAMHS to work with local media organisations in imparting positive information about children's mental health and help that is available. In this respect, local newspapers, television and cinema could be supportive in getting information about children’s mental health out in the public domain.

The move towards involving children and parents as citizens, partners and decision-makers (discussed in Section 7.4.2), requires a coordinated and practical approach at a local level. The request from children and parents/carers to be involved in all aspects of their care requires professionals, across the tiers of CAMHS, to identify opportunities to mainstream this approach. In order to develop a participatory approach, professionals need to understand techniques and processes that promote participation, and to ensure that these are embedded within the service ethos. Street and Herts (2005) outlined a range of participatory activities for CAMHS. However, to design and implement such effective participation plans for children and families requires local services to identify staff and resources. Although such an approach could have implications for funding, it should become a fundamental part of effective service delivery to ensure that participation of children and parents moves from tokenism to partnership.
7.5 Methodological implications

This study used Interpretative Phenomenological Analysis (IPA) as a specific qualitative methodology to explore the perceptions of mental health and stigma held by children (aged five to eleven years) and their parents/carers. In conjunction with this methodological framework, a set of techniques and procedures were devised to assist children and their parents/carers to talk about children’s mental health and stigma. The approach was seen to be generally successful and has potential benefits for future research in this field. There were, however, some methodological limitations which could have had implications for the interpretation and generalisation of the findings. This section will address the methodological limitations identified, before going on to consider the potential applications of this methodology in future research.

7.5.1 Methodological limitations

Some of the methodological limitations arose in relation to the recruitment procedure. The research ethics committee requirement for children and families to ‘opt-in’ to the study meant that the data collection period was protracted. In addition, the number of children fulfilling the age criteria for the study was lower than in older children (Green et al., 2005). Over the three and a half years data collection period, 72 invitations to participate were sent out, with 28 parents and carers agreeing to take part. The final sample group consisted of 20 child and parent/carers dyads. Overall, very few families dropped out once they had consented to participate. The concern about the sample group who did ‘opt-in’ is that they may have had something specific to say about the subject area, and on this basis may have been more inclined to contribute views that showed a greater motivation to tackle stigma, or greater awareness of mental health issues. In this respect, the perceptions and experiences of families who did not participate may have been different. However, the results are comparable with other research in the field (as presented in the discussion of the findings in Sections 7.1 and
7.2), and children and their parents/carers were able to portray both positive and negative views.

In terms of the characteristics of the sample, although qualitative research does not require a large number of subjects, and IPA is considered to be a particularly appropriate methodological approach with very small numbers (Smith, 2004), the sample cannot be considered to be representative of all children and parents/carers. Although this group may be representative of service attendants, in that they were selected from consecutive referrals, the process of opting in to the study meant that the group was not wholly representative of the local population. As can be seen in the demographic characteristics of the sample (presented in Tables 4.5 and 4.8), there is a gender imbalance in both the child group, which is skewed towards boys, and the parent/carer group which mainly consisted of females. Such an imbalance could be a prompt for consideration of further research to establish if there are differences in perception between genders; however, the aims of the study were not to consider perceptions on this basis. In addition, although the local population was known to have a higher representation of people from black and minority ethnic communities, they are not thoroughly represented in the sample group. Reasons for this may need to be considered in future research. However, due to CAMHS desire to protect the identity of those who did not wish to opt in to the study, then it was not possible to establish if the differential occurred as a result of low levels of referrals from the black and minority ethnic communities, or that they simply did not wish to participate. All of these considerations could help to ensure the findings are more generalisable. However, Day et al (2006) encountered similar issues within the demographics of their sample group, and suggested that, although demographics have a degree of bias; this does not infer that the emerging concepts are not representative. In such circumstances, it is possible to ensure some representativeness of concepts through saturation of themes in the analysis (Strauss and Corbin, 1990). This approach was
used in this study to ensure that theoretical saturation was achieved (presented in 4.11.2).

The approaches to enable children and their parents/carers to elicit their perceptions about mental health, child mental health services and stigma seem to have been effective, and the child-focused techniques appear to have specifically been valuable in engaging and assisting children to participate. However, some considerations do arise from the methodology and techniques used. In relation to the child participants, the age range was wide in terms of their developmental stage and abilities. So was the variety and complexity of their mental health problems (presented in Tables 4.6 and 4.7). Consequently, some children may have misunderstood some of the questions or may not have been able to concentrate. On occasions, this did seem to arise within the interviews. However, because of the responsive and flexible ethos of IPA, the researcher was at liberty to include adjunctive questions or prompts in order to probe children's understanding, and to draw the child back into the interview using a variety of activities. Although this was considered an effective way of encouraging understanding and dialogue with the children across the age-range and levels of ability, it did highlight that specific skills are required by the researcher (discussed in Section 4.6) to ensure that such additional questions are not leading and do not introduce bias. The recognition of aspects of reflexivity, which are discussed in Section 7.6, assist the researcher in ensuring that they are acutely aware of the potential for this to happen.

Within the parent/carer group, was the propensity to involve the researcher in extended discussion about the child's mental health problems. Although this was not an aim of the study per se, it was important to understand the bearing that this had on perceptions. However, this resulted in a large amount of data which required analysis, but was not always relevant to the study. In future research it may be useful to set the
boundaries of the interview in relation to such aspects, while remaining attentive to parents/carers’ views, which is essential in developing rapport with interviewees.

Some of the implications which arose from the use of IPA, centred on the potential for the researcher to lean towards the identification of stigma. Within approaches that employ a purely phenomenological framework, the researcher tends to be a conduit for the participants to elucidate their views (Giorgi and Giorgi, 2003). However, within IPA the researcher is an active partner in the research and uses their interpretations as part of the process of data collection and data analysis. The temptation within this approach is to interpret certain issues that may not have been as strongly represented by participants, or to probe certain aspects that perhaps meet the aims of the study. The important consideration arising from these issues is for the researcher to employ certain safeguards to prevent such bias. In this study, the use of reflexivity, reflection, supervision, and a group of colleagues to validate the emerging themes enabled the researcher to reduce potential bias to a minimum.

Finally, it must be recognised that IPA has been infrequently used with younger children. Although it seems to lend itself well to the subject area in this study, the process of adapting it for use with this age group required a great deal of consideration in contrast with other research approaches and techniques used with children. Although this seems to have been an effective approach in building rapport with children and in assisting them to express their perceptions, further research on the use of IPA with children of this age group is required, particularly on the indications and adaptations of this methodology.
7.5.2 The applications and benefits of IPA methodology for future research

The IPA methodology seems to be highly beneficial in enabling children and their parents to explore, in detail, their perceptions around a difficult and sensitive subject. In conjunction with this, enabling the researcher to be an active participant means that techniques and questions can be adjusted to all levels of ability and understanding. It is an interactive and flexible process that engages the participants as partners and ensures that they are on an even footing with the researcher. As has already been highlighted, parents and children wish to be seen as partners in all aspects of their life (Hart, 1992; Street and Hertz, 2005). Being able to be part of the research process means that participants can feel that they are making valid contributions, rather than just being passive recipients. In addition, this methodology gives rise to discussions about issues which the participants had perhaps not previously explored or considered, and on this basis it enables the in-depth exploration of sensitive subject areas, which can have a huge impact on the participant's life. In this respect, it allows researchers to communicate such effects to a wider audience, where before they may not have been accessible or even considered.

Being able to develop an understanding of previously unexplored areas, or to add a greater depth of understanding, means that organisations can be more responsive to the needs of their consumers. It also allows participants to elucidate their perspectives and to take part in the shaping of services. IPA, therefore, lends itself to research with people in a range of settings across health, education and social care, and even within industry. The key principle of the use of the IPA methodology is that it is appropriate to understand people's perspectives, whether they are consumers, patients, clients, school children or within the general population. It is particularly beneficial for use with vulnerable groups, as it does encourage the building of rapport between the
researcher and the participant. Being able to be interpretative in analysis means that new theories and concepts can emerge from participants' stories, which provide a theoretical perspective to new developments or service improvements.

The techniques used with children in this study have potential benefits for future research. The process was found to be thoroughly enjoyable by children and it even engaged those who were, at times, a little excitable or seemed to have a short attention span. All of the children who participated in the study were able to be fully involved in the process, and the use of the cartoon characters meant that they did not feel under pressure to answer to an adult, to whom they may have given answers they thought they wanted to hear. Employing such techniques when consulting with children means that it is possible to develop an understanding of their views, in whatever field of study, where previously research may have tended to focus on older and more articulate age groups. Utilising interactive, age-appropriate techniques enables the development of trust and confidence in children, who otherwise may have been excluded from research due to concerns about their vulnerabilities or sensitivities.

7.6 Reflexivity

Reflexivity has been described as 'the turning back of the experience of the individual upon [himself or herself]' (Mead, 1934:134). It relates to the development of an appreciation of the role of the self in the research process and requires the researcher to develop the skills of self-awareness and analysis regarding the way that they contribute to or influence the process and findings of the research (Yardley and Marks, 2004). Reflexivity requires the researcher to be concerned with critical self-scrutiny, and from this to explicitly identify the assumptions, pre-conceptions and perspectives that they bring to the research field. It can also assist in the identification of the unique
skills and expertise that they bring to the analysis (Ballenger et al, 2004). Reflexivity is also concerned with being aware of the potential areas of bias through systematic reflection on the researcher's activities, position, perceptions and views (Robson, 2002).

Within IPA, the role of the researcher is to be an active participant within the research, and to use skills of interpretation throughout the data collection process and the analysis of the findings (Smith, 2004). In this respect, reflexivity is an integral part of the methodology and the research design. The astute awareness of the aspects of reflexivity ensures that the researcher remains critical of the emphasis they bring to the research. The reflection of the aspects of reflexivity which are specific to the research enables the reader to develop their own understanding of the study.

Within this study, I was aware that my training as a Registered Mental Nurse (RMN) and my post-registration training in Child and Adolescent Mental Health, coupled with my experience as a clinician within CAMHS over a lengthy period, could give rise to a propensity to want to help or support the children and parents/carers. As parents/carers tended to want to gain an understanding or a professional perspective on their child's problems, there was an inclination to seek affirmations from me. This scenario sometimes required specific skills to steer parents/carers back on track, without breaking our rapport. I was aware that this could raise potential difficulties, in that I was not party to confidential information about them prior to meeting them. In this respect, there was no requirement for them to give me personal details about their problems, and no need for me to probe them for information. In addition, no longer being a clinician within the service meant that I had to ensure that they followed up their concerns with the service, rather than looking to me for help. Sometimes children would talk about specific aspects of their problems, which they may not have previously discussed. In this respect, it was important for me to recognise that my role
was not to enter into a therapeutic relationship with them, but rather to ensure that they knew they could talk about their problems when they visited CAMHS. To convey this message, it was important to reassure them about their visit to CAMHS. Timing of this was crucial, in that reassurances about the service during the interview could bias the outcomes of the study, therefore making it difficult to gain a clear perspective from the children. This was an aspect that I continued to reflect upon throughout the study, and adjusted my techniques to ensure that I discussed concerns after the interview with the child had finished.

The subject of my study has arisen from experiences that some individuals who are close to me have had in relation to their own mental health problems, and the way they were treated by employers and others close to them. My observations of the discriminatory and stigmatising practices they were subjected to led me to consider the effects of my own practice on the families that I worked with as a clinician, and to observe the behaviour of the community in relation to people with mental health problems. Of course, the nature of the experiences that have led me to research children's and parents'/carers' perspectives mean that I am passionate about the subject. I was, thus, acutely aware of the emphasis I might bring to the study, and that within my interpretations I may have a tendency to communicate aspects of stigma more assertively than may have been intended by the participants. In order to challenge my beliefs, I kept notes of the dilemmas I encountered and frequently discussed them with colleagues to ensure that I was aware of their influence within my data collection and analysis. My ability to recognise that the participants were active partners in the study enabled me to ensure that it was their view, not mine, that I was trying to explore.

The final aspect that I was required to consider when undertaking this research was my current position as a regional CAMHS programme lead, with responsibility for
assisting local CAMHS in my region to develop a comprehensive service across the
tiers, and to ensure that the NSF (Department of Health, 2004b) is implemented. As a
result of this role, I have an in-depth knowledge of policy, how CAMHS should be
organised and developed, and of some of the barriers to achievement. Within the
interviews with parents/carers and children, there was temptation to make suggestions
about how services could be better, or to be critical of the experiences they had in
their attempts to gain help. In order to present a balanced view, it was imperative for
me to reflect upon my own perspective and to remember that the aims and objectives
of the study focused on the perceptions of the child and their parent/carers.

In my view, it is through my rigorous exploration of my own beliefs and perceptions
about mental health and stigma and my current and previous role in CAMHS, that I
have been enabled to conduct this research using a systematic, ethical and reflexive
approach.

7.7 Future directions for research

The key findings of this study give rise to a number of future directions for research.
The emerging concepts about children's mental health, mental health services and the
cycle of stigma that have been identified, suggest that there is more understanding to
be gained in relation to parents'/carers' and children's perspectives about mental
health and their experiences of stigma.

Future research should consider some of the methodological implications raised in
Section 7.5, in terms of the variability of perceptions between genders, and within
vulnerable groups or those who may not readily access CAMHS. Research on the
perceptions of mental health and stigma among black and minority ethnic groups,
children who are cared for away from home, young offenders, and refugees and
asylum seekers are amongst the groups who were not represented in the sample. For these children and families stigma may be a particular issue, as it is probable that they would have to deal with discrimination related to other aspects of their identity, as well as having higher rates of mental health problems (Anderson et al., 2002; Richardson and Lelliott, 2003; Malek, 2004). In addition, future research on the effectiveness of IPA as a methodology for use with children would enable researchers and service evaluators to consider the potential for the successful participation of younger children across all organisations.

As the current emphasis is on the reform of CAMHS (Department of Health, 2004b) with a particular focus on making services more accessible and less stigmatising, it is imperative for future research to evaluate changes in perceptions of mental health and stigma over time, and to explore if the experiences outlined in the findings of this study improve with changes to services. Such research would need to establish a current baseline of services and to take account of changes in service configuration, to evaluate if there has been any impact of parents'/carers' and children's perceptions. It would be specifically pertinent to consider the impact of specific services and roles which have been introduced with CAMHS to improve knowledge of children's mental health and to improve the capacity for intervention in Tier one. Evaluating the impact of new skills and provisions such as the Primary Mental Health Worker role, their impact on Tier one and on the care pathway for parents/carers and their children, could be addressed by future studies.

The core meaning of the term 'mental health' requires further research. Issues raised within this study indicate that the uncertainty about terminology gives rise to felt and enacted stigma, and contributes to the internalisation of negative perceptions of children and their parents. The focus of future research should not only address the effects of the label on the child and their parents, but also the perceptions of
professionals who are seen to use a variety of terms to describe mental health and mental health problems.

Although some studies have explored the perceptions of mental health and stigma in children, and suggest that negative attitudes are developed at an early age (Weiss, 1994; Hinshaw, 2005), there is a requirement to evaluate the impact of stigma on children with mental health problems longitudinally. The stigma associated with mental health is suggested to have severe and pervasive effects on adults (Crisp, 1999; Corrigan, 2000). The findings of this study define some of the experiences of stigma that children have as a result of their mental health problems. It is, therefore, imperative to understand the long-term effects and impact of stigma on children's life-chances and development.

Finally, an important research question relates to the impact that anti-stigma and education programmes may have on parents'/carers' and children's attitudes and their experiences of stigma, individually and as a dyad. If some of the recommendations for action arising from this study and from the NIMHE strategy to tackle stigma (NIMHE, 2004b) are implemented on a policy or local level, then it is vital that the impact is evaluated and disseminated widely.

This chapter has discussed the key concepts arising from the findings, in relation to children's mental health, children's mental health services and stigma attached. It has presented a conceptual framework of the stigma associated with children's mental health problems, and has proposed a multi-dimensional framework for improving the understanding of children's mental health and tackling stigma. It has also discussed the methodological implications and the transferability of the approach and has suggested a focus for future research directions.
The final chapter will present the conclusions to the study.
Chapter Eight

Conclusions

8.0 Conclusions

The thesis presented the findings of a study which established the perceptions of primary school age children who had been referred to CAMHS, and those of their parents/carers, in relation to mental health, child mental health services and the stigma attached. The aim of the study was to develop an understanding of children's and parents'/carers' perceptions and experiences of stigma, their expectations of child mental health services, and the impact of their perceptions on the process of seeking help. In addition, the study examined the interplay between parents'/carers' and children's perceptions through exploration of the shared themes for the participants. The outcomes of the study sought to enable the strategic development and improvement of accessible child mental health services, and plans to tackle stigma at a local and policy level.

The findings indicate that the stigma of mental health impacts on children and parents/carers on a number of dimensions. Children and parents/carers have sophisticated and complex perceptions of mental health and the stigma attached. Their understanding of mental health is not salient, and in this respect it contributes to their experiences of stigma and their engagement with the stigmatisation process. The identification of experiences of stigma and discrimination pose barriers to seeking help, and achieving timely assessment and responsive intervention for children's mental health problems. As a result, participants experience feelings of shame, marginalisation and powerlessness. The cycle of shame and powerlessness
originating from stigmatisation is communicated within the parent/child dyad, and is confirmed by stigmatising attitudes in society, and through unclear care pathways and organisational systems.

In their attempt to protect their children, parents appear to identify with them and to accept stigma as if this was directed at them. This seems to be particularly related to the young age of the children and the level of responsibility that parents feel they have for them. In this respect, parents/carers are unable to distance themselves from the pervasive effects of stigma. Children experience the effects of stigma to a similar degree, however, this is a result of the communicated fears and negative concepts they hold about mental illness, feeling that they are ‘different’ and being treated differently by others, as a result of their problems.

The legacy of mental illness and the stigma attached is embedded in the language and thinking of the participants. This contributes to stigma in a number of ways. Firstly, it perpetuates fear and shame, therefore reducing the likelihood of admitting to problems, or accessing services. Secondly, although the participants recognise the effects of stigma and demonstrate some positive attitudes toward mental health, they continue to inadvertently contribute to the stigmatisation process through their language, and their concerns about being identified with a stigmatised group. Finally, their concerns about seeking help for mental health problems can delay their approach to services, and thus by default, can enhance and perpetuate the existing mental health problems.

Participants advocated for the need to change attitudes toward mental health, through far-reaching education programmes to improve the understanding of mental health and stigma among children, professionals, organisations and the general population, and through their active participation in service development and care
provision. Children established that they can develop a positive understanding of health through the school curriculum, were able to conceptualise positive aspects of mental health and displayed empathy for peers who may have problems similar to them. In this respect, children and parents/carers should be key stakeholders in the planning and implementation of collaborative approaches to tackling the stigma of mental health.

Challenging the stigma of mental health can be tackled by mainstreaming a multidimensional framework of interventions, arising from the implications of the findings in this study. These interventions include dissemination of clear information; education; redesign of services; partnership with children and parents; and integration of child mental health into social justice frameworks and policies.

This study has been an important step in recognising that the detrimental effects of stigma can begin at an early age, and that once the cycle of stigma within families is established, it can be difficult to break. The findings emphasise the importance of working collaboratively with young children and parents/carers to gather the evidence base which will inform the future development of accessible, non-stigmatising mental health services, and will assist in eradicating stigma.
References


Fryer, D. (1991) Qualitative methods in occupational psychology: Reflections upon why they are useful but so little used. The Occupational Psychologist. 14, 3-6.


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Sessa, B. (2005) I'll have to lie about where I have been. *Young Minds Magazine*. 76, 34-35.


pp 9-27.


Appendices
Appendix 1: The four-tier strategic model for CAMHS

Tier 4
Very specialist services, often children away from home

Tier 3
Specialist multi-disciplinary teams

Tier 2
Individual professionals trained in children and young people's mental health e.g. Psychiatrists, Psychologists, Nurses, Therapists etc

Primary Mental Health Workers etc

Tier 1
GPs, Paediatricians, Teachers, Health Visitors, Social Workers etc

Adapted from: 'Together We Stand' (Health Advisory Service, 1995)
Appendix 2: Professional focus group flyer and confirmation letter

University of Leicester
And
Child and Adolescent Mental Health Services

Research Project

Children's and Parents'/Carers' perceptions of mental health services and stigma

Focus Group for Professionals
Your expert knowledge is required!

You have been invited to join a multi-agency focus group to assist us in developing research tools to help children and their parents talk about mental health.

Date: 27/09/2001
Time: 12 noon till 1.30pm

Venue: Westcotes House, Conference room

A light lunch will be provided.
The group will start at 12.30pm

Please see the enclosed information letter for more details
INFORMATION LETTER FOR PROFESSIONALS

RESEARCH STUDY: EVALUATION OF PRIMARY SCHOOL-AGED CHILDREN AND PARENTS'/CARERS' PERCEPTIONS OF MENTAL HEALTH AND STIGMA

Dear Colleague,

Thank you for agreeing to take part in the Focus Group. I am writing to you with confirmation of the details of the group and information about my study.

Why are we doing the study?
The Child Mental and Adolescent Mental Health Service (CAMHS) aim is to provide an efficient service to children who may have mental health problems, and their families. We understand it is sometimes difficult for families to go for help to such services. For this reason we are undertaking a study to develop more understanding about children’s and their parents'/carers' perceptions of mental health, the services available to children and stigma. In order to help us with service development, we very much rely on users, i.e. children, parents or carers, to help us determine which is the best approach for them. The outcomes of the study will hopefully help the service improve in the future.

What is involved for professionals?
We are running a multi-agency focus group to help us develop the research tools for children and parents, to enable them to talk about mental health and stigma. The group will consist of up to 10 professionals from statutory and non-statutory agencies, who work with children. Your knowledge and expertise of working with children and families will be invaluable in helping us decide on the best approach to engage children and their families in the study. The focus group is to take place on:

Thursday 27th September 2001

At 12 noon until 1.30pm
At Westcotes House, Westcotes Drive, Leicester
In The Conference Room.

A light lunch will be provided

Lunch will be available from 12noon. The Focus Group will start at 12.30pm. This should be completed in not more than 1 1/2hrs. Please allow time in your diary.

- We feel it is important to remember as much information as possible from our discussions, therefore, we would like to record the group. The tapes will be used only for the purposes of the study. They will not be identified in any way as belonging to you and will be destroyed after the study.
Will the study be anonymous?
All information will be coded so that individuals cannot be identified. All
information will be confidential, and your name and address will not be
included in any report.

What if I do not want to take part or wish to withdraw from the study?
If you do not wish to participate in the study, you may do so without giving a
reason for your decision, and this will not affect future work with the team in
any way.

What if I am harmed by the study?
None of the questions asked are anticipated to cause distress or worries.
Medical research is covered for mishaps in the same way as for patients
undergoing treatment in the NHS, i.e. compensation is only available if
negligence occurs. The study has been agreed by the Local Research Ethics
Committee.

What will happen to the results of the study?
The results will be presented and circulated to those people who plan
services, within health and local authorities. Please ask if you wish to receive
a copy of the findings of the study.

Who is responsible for the study?
The study is being funded by the Department of Health and is being organised
by the University of Leicester. It is also part of a PhD thesis. The principal
researcher is Ms Fiona Gale, Senior Primary Mental Health Worker who is
based at:

The Primary Mental Health Team
[insert address] Telephone: [insert Tel number]

Fiona is being supervised by Professor Panos Vostanis, Professor of Child
Psychiatry at the Greenwood Institute of Child Health, University of Leicester.

Please do not hesitate to contact the above person about any matter. We will
be delighted to discuss the study in more detail at any stage.

I would like to take part, what do I do next?
Please telephone Fiona Gale on [Tel number] and let her know that you will
be attending on 27th September. If you need directions to Westcotes House,
we will arrange for these to be sent to you.

If you can't attend please let us know so that we can arrange for
someone to take your place.

We look forward to seeing you on the day.
Appendix 3: Professionals’ focus group schedule

Introduction to the focus group

The purpose of this focus group for you to offer your thoughts on how children and families might talk about mental health.

I would be grateful if you could consider your perceptions and views of how children and families might talk about mental health, in relation to the development of a data collection tool and the interview. I would also like you to think about the understanding of children aged 5 to 11 years, the words and language they might use and some of the techniques that might be useful to engage them in the process.

Prompts

Part A – Children’s knowledge and beliefs about mental health/illness

- How would a child describe a mentally health person? What is needed for good mental health? What do children need for good mental health? How would a child describe this?
- Define mentally unhealthy/mental illness? What does it mean to children? What words do children use?
- Think about words used to describe a person with mental illness? How would a child describe a mentally unhealthy person? Is it the same in all children? When would it be different? Describe the differences? Describe a child’s expectations of mental health problems and their presentation in different situations?
- What would children say constitutes a mentally healthy person - feelings? Which constitutes a mentally unhealthy or ill person?
• What would children say causes children to become mentally unhealthy? How would a mentally unhealthy child behave?
• What feelings would a child have about seeing someone who has mental illness?
• What can be done for a child who is mentally unhealthy?

Part B: What approaches might help children to engage in the study?
• Ideas about activities and approaches that might work?
• What have they found that works?
• What does not work with children?
• How do we gain their confidence?
• Any other issues?
• Things to be aware of when talking to children?

Part C: Children’s and parents’ beliefs about their mental health difficulties / accessing help
• Think of a child who has been to CAMHS for help mental health difficulties
  How do the families feel about CAMHS?
  How difficult is it for them to go for help?
  What questions should we ask about the experience of going for help?

• Previous help – was requested or thought about? Was it more or less difficult for the family to go for help that time? What would stop them? Any help before? What happened then? Do you think it was useful?

• What do you think most children and families think about their problems? Child’s impression/Parents impression? What do you think they will feel about going to CAMHS for help?
• How do you think we could make it easier for families to ask for help? What changes could be made in the way they ask for help?

Do you have any further comments?

Thank you very much for your time
Appendix 4: Professionals’ focus group consent form

EVALUATION OF CHILDREN’S AND PARENTS’/CARERS’ PERCEPTIONS
OF MENTAL HEALTH AND STIGMA

Professionals Focus Group: Consent Form

This form should be read in conjunction with the Information Leaflet.

With regards to:

I...........................................................................
Profession.............................................
............................................................................ (Address)
.............................................................................
............................................................................
.......................Postcode...................

Have read and understood the information provided about the study

EVALUATION OF CHILDREN’S AND PARENTS’/CARERS’ PERCEPTIONS
OF MENTAL HEALTH AND STIGMA

and I agree to take part in the study.

I understand that I can withdraw from the study at any time without justifying
my decision, and without it affecting any future work with the Child and
Adolescent Mental Health Teams.

I am not currently involved in any other research study.

I agree/do not agree for the discussion to be recorded for the purposes of the
research. I understand that the tape recording will only be used for the
purposes of the research and will be destroyed when the study is finished.

Transcripts will be available for participants on request.

Please print your name
.............................................................................

Signature .............................................. Date..................................................
Appendix 5: Spacey and Jupiter's mission: Child interview tool
SPACEY THE ALIEN AND HIS FRIEND JUPITER COME TO EARTH
They have been sent by their boss to find out about boys and girls. Can you help them?

Spacey and Jupiter have some things they would like help with. They have to take the information back home to their planet Conos.
They need to write in their mission book so that they can remember.

Spacey and Jupiter's mission book

Spacey has brought some cards with him. Can you pick out some cards to tell him about some feelings that children have?

When you have finished shall we write some words about the pictures?
WHAT WOULD SPACEY SEE WHEN CHILDREN HAVE THESE FEELINGS?
WHAT CAN HE TELL HIS FRIEND ABOUT?
CAN YOU TELL JUPITER WHAT YOU THINK 'HEALTHY' MEANS?
LET'S USE SOME OF THE WORDS FROM BEFORE. DO YOU KNOW ANY OTHER WORDS THAT MEAN HEALTHY?
Can you tell Spacey what you think the word 'Mental' means?

He has brought some felt pens for you to use. Shall we use them to write the next mission report?
Can you tell Spacey what kind of things you think children who are mentally healthy are like to do? Shall we draw them?

Show Spacey with the drawings we have done.
JUPITER WANTS TO KNOW WHAT YOU THINK MENTALLY ILL MEANS?

WHAT FEELINGS DO YOU THINK A MENTALLY ILL CHILD WOULD HAVE? HOW WOULD YOU KNOW A CHILD WAS MENTALLY ILL?
IF YOU SAW A MENTALLY ILL CHILD WHAT WOULD YOU THINK?
WHAT WOULD YOU DO?
CAN YOU TELL JUPITER?
Spacey is very interested in your mission reports. He would like to know a bit more about you. Can you help him?

Spacey heard you were coming to see a worker who can help you with your problems. Can you help him to understand about them? Can you tell him what you think your problems are?
Can you tell Jupiter what you think about the worker who will help you? What will happen? What will the person be like?

You can draw your answer if you like.
Spacey would like to tell his boss about the help workers can give you.

Can you tell Spacey what you would like to help you with your problems?
Spacey and Jupiter will be going home soon. They would like to know if you have ever met any other children who have had problems? What do you think about them?

Shall we put some words on the mission report?
SPACEY, JUPITER
AND THE BOSS
WANT TO SAY...

A BIG THANK YOU
FOR YOUR HELP.
Appendix 6: Mission reports
Appendix 7: Examples of flash cards for child interview
Appendix 8: Space certificate

We certify that Earthling Spacer has helped us in our mission to understand about Earth boys and girls.

We are grateful for the help we have been given and we would like to award this certificate to this Earthling for completing our mission.

A big thank you from...

[Image of a certificate with handprints and the names Spacer and Jupiter]
Appendix 9: Child interview supplementary prompts

Using 'Spacey and Jupiter's Mission' storybook and activities

Page 1 - 3: Describe the 'mission' and introduce the characters. Ensure that the child is familiar with the procedure and the equipment.

Page 4 - 5: Using cards to describe feelings, what feelings do children have when they are having a good day? When they are not having a good day? Examples in different environments, i.e. school, home and with friends. What sort of activities, actions are associated with the feelings?

Page 6: How would a child become healthy? What activities? What feelings does a healthy child have?

Page 7: Does the child know any other words for mental? What would the child see if someone was mental? What feelings would they have? If the child doesn't know the word, suggest some commonly used terms?

Page 8: What does mental health mean? How can children be mentally healthy? What would they be doing? What feelings would they have?

Page 9: How would the child feel if they met someone who was mentally ill? Do they think children can have mental illness? What sort of things would mean someone was mentally ill?

Page 10: How would it make them feel if they saw a child behaving that way? Would the child help them? How?

Page 11: What does the child think about their problems? How do they affect them? What is the impact on their life, school etc?

Page 12: What did the child know about CAMHS? Had they been given information? Did they know what to expect? How did it make them feel?

Page 13: How would they like help? What would help them? What changes would they like to happen?

Page 14: What did they think about other children with problems? What were they like? Would they help them? What would they do? What were other children like towards them?

Page 15: Thank child for their help and present certificate. Final comments? What would make services better? What would make it easier to go for help?
Appendix 10: Table of emotions used for the flash cards in child interview tool

<table>
<thead>
<tr>
<th>Emotion</th>
<th>Age from which each emotion is included (years)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Happy</td>
<td>5+</td>
</tr>
<tr>
<td>Sad</td>
<td></td>
</tr>
<tr>
<td>Afraid</td>
<td></td>
</tr>
<tr>
<td>Angry</td>
<td></td>
</tr>
<tr>
<td>Shy</td>
<td></td>
</tr>
<tr>
<td>Proud</td>
<td></td>
</tr>
<tr>
<td>Worried</td>
<td>7+</td>
</tr>
<tr>
<td>Grateful</td>
<td></td>
</tr>
<tr>
<td>Excited</td>
<td></td>
</tr>
<tr>
<td>Surprised</td>
<td></td>
</tr>
<tr>
<td>Jealous</td>
<td></td>
</tr>
<tr>
<td>Guilty</td>
<td></td>
</tr>
<tr>
<td>Disappointed</td>
<td>10+</td>
</tr>
<tr>
<td>Curious</td>
<td></td>
</tr>
<tr>
<td>Relieved</td>
<td></td>
</tr>
<tr>
<td>Disgusted</td>
<td></td>
</tr>
<tr>
<td>Ashamed</td>
<td>14+</td>
</tr>
<tr>
<td>Shocked</td>
<td></td>
</tr>
<tr>
<td>Embarrassed</td>
<td></td>
</tr>
<tr>
<td>Depressed</td>
<td></td>
</tr>
</tbody>
</table>

(After Harris et al, 1987)
Appendix 11: Parent/carer semi-structured interview schedule

Introduction
Ensure participant understands the purpose of the study. Encourage questions. Ensure that they have signed and understood the consent form. Introduce the study and the process. Set ground rules. Explain recording and transcription. Emphasise that they can cease interview at anytime.

Interview Schedule and Prompts

Part A - Knowledge and perceptions of mental health/illness
- Describe what would make a mentally health person? Is this the same for children? What do we need to have good mental health? What do children need for good mental health? How would you promote mental health in your child?

- What does the term 'mental health' mean to you?

- What do you think 'mentally unhealthy' means?

- Describe a mentally unhealthy person? Is it the same in children? When would it be different? Can you describe what a mentally unhealthy child would look like? What would you expect in different situations?
  - Home
  - School
  - Social
  - Relationships family - friends

- What feelings would a mentally healthy person have? Which constitutes a mentally unhealthy or ill person? How about children?

- Do you know any other words for 'mental'?
• What words do you use to describe a person with mental illness?

• What does mental illness mean to you? Can children have mental illness? Is it different to 'mental health problems'?

• Do you think that there is a stigma attached to mental illness or the word 'mental'? Is it the same for children?

• Have you or your child experienced stigma (discrimination, been treated differently)?

• What do you think causes children to become mentally unhealthy or to have mental health problems?
  - How do you think a mentally unhealthy child would behave?

• What are your feelings about seeing someone who has mental illness
  - When I say 'mentally ill', what does it make you think of?

• What can be done for a child who is mentally unhealthy (has mental health problems)?

• Where have you heard or learnt about mental illness/ mental health problems?

**Part B: Beliefs about the difficulties / accessing help** (After short break, easy conversation)

• _______(Child) will be attending CAMHS soon to get help with their recent difficulties - what do you think the problems are? Was it difficult for you to go for help? How do you feel about being referred to CAMHS?

• What do you think about attending CAMHS?
• Did it take along time for you to receive an appointment? Was it too long? Where did you think you should have got help from when you went to see ______ (referrer)?

• What do you expect from the CAMH service/professional?

• Previous help - requested or thought about? Was it more or less difficult to go for help that time? If you didn't go, what stopped you? If you have had help before, who helped you? What happened then? Do you think it was useful?

• What have you tried yourself? What do you think works?

• How have your child's problems impacted on you and your family? On the child?

• What do you think your child thinks about his/her problems? What do you think they will feel about going for help? Knowledge of any other children with similar problems? What did you think about them?

• How do you think we could make it easier for families to ask for help? What changes would you make in the ways you can ask for help?

Any further comments? Thank you for your time?
Appendix 12: Confirmation of interview appointment letter

Dear [Parent/carer],

Re: Study: Evaluation of children and parents/carers perceptions of mental health and stigma

Thank you for agreeing to take part in this study and for completing and returning the forms sent to you by the Child and Adolescent Mental Health Services (Westcotes House, Leicester), consenting for you and [child] to take part. As you know from my letter, it is really important for us to be able to talk to parents/carers and children so that we can understand your point of view and make child mental health services better for everyone.

I would like to come and talk to you and [child] at your [chosen venue] on: 

[Date and time]

I have also enclosed a questionnaire for you to complete. I will collect it from you when I come to see you.

If this time is not convenient to you please contact my Personal Assistant [name] to arrange a better time on [Tel. Number]. Please be aware I will be travelling to meet with you from a distance, so if you can't make the appointment, please let me know in advance.

I will look forward to meeting you.

Best Wishes

Fiona Gale
Principle Researcher/ CAMHS Regional Programme Lead.
Appendix 13: Feelings identification chart for the child interview

Happy
Guilty
Sad
Disappointed
Surprised
Afraid
Disgusted
Excited
Grateful
Angry
Jealous
Proud
Relieved
Shy
Worried
Appendix 14: Invitation letter to parents/carers

EVALUATION OF CHILDREN'S AND PARENT/CARERS' PERCEPTIONS OF MENTAL HEALTH AND STIGMA

Dear

We are writing to you to ask you to take part in the above study. Your child has recently been referred to the Child and Adolescent Mental Health Services (CAMHS) at Westcotes House and you are soon to have an appointment with a worker, regarding your child's difficulties.

Why are we doing the study?
The Child and Adolescent Mental Health team is made up of qualified staff from the NHS (Doctors, Nurses etc). Their aim is to provide a more accessible and efficient service to children and their families. We understand it is sometimes difficult for families to go for help to such services and for this reason we would value your opinions about mental health and the services available to children, and your views on the stigma of mental health. When developing services, we very much rely on users, i.e. children and parents or carers to help us understand which is the most helpful approach for them. The outcomes of this study will hopefully help the service to improve in the future.

What is involved for parents?
• We are contacting you in writing, before you have an appointment with the worker, to ask if you will take part in the study. If you decide to take part, a researcher will arrange to meet with you at a time, which is convenient to you. The visit can take place at home or we can meet at the service - you can decide. S/he will go through a brief interview with you about your opinions about mental health and your expectations/impressions of the service. This should be completed in not more than 30-45 minutes. We would also like to ask your child similar questions about what s/he thinks.

• We feel it is important to remember as much information as possible from our discussion. If possible we would like to tape record the discussion. If you agree, then the tapes will be used only for the purposes of the study. They will not be identified in any way as belonging to you and will be destroyed after the study. If you do not wish to be taped, you may still take part in the study and the researcher will keep written notes. Your decision will in no way affect the help you receive in the future.

Will the study be anonymous?
All information will be coded so that no parent or child can be identified. As with all health records, your information will be confidential, and your name and address will not be included in any report.
What if I do not want to take part or wish to withdraw from the study?
If you do not wish to participate in the study, you may do so without giving a reason for your decision, and this will not affect your child's treatment or care in any way.

What if I am harmed by the study?
None of the questions asked are anticipated to cause distress or worries. Medical research is covered for mishaps in the same way as for patients undergoing treatment in the NHS, i.e. compensation is only available if negligence occurs.

What will happen to the results of the study?
The results will be presented and circulated to those people who plan services, within health and local authorities. Please ask if you wish to receive a copy of the findings of the study.

Who is responsible for the study?
The study is being funded by the Department of Health and is being organised by the University of Leicester. The principal researcher is Ms Fiona Gale:

The Greenwood Institute of Child Health,
[Insert address]  
Telephone: [Insert tel. number]

Fiona is being supervised by Professor Panos Vostanis, Professor of Child Psychiatry at the Greenwood Institute of Child Health, University of Leicester.

Please do not hesitate to contact Fiona or Professor Vostanis about any matter. We will be delighted to discuss the study in more detail at any stage.

We have also enclosed a letter for your child to explain about the study, if you require any further help, we would be glad to talk to you about it.

I want to take part, what do I do next?
If you decide to take part, please complete the slip below with your contact details and the best time and for Fiona to contact you to arrange an appointment. Also would you kindly complete the enclosed consent form, and return both items in the stamped addressed envelope provided.

Thank you for taking the time to read this information.
Reply slip

EVALUATION OF CHILDREN'S AND PARENT/CARERS' PERCEPTIONS
OF MENTAL HEALTH AND STIGMA

Name ---------------------------------- (parent/carer)

And ----------------------------------

- Yes, we would like to take place in the study □

Please contact us on Tel------------------

The best time to ring us is -

Mornings □
Afternoons □
Evenings □

- Sorry we don't have a phone, but still want to take part. Please send us an appointment. The best time to see us is:

Mornings □
Afternoons □
Evenings □

We would like to meet you:

At home □
At Westcotes House □

Thank you for taking time to complete this form. If you are taking part please complete the consent form and send both items back to Fiona Gale, in the enclosed pre-paid envelope.
Appendix 15: Parent/Carer consent form

EVALUATION OF CHILDREN'S AND PARENTS'/CARERS' PERCEPTIONS OF MENTAL HEALTH AND STIGMA

Consent Form

This form should be read in conjunction with the Information Letter. Please return to Fiona Gale in the envelope provided.

With regards to: ..................................(Child's Name)
...........................................(Date of Birth)
.....................................................(Address)
..................................................
..................................................
..................................................
..................................................
Postcode

I/We as the Parent(s) / Guardian(s) of ..........................................................

Have read and understood the information provided for ourselves and our child about the EVALUATION OF CHILDREN'S AND PARENTS'/CARERS' PERCEPTIONS OF MENTAL HEALTH AND STIGMA

and we agree to take part in the study.

I/We understand that I/We can withdraw from the study at any time without justifying my/our decision, and without it affecting the future treatment or care of my/our child in any way.

I/We are not currently involved in any other research study.

I/We understand that medical research is covered for mishaps in the same way as for patients undergoing treatment in the NHS, i.e. compensation is only available if negligence occurs.

I/We agree/do not agree for the discussion to be recorded for the purposes of the research. I/We understand that the tape recording will only be used for the purposes of the research and will be destroyed when the study is finished.

Please print your name ..................................................................................

Signature .......................................... Date .............................................

Please print your name ..................................................................................

Signature .......................................... Date .............................................
Appendix 16: Child information letter (children aged 5-11 years)

Dear [Child]

Your family doctor has asked someone from the health service to talk to you and your family about some worries or problems you have been having recently and to find out how we might help you.

We are trying to find out what you think about asking for help and what you think about your worries or problems. We also wanted to know what you think about how we might help you.

I would like to come and see you before you see the person from the health service. If you think it is ok for me to come and see you, I will ask you a few questions about what you think about coming for help and what you think you might need. The questions aren't very hard and it doesn't matter if you can't answer them.
I would like to tape us on a tape recorder, so I don't forget the important things you say. If you want, you can have a go on it before we start. It doesn't matter if you don't want to be taped, because I can write things down instead.

If you decide you don't want to talk to me, you don't have to. You can still see the person from the health service to talk about your worries or problems, anyway.

I hope you would like to talk to me and will look forward to seeing you soon.

Thank you for your help

From Fiona Gale

Researcher
Appendix 17: Pro-forma for gathering baseline information

Section 1: Child's details

1. Child’s age ........

2. Gender  m/f

3. Ethnicity (please tick)
   - Black African
   - Black Caribbean
   - Asian – Indian
   - Asian – Bangladeshi
   - Asian-Pakistani
   - Other ethnic group (specify)
   - Asian – Chinese
   - Asian – Other
   - Black - other
   - White (specify)
   - Dual heritage (specify)

4. Number of siblings living at home (please specify) ....................

Section 2: Parent’s/carer’s details

1. Age ............... 

2. Gender  m/f

3. Relationship to child (please tick)
   - Mother
   - Father
   - Grandmother
   - Step-mother
   - Step-father
   - Grandfather
   - Another relationship (please specify) ..........................
4. **Martial status (please tick)**

- Single  
- Married  
- Divorced  
- Separated  
- Widowed  
- Co-habiting  

Another type of relationship (specify) ..................

5. **Employment (please specify)**

6. **SDQ returned? y/n**

Date of interview ............................................
Appendix 18: Strengths and Difficulties Questionnaire
**Strengths and Difficulties Questionnaire**

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft! Please give your answers on the basis of the child's behaviour over the last six months or this school year.

**Child's Name** ........................................................................................... Male/Female

**Date of Birth** ..............................................................................................

<table>
<thead>
<tr>
<th>Item</th>
<th>Not True</th>
<th>Somewhat True</th>
<th>Certainly True</th>
</tr>
</thead>
<tbody>
<tr>
<td>Considerate of other people's feelings</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Restless, overactive, cannot stay still for long</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Often complains of headaches, stomach-aches or sickness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shares readily with other children (treats, toys, pencils etc.)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Often has temper tantrums or hot tempers</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rather solitary, tends to play alone</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Generally obedient, usually does what adults request</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Many worries, often seems worried</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Helpful if someone is hurt, upset or feeling ill</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constantly fidgeting or squirming</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has at least one good friend</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Often fights with other children or bullies them</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Often unhappy, down-hearted or tearful</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Generally liked by other children</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Easily distracted, concentration wanders</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nervous or clingy in new situations, easily loses confidence</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kind to younger children</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Often lies or cheats</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Picked on or bullied by other children</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Often volunteers to help others (parents, teachers, other children)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thinks things out before acting</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Steals from home, school or elsewhere</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gets on better with adults than with other children</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Many fears, easily scared</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sees tasks through to the end, good attention span</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Signature** ........................................................................................... **Date**............................................................................................

Parent/Teacher/Other (please specify:)

*Thank you very much for your help*
Scoring the Informant-Rated Strengths and Difficulties Questionnaire

The 25 items in the SDQ comprise 5 scales of 5 items each. It is usually easiest to score all 5 scales first before working out the total difficulties score. Somewhat True is always scored as 1, but the scoring of Not True and Certainly True varies with the item, as shown below scale by scale. For each of the 5 scales the score can range from 0 to 10 if all 5 items were completed. Scale score can be prorated if at least 3 items were completed.

<table>
<thead>
<tr>
<th>Emotional Symptoms Scale</th>
<th>Not True</th>
<th>Somewhat True</th>
<th>Certainly True</th>
</tr>
</thead>
<tbody>
<tr>
<td>Often complains of headaches, stomach-aches ...</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Many worries, often seems worried</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Often unhappy, downhearted or tearful</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Nervous or clingy in new situations ...</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Many fears, easily scared</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Conduct Problems Scale</th>
<th>Not True</th>
<th>Somewhat True</th>
<th>Certainly True</th>
</tr>
</thead>
<tbody>
<tr>
<td>Often has temper tantrums or hot tempers</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Generally obedient, usually does what ...</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Often fights with other children or bullies them</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Often lies or cheats</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Steals from home, school or elsewhere</td>
<td>0</td>
<td>1</td>
<td>2</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Hyperactivity Scale</th>
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<th>Certainly True</th>
</tr>
</thead>
<tbody>
<tr>
<td>Restless, overactive, cannot stay still for long</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Constantly fidgeting or squirming</td>
<td>0</td>
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<td>2</td>
</tr>
<tr>
<td>Easily distracted, concentration wanders</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Thinks things out before acting</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Sees tasks through to the end, good attention span</td>
<td>2</td>
<td>1</td>
<td>0</td>
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<table>
<thead>
<tr>
<th>Peer Problems Scale</th>
<th>Not True</th>
<th>Somewhat True</th>
<th>Certainly True</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rather solitary, tends to play alone</td>
<td>0</td>
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<tr>
<td>Has at least one good friend</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Generally liked by other children</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Picked on or bullied by other children</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Gets on better with adults than with other children</td>
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<td>2</td>
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</table>

<table>
<thead>
<tr>
<th>Prosocial Scale</th>
<th>Not True</th>
<th>Somewhat True</th>
<th>Certainly True</th>
</tr>
</thead>
<tbody>
<tr>
<td>Considerate of other people's feelings</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Shares readily with other children</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Helpful if someone is hurt, upset of feeling ill</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Kind to younger children</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Often volunteers to help others</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

The Total Difficulties Score:

is generated by summing the scores from all the scales except the prosocial scale. The resultant score can range from 0 to 40 (and is counted as missing if one of the component scores is missing).
Interpreting Symptom Scores and Defining "Caseness" from Symptom Scores

Although SDQ scores can often be used as continuous variables, it is sometimes convenient to classify scores as normal, borderline, and abnormal. Using the bandings shown below, an abnormal score on one or both of the total difficulties scores can be used to identify likely “cases” with mental health disorders. This is clearly only a rough-and-ready method for detecting disorders – combining information from SDQ symptom and impact scores from multiple informants is better, but still far from perfect. Approximately 10% of a community sample scores in the abnormal band on any given score, with a further 10% scoring in the borderline band. The exact proportions vary according to country, age and gender – normative SDQ data are available from the web site. You may want to adjust banding and caseness criteria for these characteristics, setting the threshold higher when avoiding false positives is of paramount importance, and setting the threshold lower when avoiding false negatives is more important.

### Parent Completed

<table>
<thead>
<tr>
<th></th>
<th>Normal</th>
<th>Borderline</th>
<th>Abnormal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Difficulties Score</td>
<td>0-13</td>
<td>14-16</td>
<td>17-40</td>
</tr>
<tr>
<td>Emotional Symptoms Score</td>
<td>0-3</td>
<td>4</td>
<td>5-10</td>
</tr>
<tr>
<td>Conduct Problems Score</td>
<td>0-2</td>
<td>3</td>
<td>4-10</td>
</tr>
<tr>
<td>Hyperactivity Score</td>
<td>0-5</td>
<td>6</td>
<td>7-10</td>
</tr>
<tr>
<td>Peer Problems Score</td>
<td>0-2</td>
<td>3</td>
<td>4-10</td>
</tr>
<tr>
<td>Prosocial Behaviour Score</td>
<td>6-10</td>
<td>5</td>
<td>0-4</td>
</tr>
</tbody>
</table>

### Teacher Completed

<table>
<thead>
<tr>
<th></th>
<th>Normal</th>
<th>Borderline</th>
<th>Abnormal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Difficulties Score</td>
<td>0-11</td>
<td>12-15</td>
<td>16-40</td>
</tr>
<tr>
<td>Emotional Symptoms Score</td>
<td>0-4</td>
<td>5</td>
<td>6-10</td>
</tr>
<tr>
<td>Conduct Problems Score</td>
<td>0-2</td>
<td>3</td>
<td>4-10</td>
</tr>
<tr>
<td>Hyperactivity Score</td>
<td>0-5</td>
<td>6</td>
<td>7-10</td>
</tr>
<tr>
<td>Peer Problems Score</td>
<td>0-3</td>
<td>4</td>
<td>5-10</td>
</tr>
<tr>
<td>Prosocial Behaviour Score</td>
<td>6-10</td>
<td>5</td>
<td>0-4</td>
</tr>
</tbody>
</table>

Generating and Interpreting Impact Scores

When using a version of the SDQ that includes an "Impact Supplement", the items on overall distress and social impairment can be summed to generate an impact score that ranges from 0 to 10 for the parent-completed version and from 0-6 for the teacher-completed version.

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Only a little</th>
<th>Quite a lot</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Parent report</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficulties upset or distress child</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Interfere with HOME LIFE</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Interfere with FRIENDSHIPS</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Interfere with CLASSROOM LEARNING</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Interfere with LEISURE ACTIVITIES</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

|                        |            |               |             |              |
| **Teacher report**     |            |               |             |              |
| Difficulties upset or distress child | 0       | 0             | 1            | 2            |
| Interfere with PEER RELATIONSHIPS | 0       | 0             | 1            | 2            |
| Interfere with CLASSROOM LEARNING | 0      | 0             | 1            | 2            |

Responses to the questions on chronicity and burden to others are not included in the impact score. When respondents have answered "no" to the first question on the impact supplement (i.e. when they do not perceive the child as having any emotional or behavioural difficulties), they are not asked to complete the questions on resultant distress or impairment; the impact score is automatically scored zero in these circumstances.

Although the impact scores can be used as continuous variables, it is sometimes convenient to classify them as normal, borderline, or abnormal: a total impact score of 2 or more is abnormal; a score of 1 is borderline; and a score of 0 is normal.
Appendix 19: Example of an interview transcript

PHD Interview 11.07.05
* Child Interview
* Harry

* FIONA: Right we have got a story here I will just explain it to you. It is called Spacey and Jupiter's mission. How old are you?

*HARRY: Nine

*FIONA: Nine, ok it might be a little bit young for you but you will get the idea. So the thing that you have to think about is that Spacey and Jupiter have come down to earth and they don't know anything about boys and girls at all. They have no idea what we do on a day to day basis or that kind of thing. So they have been sent by their boss, who looks a bit like mine. I'll have to show you a picture because he doesn't know that I am saying that. This is the boss and he has sent them down to collect loads of information, I have been to see loads of boys and girls and you are the last one today. The idea is that you give Spacey and Jupiter the information and they take it back to their planet. Do you do this kind of thing at school?

*HARRY: Yes.

*FIONA: You do? Good, I remember when I was at school we had to write a story about the inside of a golf ball. Have you done that one? No, it wasn't just to be about the inside of a golf ball like all the stuff inside, its like spaghetti in there but there was supposed to be people living inside it as well. Anyway you get the idea? Good, so we need to write it in the mission book and we also need to record it on the tape, so that's part of it. You can do some writing and drawing if you like using the mission reports, I've got an envelope of pens but there aren't that many left I started off with loads, but people have asked if they can keep them. Ok, the first bit of the mission is Spacey pulling all these various faces about things that children feel and their feelings, there's a blank one in case you want to draw some of your own feelings. It's a good job I've cleaned them because I left the last ones on. Now I wondered if you can tell Spacey and Jupiter the kind of feelings boys and girls have everyday when they are feeling ok, you can use the cards to put in pile if you want or you can draw your own if you think I have missed some. So look at those and have a think about the sort of feelings you or your friends will have when you are having a good day.

*HARRY: Happy, proud

*FIONA: Let me find the happy one so that I can remember, can you see it coming? That one's happy, proud you said. When might you be proud?

*HARRY: When you do good work and you get told so.
**FIONA:** I can't find proud now, never mind I know you have said it now and it's on the tape. What kind of things might make you happy?

**HARRY:** When you do good work and you get free time, or when you have had a good day.

**FIONA:** What about at home, what kind of things make you happy at home?

**HARRY:** Maybe if you got to play out with your friends or your friends came over.

**FIONA:** That's good. Did you say another word before?

**HARRY:** Maybe sometimes relieved.

**FIONA:** When might you be relieved?

**HARRY:** If you finished your work when you have to finish it.

**FIONA:** What about at home, when might you be relieved at home? When you have just finished cleaning your bedroom when your Mum has just come in?

**HARRY:** Maybe if you finish your jobs.

**FIONA:** Any others? We will call that your feeling good pile, think about boys and girls who you might know who perhaps aren't feeling so good what sort of things might they be feeling during the day.

**HARRY:** They might be feeling sad or disappointed.

**FIONA:** What might make them sad?

**HARRY:** If you didn't do very well at school.

**FIONA:** Did you say another? Disappointed was it? What might make you disappointed?

**HARRY:** If you do bad work you might get disappointed and you might get told off, and then get disappointed with yourself for being naughty and not doing your work.

**FIONA:** That's good. Any other words, I can't find disappointed now.

**HARRY:** Shall we draw it?

**FIONA:** Yes, you can draw it. Do you want to have a go? That's a good idea.

**HARRY:** Yes.
*FIONA: That's good, excellent well done.

*HARRY: He looks a bit angry around the eyes though.

*FIONA: Perhaps he is a bit angry, as well, do you think? Would you pick anymore out of those for some one who is perhaps not having quite such a good day some of the feelings?

*HARRY: Disgusted.

*FIONA: Disgusted, I hope I have got that one in my bag because if I haven't someone has been pinching them out of here. There it is what kind of things would make you disgusted?

*HARRY: Like if you have done bad work, and you got told off for it.

*FIONA: Any others or have we got them all?

*HARRY: That's it.

*FIONA: We are done? Ok so we can keep those there for later. The next thing we wanted to know was what sort of things might make you feel all those things, but we have already done those haven't we? That's me getting ahead of myself isn't it? Here's a word that Jupiter is holding, she is a girl robot can you tell with all her matching stuff there. Jupiter is holding a board that says 'healthy' on it, what do you think healthy means?

*HARRY: If you are fit and you don't really get poorly much.

*FIONA: What sort of things would you do to get like that?

*HARRY: By eating fruits and vegetables.

*FIONA: Do you do that?

*HARRY: Yes, mostly veggies.

*FIONA: That's good, where did you learn about that?

*HARRY: School.

*FIONA: Did you? I think they have all done that, everyone has said that. What sort of things out of these words or any others that we haven't, what sort of things would you expect a healthy person to be feeling?

*HARRY: Have we already got proud?

*FIONA: Yes, we've got happy proud and relieved. We have also got some of the ones on the other side.
*HARRY: We have got proud for healthy.

*FIONA: Yes, that's for that one. Ok, do you think that they would be happy?

*HARRY: They could be just proud.

*FIONA: Just proud, any which aren't there that you can think of that I have missed?

*HARRY: They could feel a little bit surprised.

*FIONA: You can be surprised sometimes. Sometimes I'm surprised when I run and I think god how did I do that? So we have that one, anymore or are you done?

*HARRY: I'm done.

*FIONA: Well done. You're good at this. Right, we have another one here and this one Spacey has got and he is asking you what you think the word 'mental' means have you heard of it?

*HARRY: Yes.

*FIONA: Yes, ok what do you think the word mental means?

*HARRY: Maybe if you have got things wrong with you or maybe you go sometimes a bit crazy.

*FIONA: You can write it down or you can use one of these. What the sort of things, you said a few things before like when you go crazy, is there anything else that you might see? When you see someone who is mental what do you think they might be doing?

*HARRY: They could go a bit annoying and maybe go and do things that are illegal.

*FIONA: So they could go out and do crime or something like that?

*HARRY: Yes.

*FIONA: Ok, do you think any of those words there from the ones that we have picked out, that they might be feeling?

*HARRY: Sometimes a bit guilty and disappointed.

*FIONA: Yes, any of the others do you think. We have some down here, different ones or any others that I have missed?

*HARRY: They might be a bit afraid because they might have to go to the police or Dr, because they feel unwell.
*FIONA: That's good. Any others or have you finished on that one? Now here’s one, Spacey is scratching his head on this one, look. He wants to know if we had the word mental and the word healthy together so you have mentally healthy, what do you think that might mean? Think about what you said about healthy and feeling good?

*HARRY: It still means that you might still have things wrong with you but you are eating healthy things like good veggies.

*FIONA: What else might you be doing if you were mentally healthy, do you think other than eating veg and fruit?

*HARRY: You might be running but you might be going crazy as well.

*FIONA: Ok, Anything else that you can think of? You can draw at anytime if you want to, now we have got two more words and Jupiter is puzzling over them there and she is wondering what mentally ill means. Have you heard of that? What do you think it might mean?

*HARRY: Sometimes if you are ill, and you might go crazy, and if someone asks for help, you might do something not very nice.

*FIONA: We have got some children here at the bottom, perhaps they are feeling that way. What kind of feelings do you think a child who is mentally ill might have?

*HARRY: You could feel angry and sometimes excited, because they get over excited and might go a bit crazy and get angry.

*FIONA: So if you saw someone who was perhaps mentally ill, what kind of things would you see them doing? What would you be looking for?

*HARRY: They could maybe come up to you, and hurt you, or they could perhaps say silly words.

*FIONA: Ok that's good, so what would you think if that happened? I'm asking you if you ever saw a child that way, what would you think? Have you ever seen anyone in school being that way?

*HARRY: I think I would be very worried about them, and curious I think it is?

*FIONA: That's right, so you would be wondering why they where behaving that way?

*HARRY: Yes

*FIONA: What would you do about it do you think, say you were at school?

*HARRY: Maybe tell the nurse or teacher, and send them to the office.
*FIONA: Right, we are onto the second bit now. We have done the first bit and we want to know a bit more about you. So there is Spacey and he looks really funny from the side, doesn't he? He must have a great imagination, so there is Spacey he is looking at his mission reports, and he is wondering a little bit more about you. Do you mind helping him?

*HARRY: Yes.

*FIONA: So you were going to see someone there who was going to help you with your problems, can you help us understand a bit more about what your problems?

*HARRY: That we got robbed and I have been afraid of going upstairs with no one up there and if it's dark I don't want to go up there on my own, it's mostly when it's light and there is someone up there that I will go up on my own. I know that it makes me feel frightened.

*FIONA: So it's normally at night time when you are scared?

*HARRY: Yes.

*FIONA: Did you want somebody to help you with that?

*HARRY: Yes.

*FIONA: Ok, so you were going to go and see a worker, what sort of person did you think that you are going to see?

*HARRY: A man.

*FIONA: Before you go, did you have any idea about what the man might do when you get there?

*HARRY: No, not really.

*FIONA: So you aren't really sure? Are you worried about going?

*HARRY: Yes.

*FIONA: You are a bit.

*FIONA: So they will talk to you and your mum?

*HARRY: Yes.

*FIONA: Did you have any idea about how they might help you or what that might be like?
*HARRY: I got worried because I thought they might give me an injection.

*FIONA: So you thought they might give you an injection or some medicine or something? Did you think they would be doing anything else with you?

*HARRY: Take my mind off it, and make me forget about all of it.

*FIONA: Is that what you would like to happen really then?

*HARRY: Yes. They will talk to me and say how I can get all my problems away.

*FIONA: That’s good, are you happy with that then?

*HARRY: Yes.

*FIONA: That’s good then isn’t it? How do you think that you would be feeling once they have done that?

*HARRY: Relieved that it has gone.

*FIONA: Have you ever met anyone else who has had similar problems to you?

*HARRY: Yes, one of my best friends from my old school.

*FIONA: Ok.

*HARRY: They were scared about going upstairs.

*FIONA: Was that a boy? What did you think about him?

*HARRY: I felt sorry for him because I know what it is like.

*FIONA: That’s good that you understand his situation isn’t it? Just one more question, I know it’s not on here, but what do you think we can do to make it less scary for boys and girls to go to the place so that they wouldn’t worry about it?

*HARRY: They could say that there aren’t any worries, and they aren’t going to do anything, just talk to you.

*FIONA: So do you think that they could do a letter or something like that for children, did I send you a letter? So a bit like that, with pictures on to explain what is going to happen. Would that help? That’s really good, any other ideas?

*HARRY: You could say that they aren’t going!

*FIONA: Yes, and then surprise them? Do you think that would work?
*HARRY: It could do.

*FIONA: Ok so that's everything, unless you have anything else that you think I need to know?

*HARRY: No.

*FIONA: Everybody is saying thank you very much for your help, especially me and I have a certificate for you.