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**Children and Attention Deficit Hyperactivity  
Disorder (ADHD): a Sociological Exploration**

by

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**A thesis submitted in partial fulfilment of the requirements  
for the degree of Doctor of Philosophy in Sociology**

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**This thesis is dedicated to my father, James Albin Brady (JP), who sadly died before it's completion. In the words of one of the songs he loved:**

**'We had dreams and songs to sing' (*Fields of Athenry*)**

**- I've fulfilled a dream, Dad.**

## **Declaration**

Parts of Chapters Two, Six and Seven have been published in a chapter entitled 'Experiences of ADHD: children, health research and emotion work', Gillian Bendelow and Geraldine Brady in Bendelow, G., Carpenter, M., Vautier, C. and Williams, S. (eds) (2002) Gender, Health and Healing: the public/private divide. London: Routledge.

Parts of the same chapters have been published in an article entitled 'ADHD Diagnosis and Identity: a sociological exploration', Geraldine Brady in Clinical Psychology Special Issue Children and ADHD: Sharing untold stories, Issue 40, August 2004

## **Abstract**

Attention Deficit Hyperactivity Disorder (ADHD) is a medical diagnosis, applied mainly but not exclusively to children. Diagnosis of ADHD is a controversial issue as the validity of the condition is questioned, and the main form of intervention offered to children in the UK is Methylphenidate, better known as Ritalin, which is a psycho-stimulant. It is also controversial because it rests on the assumption of a particularly westernised cultural conception of what 'normal' childhood behaviour should be, yet dominant discourses of child development and socialisation have influenced this view of children as less competent, immature and in need of moulding to fit societal demands. The orthodox position on ADHD also appears to compound this assumption, as research which includes the experiential accounts of children who have the diagnosis is extremely rare. Children's own views and perceptions of the diagnosis have not been valued.

This thesis is based on in-depth qualitative interviews with seven children aged between 6 and 15 and their parents, plus a small-scale parental survey. In addition, observations of health care professionals' practice, carried out at a Child and Adolescent Mental Health Service, will help to demonstrate that only by giving full consideration to the complexity of medical and lay perspectives can an understanding of ADHD as a concept, a condition, a label, and an experience be achieved.

In this study 'medicalisation' debates have been used as a means of reflecting on the concept of ADHD. It is suggested that within the health professional/parent/child triangle dominant discourses position children as passive and dependent, with their health being mediated through their parents. By drawing attention to the embodied nature of the experience and meaning of ADHD it will be shown that the valuable and insightful contributions which children and young people make to the health care division of labour have largely been neglected to date.

## List of Abbreviations

ADHD	Attention Deficit Hyperactivity Disorder (explanation on p46)
ADDISS	Attention Deficit Disorder Information Services
BPS	British Psychological Society
CAMHS	Child and Adolescent Mental Health Services
CHADD	Children and Adults with Attention Deficit Disorder
DLA	Disability Living Allowance
DSM	Diagnostic and Statistical Manual of Mental Disorders
EBD	Emotional and Behavioural Difficulties
LEA	Local Education Authority
MPH	Methylphenidate (Ritalin)
SATS	Standard Assessment Tests
SENCO	Special Educational Needs Co-ordinator

### Definition of concepts used:

#### *Children and young people -*

the terms children and young people are used often interchangeably to refer to everyone under the age of 18 years.

*Disabled* - in this case a more social model includes minor impairments, such as dyslexia and ADHD. It is debatable whether such impairments should be within the same category as people with 'profound and complex needs' (McKay, 2002)

*Statement* - Statement of Special Educational Need (Lays down mandatory right to receive additional support, under Code of Practice (DfE, 1994), which governs how teacher, school and LEA should respond to children not making progress).

#### *Non or reluctant compliance or adherence -*

in this study refers to young people who are not following the medical regimen recommended by their doctor. The concept of 'compliance' is problematic, as it rests on the assumption that patients should follow doctor's orders.

## **Chapter One**

### **Making Sense of ADHD: an introduction**

#### **Introduction**

Attention Deficit Hyperactivity Disorder (ADHD) is a medical category associated with difficulties in paying attention, over-activity and impulsiveness (American Psychiatric Association, DSMIV 1994; Barkley, 1990; British Psychological Association, 1996). There is no single test for ADHD, clinicians assess behaviour in order to make a diagnosis. The dominant frame of reference is that of biomedicine, which conceptualises aspects of children's behaviour as problematic, and focuses on identifying individual pathology. The scientific community and the medical profession have been influential in swaying cultural beliefs, attitudes and practices towards the acceptance of ADHD as a mental health issue requiring medical treatment. The process is facilitated by traditional conceptualisations of children which regard them as subordinate to adults by virtue of their immaturity and as passive recipients of socialisation. However, an alternative conceptualisation which recognises children's active participation in creating the social world, and regards the expectations around 'childhood' as socially constructed, allows for the low, marginalised status of children as a social group to be taken into consideration when exploring the emergence of ADHD as an 'illness label'. The social structures within which children's lives are embedded have been given little attention in research into ADHD to date.

In this qualitative study I contend that ADHD is the result of a social process which marks certain children out as 'different' from 'the norm' and in need of help. ADHD is a construct, a way of understanding difficulties which some children have with aspects of paying attention, self-control and activity. Such behaviour may not be regarded as problematic in other parts of the world, or at previous historical moments. This is not to underplay the distress which the kind of behaviour involved causes to families and children themselves in this society. In that sense, children are experiencing very real problems of frustration, aggression, inability to reflect on their actions, high levels of distraction, difficulty in learning, and often low self-worth, but such behaviour only becomes invested with meaning in relation to a particular culture. Neither is it to say that there is no biological basis to the difficulties (although research evidence is so far inconclusive); certain children and adults may have a pre-disposition to be more active and think more quickly than others. The case becomes controversial because in US and UK society these difficulties are perceived to be a condition which warrants medical diagnosis and treatment, and marks out those diagnosed with ADHD as having a mental illness and being 'different'.

Moreover, there are long-term consequences for individuals who are diagnosed with ADHD. There is a possibility of stigma leading to discrimination, as children said to have ADHD may also be variously classified as having an 'emotional and behavioural disorder' (EBD), a 'disability', a 'mental health' problem, and possibly 'special educational needs'. These various categories have wide implications for the long term outcome of children. Thus ADHD has emerged as both a medical and social phenomenon. The medico-scientific model has been dominant in debates

surrounding ADHD and, it has been argued, this powerful discourse has been largely unchallenged by other related professions (Baldwin and Anderson, 2000). There are various ways of talking about the problematic behaviours being referred to, and to refer to them as 'ADHD' is but one way, albeit the most dominant. I wish to challenge the either/or aspect of the debate, which encourages us to choose whether to regard ADHD as a neurological disorder with a biological base, or, emerging from social and environmental causes, by proposing that listening to the experience of children and young people is a useful way of understanding the interplay of biological, social and emotional factors. In this way the 'unhelpful polarisation' of medico-scientific and socio-educational perspectives could be avoided.

It is proposed that we can learn most about this embodied perspective by exploring lay perceptions of the experience of 'living with' ADHD, from the perspective of children and their parents. The relatively scant published research literature on children and young people's own perspectives of ADHD indicates an underlying assumption that parents are the main mediators of children's health. But, as Alderson (1994:49) comments, 'Children's 'best interests' are often defined by adults and may complement or conflict with children's views of their own rights and needs'. Using examples from this qualitative research study I focus on the ways in which children and young people who have been diagnosed with ADHD adopt various strategies in order to take responsibility for their physical and emotional health and well-being, strategies which adults quite often cannot comprehend.

This critical study of ADHD examines how the condition and label are subjectively experienced. Children's subjective experience is fundamental to an understanding of the concept of ADHD; individual accounts represent the 'personal'. It is, however, important to remember that the main 'political' struggle should emphasise that social structures need to change to provide institutions, policies and practices which are more 'inclusive' (Slee, 1996; Oliver, 1997) accommodating the needs of individual children.

### **Children's 'rights' and 'needs': the legislative and policy framework**

Far-reaching legislative and policy changes across the education system, health and social services, and the criminal justice system have taken place in recent years (Home Office, 1998; Social Exclusion Unit, 2001). Lee (2001) notes how when children's behaviour is ambiguous, and contradicts the concept of children as 'becoming', the law steps in to reinforce boundaries, sometimes invoking the Crime and Disorder Act (1998). In particular, changes in education policy and legislation (Education Reform Act, 1988; Education Act 1997) have had a direct effect on the ways in which schools deal with challenging and disruptive students. With the introduction of the National Curriculum, school 'league tables' and the increasing marketisation of education, schools are under pressure to maintain or improve their standing, and this appears to have led to a reduction in tolerance of certain students.

The introduction of published league tables of examination results and other indicators of performance in schools has created a climate less likely to be sympathetic to children not only producing no positive

contribution to these indicators, but who may also prevent others from doing so. (Hayden, 1997:8)

Also, students who are perceived to be 'less able' may not be given the chance to enter external examinations, as the school's league table position could be affected by their performance (James and James, 2001). Children diagnosed with ADHD, therefore, are situated at the interface of competing discourses on childhood, positioned as either vulnerable and in need of protection (largely from medical professionals and parents who want to medicate them), or dangerous, 'out of control' and a threat to the social order.

According to recent statistics, it is estimated that 10% of all children experience emotional and behavioural disorders (Young Minds, 1999). Cooper et al (2000) state that 'the most conservative estimate is that more than 80% of children classified as experiencing emotional and behavioural difficulties are in mainstream schools (2000:11), therefore, schools may find it necessary to develop strategies to deal with such children. The development of more positive alternatives to exclusion - either from lessons, fixed term or permanent - is highly overdue. With the recent introduction of the Special Educational Needs and Disability Act (2001) all schools now need to recognise that failure to anticipate the needs of students with disabilities or special educational needs may well lead to unlawful discrimination (Oliver, 1997; Osler and Osler, 2002).

The mental health needs of children are catered for by Child and Adolescent Mental Health Services (CAMHS); their aim is to prevent problems occurring, promote mental health, and treat and manage problems and disorders which arise,

minimising adverse impact. Child mental health services have been under-funded, waiting times have been long, and children's mental health has not been regarded as a priority (Walker, 2003), evidenced by the omission of children from the National Service Framework for Mental Health (2000) which was introduced to try to make services for mentally ill people more cohesive. More recently, however, there has been recognition by government that mental health issues in children need to be prioritised in the early years (DoH, 2004), in order to prevent difficulties from becoming entrenched.

The government National Priorities Guidance, 'Modernising Health and Social Services' (1998) aimed to encourage local authorities and health authorities to work at prevention of mental health difficulties, responding quickly to any which occur. Ambiguity exists around how such services should be delivered and by whom, and 'obscure access routes for service user pathways' (Walker, 2003:3) makes co-operation between services difficult. According to Walker, 'The outcome is to create barriers to those most disadvantaged and socially excluded families requiring help' (2003:3).

Contradiction and tensions abound in social policies and discourses relating to children. Social and public concern exists around child protection issues, but equally prominent is the matter of 'juvenile delinquency'. Ironically, children with the same types of symptoms or problems can be found in very different types of services, such as special education, mental health, social services, or the criminal justice system, depending on their referral career (Mayall, 1994). Many children would not be in contact with more than one of these services, but children with

ADHD could possibly be involved with each of them at once, as aspects of their complex lives may seem to require intervention from various sources. Lack of collaboration across and between agencies can mean that services fail to address the needs of the 'whole child' (Hill and Tisdall, 1997).

There has been recognition that individual agency approaches to social problems are not particularly affective and that most agencies' practice would benefit from a more 'joined-up' approach, i.e. co-operation between various services would ensure a cohesive response and therefore better serve the needs of children. With this in mind, initiatives have been introduced such as Quality Protects Programme (2000-2004), Health and Education Action Zones, Sure Start (1998), New Deal for Communities. The 'Every Child Matters' (2003) report sets out the Government's policies on protecting vulnerable children, and how it intends to ensure that every child is able to fulfil his/her potential. Such policies recognise the need for children's services to work together, sharing information, and forming multi-disciplinary and multi-agency teams wherever possible.

All of the above aim to increase joint agency working and multi-disciplinary working practices. Various barriers to effective working have been identified as these initiatives are emerging against a background of increased marketisation, NHS reforms, and flexible and insecure employment - not a situation which is necessarily conducive to the sharing of ideas amongst professionals.

My interest in the topic of ADHD arose around 1996, when first hearing of the condition via media sources. I regarded the prescription of a Class B drug to young

children, for behaviour which had been conceptualised as non-conforming and deviant, as controversial and concerning; I wished to meet these children and find out why their behaviour was deemed to be a mental health issue. Beginning in 1999, I carried out observations of clinical encounters between clinicians and parents and children at a Child and Adolescent Mental Health Service in a city in the Midlands, in the United Kingdom. I was interested in the process involved in diagnosing children with the condition of ADHD and a combination of methods were used to explore the issue more generally, including a postal questionnaire sent to the parents of all clients (children) diagnosed with ADHD. In addition, seven families were interviewed in depth on three occasions throughout a twelve month period. In one-to-one sessions with each child I also encouraged drawing and writing to facilitate communication.

### **Thesis structure**

Chapter Two begins by contextualising children's place in the social order, reviewing the developments in the social studies of childhood which have led to a reconstruction of children and childhood (James and Prout, 1997) and giving a broad outline of the ways in which policies and practices within the spheres of education and health relate to children with disability or chronic illness. Theory and methodology interlink; a theoretical stance which regards children as competent, active, and having a valued contribution to make to social research requires the deployment of methods which are sensitive to the needs of children, enabling access to their views, and attempting to diminish adult/child power relationships.

Chapter Three moves on to use the medical condition of ADHD as a case study in order to re-visit debates about the ‘medicalisation of life’ (Illich, 1976). This substantive section draws heavily on well-established critiques of biomedicine to call into question the orthodox research literature on the topic of ADHD. Building on the work of critics of the ‘medicalisation thesis’ who drew attention to the missing lay perspective (Williams and Calnan, 1996; Cornwell, 1984) the section discusses the ways in which medical diagnosis can be beneficial, in both real and ‘symbolic’ ways, for both parents and children, whilst acknowledging that the designation of a medical label may result in children’s individuality being lost within the ‘illness’ category as they become objects of such a description (Radcliffe and Timimi, 2004).

Having established the theoretical roots of this study, I move on to describe the way in which I approached the fieldwork, paying particular attention to my role as researcher, and the selection of methods which I hoped would be meaningful to children. Chapter Five concentrates on the meaning of medical diagnosis to parents, commenting on how interactions with medical and educational professionals, family members and strangers shaped the views of parents, but in particular, mothers. It also seeks to contextualise clinical practice, with reference to the social and political background of the time. In Chapter Six I consider what receiving a diagnosis of ADHD meant to parents and to children and whether it was perceived as a resource or a constraint. Chapter Seven focuses on the health care division of labour, the ways in which health care professionals, parents and children themselves took responsibility for children’s health needs. The analysis prioritises children’s own accounts of their experience of ADHD; children offer

their perspectives of social order, health and ‘normality’, and the ensuing discussion unpacks the ways in which children actively negotiate boundaries and ‘take’ responsibility for managing their physical, psychological and emotional well-being. Previously the responses of children and young people with ADHD have been hidden; this research makes them visible.

In the final chapter I draw together the various strands of the thesis to show how these research findings contribute to important sociological debates concerning the ‘medicalisation of life’ and the child health care division of labour. I show that the lack of a research tradition which asks children about their own experiences of ADHD is crucially bound up with the way in which children have been constructed. I also draw attention to the productive aspect of the emergence of the ADHD phenomena, in that it provides an opportunity to reflect on the expectations which we have of children in UK society. This thesis seeks to go beyond the orthodox debates, teasing out the tensions around dichotomies of biology/society and adult/child. The approach taken throughout regards the disease category of ADHD as *socially constructed*, a label applied to children who violate certain social norms in certain cultures, but the experience of discrimination, disappointment and societal rejection as *lived reality*. To put it simply, complex emotional, psychological and social experiences are being defined as ADHD, in accordance with a biomedical framework. Using alternative frames of reference may lead to different explanations and less medicalised forms of treatment or intervention. The thesis concludes with reflection on the research process, paying particular attention to directions for future research, and the implications of the findings of this study for both policy and practice.

## **Chapter Two**

### **Children's Place in the Social Order**

#### **Introduction**

The previous chapter referred to the way in which historically, in the UK, children have tended to be conceptualised as relatively passive recipients of culture, lacking adult capabilities, and progressing through developmental stages in order to reach adult rationality. The most dominant definitions of children have been provided by developmental psychologists and socialisation theorists. The discipline of developmental psychology has focused on the development and maturation of children as they pass through various stages to reach the 'end goal' of adulthood. Sociology has regarded children as part of the private sphere (Mayall,1996), the object of women's work, to be moulded via socialisation into responsible citizens. Thus the 'dominant framework' (James and Prout, 1997; Mayall, 1996) has muted the voices of children, and neglected to include their views of their position in the social world.

This chapter begins by delineating these two views and then moves on to discuss the emergence of a powerful critique of these positions, namely the social studies of childhood. Referring to examples in the spheres of education and schooling, and health and illness, the following section claims that children's embodiment has been rather neglected, and seeks to address this. The examples given demonstrate the ways in which children actively take part in decision-making and managing their health care when allowed. Gaining children's participation in both health and

education issues and in research requires ethical and moral considerations. A better understanding of the lives of children through research can be gained with the adoption of more appropriate, 'child-centred' methods. These recent theoretical and methodological developments are intertwined, and have heavily influenced both the approach taken in this study and the tools chosen to collect data, particularly the use of 'draw and write' (Bendelow and Oakley, 1993; Oakley, 1995) to explore children's views and experiences. Participatory methods have been developed and used, particularly in research which examines children's health beliefs, but how child-centred can adult researchers truly claim to be?

## **Dominant Discourses**

### Child development

Psychology, unlike sociology, never made the mistake of questioning its own status as a science and, in the guise of developmental psychology, firmly colonized childhood in a pact with medicine, education and government agencies (James, Jenks and Prout, 1998).

Aries (1962) identified the mid Eighteenth Century as a watershed in the European 'birth' of childhood, childhood being a distinctly modern phenomena. The discipline of developmental psychology emerged at around the beginning of the twentieth century and became the most dominant theoretical paradigm in the study of children, in particular the theory of child development, giving 'prominence to biological and psychological explanations of children's every day social experiences' (James and Prout, 1996:43). Health, education and welfare services began to take a new interest in children. Paediatrics developed as a specialty, initially dealing with the diseases of children, but later becoming concerned with their health and development:

Paediatrics pioneered the panoptical techniques of surveillance and normative regulation through which different versions of the child's body and of children were created: 'Nervous children, delicate children, over-sensitive children and unstable children were all essentially inventions of a new way of seeing children' (Armstrong, 1983:15).

Piaget's use of the concept of 'primitive mentality' led to children being conceptualised as relatively underdeveloped, immature, wordless, and without knowledge (Jenks, 1982). Reliance on the notion of developmental stages, with the development of children unfolding along predetermined lines, has meant that 'Paradoxically, developmental psychology has been both individualist and universalist: individualist in its focus on the child set apart from social context; and universalist in aiming to uncover truths applying to all children' (Mayall, 1996:43). This universal, asocial developmental process regarded the social context as unimportant, trivialising the social world rather than regarding it as intrinsic to the developmental process itself (Richards, 1986). It was later discovered that Piaget had underestimated the abilities of children; if the social context of adult-child communication is taken into account and tasks are explained properly children are able to demonstrate their competence at ages earlier than previously thought (Alderson, 1993; 1995). As developmental psychology underpins much theory of learning, children are generally regarded as passively absorbing knowledge, rather than actively using their knowledge to make decisions. With an emphasis on childhood as 'natural' rather than social, it has been difficult for sociologists to suggest a different conceptualisation of childhood, a 'reconstruction of childhood', because:

The establishment in the minds of psychologists of the concept of developmental stages, tied to age and maturation, with Piaget widely credited as the principal twentieth century influence, has such wide and

deep currency that it is difficult to think of children without using his scheme (Mayall, 1996:45).

Piaget's neglect of the social dimensions of language and cognition have been repeatedly pointed out (Ingleby, 1986).

### Socialisation theory

Indeed, until recently, sociology was concerned with children only as the future generation, but not in and of themselves. Parsons (1956) is typical of early sociologists concerned with the socialisation of children. 'Socialisation is the passage to adult stability' (Lee, 2001:40); the process involves 'the internalisation of the culture of the society'. Adults are concerned to maintain the social order, and far less concerned with the intimacies of children's relationships. According to Parsons, without adequate socialisation society will not be able to reproduce itself. For Parsonian functionalists the socialisation of children provides the link between the biological survival of the species and the transmission of culture (Lewis, 1986). In part, this is the reason that children have not been regarded by 'malestream' sociology as worthy of studying in their own right, as independent social actors; children have been viewed in an 'adultcentric' way (Pilcher, 1995), regarded as recipients of socialisation, positioned within families, and part of the private sphere (Mayall, 1996). The ideas of 'socialisation' and 'development', for example, carry that sense of childhood as a journey toward a destination' (Lee, 2001:8), and of children as 'human becomings' rather than 'human beings' (Qvortrup, 1994).

As discussed above, functionalist sociologists uncritically accepted psychology's theory of child development (Qvortrup, 1994; Prout and James, 1990). Located

within the private sphere of the family and home, not regarded as rational or competent, any investigation or understanding of children was left largely to the realm of 'scientific' medico-psychological investigation (Bendelow and Brady, 2002). Sociology only considered children as part of the family unit; with the dominance of the functionalist perspective children have generally been studied in terms of their socialisation into responsible adults, when in fact they actually do have 'an important role to play in shaping the social world' (Pilcher, 1995).

In addition, research in the disciplines of anthropology and sociology has focused on the particularity of cultural forms of childhood (Benedict, 1955; Mead and Wolfenstein, 1955). For example, the work of Aries (1962) shows that childhood has varied historically and cross-culturally, and is not merely a biological given, but understood in different ways at different times. These accounts were amongst the first to draw attention to the socially constructed nature of modern western 'childhood' as a period of passivity and dependence.

In some accounts it would seem that the physiological contrasts between children and adults are sometimes less well defined in other cultures. Children are included in the lives of adults in a way which encourages 'responsible social participation' (Benedict, 1955:21), as all experience is regarded as invaluable. In Solberg's study of a Norwegian fishing village she notes how 'workers, ranging in age from 8 to 60, mingled as they prepared the tubs of longlines for fishing. In spite of the differences in age they did exactly the same kind of work ... the status of the worker seemed to make the status of child subordinate in the baiting session' (Solberg, 1996:56). In a further example Chandra (2002 unpublished thesis) shows

the large and important part that South Asian children play in maintaining the family business in both India and the UK. Their work is valued and their contribution helps to provide a family income. (See Alanen and Mayall, 2001 for further cross-cultural comparisons, also Penn, 1999). However, children in western society have become economically worthless, but emotionally priceless (Zelizer, 1994:39). Jackson claims that children are treated like an accessory, something worth having because they make people feel good, 'it may be that children are surrogate pets' (Jackson, 1982:25). Solberg (1996) appears to agree with this sentiment, using the term 'barnefamilier' - 'child families' because to talk about families with children implies that the adults have children, amongst their other belongings.

Indeed the 'psycho-medical construction of childhood' (Hendrick, 1990) justifies the treatment of children in western society as physically and mentally immature and subordinate. Children have little inherent value, their value lies in being the future generation of producers of the social order. Professions have played a role in creating frameworks through which children's bodies are understood (Prout, 2000:112). Parents, teachers, doctors, social workers, psychiatrists, have combined in order to construct childhood, and they each operate with their own 'regimes of truth' (Foucault, 1977); this dominant way of viewing 'the child' appears to be 'the truth', and quite 'natural'. The sociology of childhood is a powerful critique of the 'naturalness' of childhood as a category; there is little that is universal about 'the child' and it would be more accurate to refer to a variety of childhoods (James and Prout, 1990). From this perspective children are regarded as a minority group whose 'voice' is rarely listened to, and childhood itself as socially, historically and

culturally constructed (James and Prout, 1990; 1996; Mayall, 1996, 2002; Solberg, 1996; Qvortrup et al, 1994).

### Research on children

Within the discourses of developmental psychology and sociology, research on children and childhood has previously been carried out in a way which can only be described as 'top-down'. Research has often used adult categories, classifications and taxonomies into which children are expected to fit, and children have been regarded as incompetent or, at best, immature adults (James and Prout, 1996; Mayall, 1996). Such research has objectified children.

Moreover, much social research which has been concerned with the contexts of children's lives, such as school or family, has not directly involved children in fieldwork, largely because their contributions were under-valued (Hill and Tisdall, 1997) or not considered reliable, but partly because research with children often entails much ethical consideration (Alderson, 1995). Exceptions to this include some of the classic texts emerging from the tradition of ethnographic educational research, such as Hargreaves (1967), Willis (1977) and Burgess (1983) which investigated 'classroom cultures' and presented the voices of students wherever possible.

Research approaches which have been influenced by theories of socialisation and child development have made assumptions regarding the reliability and competence of children. Generally, research which has been carried out on children, asks parents and professionals to give their perceptions of children's

views. It has rarely been appreciated that children possess their own body of knowledge with which to consider issues which confront them, and their ability to make decisions, provide information, or contribute, is often underestimated. In some cases, there may be a discrepancy between what adults think is a child's experience, and what the child's experience actually is. For example, parents involved in domestic violence quite often claim that children have not seen and are not aware of the violence. Yet when Mullender et al (2002) interviewed children, it transpired that they could reveal detailed accounts of violent behaviour which their parents were unaware they had witnessed. Such examples serve to reinforce the need for children's accounts, as they may well differ from those given by adults.

### **The Social Construction of Childhood**

During the past twenty years a body of research has emerged which challenges notions of children as incompetent, immature and under-socialised (Prout and James, 1990, 1998; Qvortrup, 1994; Alanen, 1992; Mayall, 1994, 1996, 2003; Jenks, 1982, 1996). Through both theoretical and empirical research, sociologists of childhood have focused on the competency of children in relationships, in looking after their own health, and in making decisions. Legislation and policy are also beginning to recognise children's rights; Article 12 of the United Nations Convention on the Rights of the Child (1990) asserts that the child has the right to express his or her opinion in all matters affecting him or her. The Children Act (1989) also draws attention to children's rights to participation. However, there is a tendency to focus on individual children, rather than on children as a social group (Hill and Tisdall, 1997).

The promotion of children's rights as a social group was achieved through a sixteen country ESRC project called 'Childhood as a Social Phenomenon' (1985-1992). The programme emphasised that interests between adults and children are not one and the same, and that childhood experience is culturally diverse. Neither are children passive recipients of adult socialisation, they actively contribute to the social order, and help to construct family life (Mayall, 1996; Solberg, 1996; Hallden, 1992). Children are affected by the relationships which they have with significant key people, such as parents, siblings, teachers, and friends, and in turn reciprocally affect interaction.

More recently, as part of the ESRC 'Children 5-16 Programme: Growing into the Twenty-first Century' (1995-2001), a further body of influential research has emerged. The ultimate aim of the Programme was to develop new knowledge about children as social actors and both the structural contexts and the micro systems of children's lives were investigated. Fundamentally, the scholars involved began by problematising the concept of 'childhood', arguing that the institution of childhood has been used to provide an interpretive frame for understanding universal biological immaturity (James and Prout, 1990; James, Jenks and Prout, 1998). Adopting a deconstructionist approach to children and childhood helps to reveal the assumptions which are embedded in the concepts. The emergent paradigm of the sociology of childhood focuses on the ways in which children actively negotiate relationships, having more success in the family than within the setting of school. Through empirical research, children are shown to be competent social actors, sometimes contesting and resisting boundaries set by adults; their contribution to

the social order and the division of labour (Qvortrup, 1985; Solberg, 1990; Mayall, 1996) through health care, unpaid work, caring for disabled family members, and taking care of their own health and well-being, is considerable.

#### Limits to social constructionism

The sociology of childhood has challenged the dominant concepts of socialisation and developmentalism, but it cannot be regarded as an homogeneous body of thought. As the field has developed there have appeared 'new but productive divisions' (James and Prout, 1999) between contributors, some of whom specifically emphasise the socially constructed nature of childhood and others who focus on children as agents or social actors. By opposing the idea of childhood as a given biological fact, social constructionism has succeeded in demonstrating the social, historical and cultural variability of childhood, but some accounts are in danger of becoming relativist, and neglecting the political and economic context of disparate children's lives (James and Prout, 1999).

Children are politically and economically situated and we must remain aware of the differences of gender, class, ethnicity and disability which differentially structure their lives. Although children share 'childhood', they experience 'childhoods'. An over-arching emphasis on the agency of children risks becoming a sociology of choice, which fails to recognise the structural freedoms and constraints that the agency of children expresses (Pole et al, 1999:42).

A further criticism of social constructionist accounts claims that anti-foundationalist views of children have not concerned themselves with 'the

childhood body as an experienced entity' (Prout, 2000:112). The discipline has been concerned to distance itself from nature and turn towards culture and the social construction of childhood and childhood bodies. Turner (1996) regrets that sociologists have neglected embodiment,

Any reference to the corporeal nature of human existence raises in the mind of the sociologist the spectre of social Darwinism, biological reductionism or sociobiology (1996:37).

However, it can be argued that this tendency for new movements to go to extremes is an understandable part of gaining recognition:

All revolutionary movements, whether they are political or religious or philosophical, usually begin with absolute and unilateral positions; they then pass through a reflective and critical revisionist phase to a more pluralist position characterised by the emergence and acceptance of differing perspectives and interpretive frameworks (Charlesworth, 1995:126).

Taking theoretical arguments to the extreme may be necessary in order to stimulate debate about the status of knowledge. Historically, certain groups of people have been regarded as inferior, lacking in the necessary competence to fully participate in the social order, or at least in the public sphere. Take as example the case of women and children; both are members of minority groups, both have been considered 'incapable of adult competencies' (Oakley, 1994:15) and both tend to be confined to the private, domestic sphere. In order to have their cause recognised, feminists invariably distanced themselves from children, understandably at the time as motherhood was identified as a social and political institution, the basis of women's oppression. Women were slaves to their biology, relegated to the home where the division of labour around child care was extremely unequal, and left them subordinated to men (Firestone, 1979; Chodorow, 1978). Children were

conceptualised as a constraint on women, therefore 'the feminist theoretical project about the liberation of women could not simultaneously consider the liberation of children' (Alanen, 1994:34).

Oakley (1994) draws attention to the parallels between the situation of women and children. Early feminist theory recognised that women and children were lumped together in the private sphere, but by concentrating on the needs and demands of women, feminists continued to objectify and marginalise children, 'children were not considered social actors like women' (Alanen, 1994:33). Mayall notes how the women's movement has 'taken some time to explore positive characteristics of their relationships with their children', and believes that these explorations have led to deeper understanding of both women's and children's structural position (Mayall, 1995:35). In a similar vein, the disciplines of education and health have not always granted children the right to participate in decisions which affect them, preferring instead to liaise with parents in such matters.

### **Children as Embodied Actors/Agents**

The social studies of childhood overtly challenged long held assumptions made about children and childhood, and succeeded in drawing attention to children's agency and active negotiation of social life. Although social constructionism highlights the constructed nature of the body, through knowledge and discourse, and has been crucial in offering a way out of biological explanations, it does tend to deny the existence of the body as a material entity. (Prout, 1996:3). But the experientially grounded concept of 'embodiment' 'lies ambiguously across' (Williams and Bendelow, 1998) the divisions of 'nature/culture' and 'mind/body'.

This is particularly significant in the case of children's lived worlds, and the meanings which they give to their bodily experiences (James, 1993). Shilling (1993), building on Elias (1939), regards the body as biologically and socially 'unfinished', biologically changing over time and being transformed by its participation in society, simultaneously social and biological. It could be argued that the children on whom this research focuses are 'inadequately socialised future adults', regarded in a different way as 'unfinished'. 'Children who don't acquire the level of control of emotions demanded by society are regarded as 'ill', 'criminal' or simply 'impossible' (Elias, 1939) . The children are clearly living with an experience of their body which is real, for them and their families. Study of children's 'embodied experience will throw light on the social and political issues central to childhood experience' (Mayall, 1998:283).

Yet other writers criticise sociologists of childhood for going a little too far in their emphasis on children as autonomous, independent individuals;, after all, the majority of children still remain family members (Brannen and O'Brien, 1996). Brannen and O'Brien's work seeks to recontextualise children within families, as active subjects. They draw attention to the structural processes which shape children's agency; '[...] it is important not to lose sight of the practical and legal realities of children's relations with their parents and other family members' (Brannen and O'Brien, 1995).

More recently, Alanen and Mayall (2001) have argued that the concept of generational order should be the central organising concept of the social study of childhood. In the initial analyses of contemporary childhood it was necessary to

conceptualise childhood as distinct and separate, in order to allow it to be theorised apart from the institutional contexts of the family, school, and welfare system. Moreover, childhood is a permanent component of society (Mayall, 2003); individual children move through it, but the inter-generational relationship remains constant. Membership of the group 'children' 'is always shaped by large-scale historically rooted influences, ideologies and policies' (Mayall, 2001:114). Therefore, childhood should be treated as a relational concept, part of the system of relations between generations (Prout, 2002). Indeed, analysis which includes the concept of generation is able to take a broader view of children's lives, regarding them not just as individuals, or as members of a family, but as a social group with a shared understanding. Taken together, the recent reconceptualisation of children and childhood has implications for the ways in which their participation in social research is sought.

Mayall (1994) draws attention to the ways in which children are constructed by adults in different settings, particularly the home and the school. Within the home, parents (mothers) display an understanding of their individual children, based on 'experiential knowledge' acquired by living with them. This then informs the relationship and positioning of the child, and children are more likely to be successful in influencing their social environment. However, within school there is less opportunity to negotiate and influence daily life; the social norms of school tend to be fixed and not open to debate. Children are expected to fit in to a predetermined institutional structure. School severely limits children's management of their own bodies (Mayall, 1998). Whilst in the family they 'continuously create the family' (Mayall, 1994:120), negotiate the division of

labour, interacting productively with siblings and adults; at school such opportunities are limited.

### **Researching Children: Embodied Agendas**

#### **Education and Schooling**

Getting an education is regarded as the principal activity of childhood in western societies; children have become scholarized and dependent (Mayall, 2002). However, social research into the education system in the UK has focused predominantly on institutions, the curriculum and pedagogy, implicitly regarding children as passive recipients of education. The reluctance to give children a voice has its roots in the dominant models of childhood which have prevailed (Lloyd-Smith and Tarr, 2000). Alongside this macro approach, the tradition of ethnographic research, involving participant observer studies of classroom interaction, has existed (Burgess, 1983; Delamont, 1992). More recently, there is a growing body of research which aims to explore the influence of class, ethnicity (Troyna and Hatcher, 1992), gender (Mac an Ghail, 1994; Epstein et al, 1998) and disability (Lewis, 1995) on children's experience of schooling.

Related to the growth in numbers of children being identified with 'special needs', research into special educational issues has become very topical (Tomlinson, 1982; Cooper, 1993; Cooper et al, 1995; Lewis, 1995). It is generally understood that existing UK educational legislation is heavily influenced by the medical model, which assumes that children's behaviour or their impairment is 'the problem'. Under Part IV of the Education Act, 1996, a child has 'special educational needs' if s/he has a learning difficulty which calls for special educational provision to be

made (s312, Education Act 1996). The use of the term 'special educational need', used in the Warnock Report (DES,1978) was intended to emphasise the part played by schools in generating such needs, implying that schools should be responsible for adapting (Hill and Tisdall, 1998). The Warnock Report has been widely criticised for adopting a simplistic approach to inclusion (Lloyd, 2000). Despite an increasingly 'inclusive' ethos in education, the reality for children with chronic illness or disability is that their diversity is not provided for, yet the idea of 'inclusive education' is to meet the support requirements of all children within mainstream school and to promote equality and social justice. Children have a right to be included, however their difficulties are defined.

Local Education Authorities are often reluctant to fully provide for children's needs, particularly if the disability is 'hidden', as in the case of ADHD. The Audit Commission's Report on statutory assessment and special educational needs (2002) states that 'each Statement costs in the region of £2,500 to produce' and that '36,000 new Statements were issued in 2000' (2000:119). Basing assessment on the medical model has meant that educational psychologists and Special Educational Needs Co-ordinator's work involves identifying deficits and differences to prove children's eligibility; their time would be better spent 'supporting problem solving around the difficulties children experience in learning' (Florian, 2002:165).

Approximately twenty per cent of all children need some special educational provision at some stage, but only about two per cent need a 'Statement of Educational Need' (Read and Clements, 2001). The five phase response

recommended by the Code of Practice can be quite controversial, as there are many cases where significant resources are only provided if the child is granted a 'Statement' (Stage 5), which makes provision mandatory. Many parents who seek assessment with a view to receiving a statement for their child are disappointed by the outcome, either finding themselves in disagreement with the school regarding the extent of their child's difficulties, or not being provided with enough support in terms of personnel or equipment (Osler and Osler, 2002; Lightfoot et al, 2001). Various studies reveal inadequacy of support and inconsistency (Audit Commission, 1992; Osler and Osler, 2002; Simpson, 1999) in provision for children and young people. Parents need to be prepared to 'fight' for the recognition of their children's difficulties, and the resources to give them an equal chance (Read, 2000; Kenworthy and Whittaker, 2000).

However, special education has a long history of controversial issues (Hornby, Atkinson and Howard, 1997:2). Developments surrounding the 'inclusive' agenda of recent years emphasise that as long as the organisation of schooling, the curriculum and assessment and testing procedures remain unchallenged the opportunity for equal education will remain a myth (Lloyd, 2000). Existing legislation assumes that what is on offer in mainstream schools is appropriate for all children and, given extra support, children will receive equal opportunity in education (Tomlinson, 1982; Barton, 89; Ball, 1990; Slee, 1996). But the concept of special educational needs individualizes the issue and works towards normalizing children to fit into existing structures. Oliver (1997) argues that education needs to recognise and celebrate difference and personal identity, challenging the current focus on conformity to the norm. Children with labels such

as ADHD would be better served by the approach advocated by Skrtic (1991) which is firmly rooted in problem-solving, critical reflection and interdependence. Kenworthy and Whittaker suggest that adult's intolerance is at 'the root of social and political practices which lead to categorisation, segregation, isolation and ultimately rejection' (2000:222). Both structural and attitudinal barriers have a huge impact on the educational and social experiences of children and young people with disability or special needs.

[...] the experience of childhood is fragmented and stratified by class, age, gender and ethnicity, by urban or rural locations and by particularised identities cast for children through disability or ill health (James and Jenks, 1996:317).

Children spend the majority of time in school, yet their health needs are often not catered for. A House of Commons Committee (1997) found that there seemed to be 'a considerable degree of confusion about whose responsibility it should be to provide care for children with clinical needs at school' (House of Commons Committee, 1997, Paragraph 88) and that the school health service should play a more 'hands on' role (Mayall and Storey, 1998; Mayall, 2002)

### Health and Illness

It is important to recognise that the social and political concerns regarding children's rights have been reflected centrally within sociological debates around health and illness. There has been a gradual recognition that the voices of children and young people should be the focus of research into issues of illness and disability. In this next section it will be shown how lay perspectives of illness experience tell a story which differs from that of professionals. Addressing children directly, confirming their understanding and agreement, and discussing their subjective views is becoming an accepted part of social research, but parts of the

health care system have some way to go before children are accepted as being competent enough to fully engage in decision-making (Alderson, 2002).

In Stacey's (1984; 1988) account of the division of labour in health care she focused on the processes of seeking and receiving child health care, and the meaning given to these actions by the participants. Each of the participants in the division of labour, paid and unpaid, plays an active, valued part, although the system is hierarchical and the division of health care work most certainly gendered. Patients should be considered partners in the health care system, although this is not to imply that they are equal partners (Stacey, 1984). The work which patients do to maintain their health and well-being is undeniable, their actions and behaviour being influenced both by medical practice and lay belief systems (Cornwell, 1984; Blaxter, 1987). Stacey notes how early research into lay concepts of health 'assumed not only the primacy of biomedicine but the correctness of its understandings' (1988:142); her account shows how people's understanding of illness is often complex, and always valid. Their understanding is arrived at through a process which inevitably involves drawing on information received from a variety of sources:

Ordinary people, in other words, develop explanatory theories to account for their material, social and bodily circumstances. These they apply to themselves as individuals but in developing them they draw on all sorts of knowledge and wisdom, some of it derived from their own experience, some of it handed on by word of mouth, other parts of it derived from highly trained practitioners (Stacey, 1988).

It is only recently that doctors have come to realise that there is often a correlation between patient satisfaction (with their visit to the doctor) and compliance with medicine regimes. 'Non-compliance' is common and widespread in children,

although limited literature exists on adherence among child populations in comparison to the extensive literature on adults (Bauman, 2000). Non-compliance in psychiatry has often been associated with resistance; families who do not follow the advice of doctors can be regarded as uncooperative, and even deviant. The paediatric diabetes literature in particular is also very concerned with regimen adherence (Delamater, 2000). In certain cases, not complying with the request to take medication, and not admitting this to the health care professional in charge of one's case can affect decisions made. For instance, if a medicine is seen not to be working, the dose may be increased, without the doctor realising that it is not being taken as prescribed. There has been much criticism of the term 'non-compliance', as it implies that parents or children are at fault (Matsui, 2000), when clearly there are deeper issues around the reasons for not 'following doctors orders' which need to be explored. More recently medics are coming to realise that information given during consultations needs to be tailored to children's individual needs, tastes, personality and culture in order to make sense in the context of their daily lives (Korsch and Marcy, 2000).

The importance of including children and young people in decision-making has also been under-estimated. Lewis et al (1991) carried out a study of paediatric consultations, dividing their sample into those that experienced a brief educational intervention programme and a control group. In the intervention group, doctors included children in discussions more often which meant that, when evaluated, children in this group were more able to recall the recommendations and also reported greater satisfaction than the control group; the children preferred a more

active, inclusive health role. It has also been known for some time that increased patient participation may also result in better compliance.

Perhaps understandably, given the model of childhood which has been dominant, assumptions have been made that child patients are passive advice takers, when in fact they are active decision-makers. Strong's (1979b) research into paediatric consultations drew attention to the silence and passivity of children during such meetings, and the ways in which children were positioned, both by health professionals and parents. But given the opportunity to talk through their fears, anxieties and general concerns, children will be empowered to make choices regarding their own health and well-being (Alderson, 1995). The research discussed here gives a strong indication that children have the potential to participate in their health care at all levels; during doctor-patient consultations, in decision-making, and across each of the domains they encounter in daily life. Medical personnel diagnose conditions and provide treatment, but both children and parents have a critical role to play in managing the condition (Stacey, 1984; Mayall, 1996; Delamater, 2000).

Mayall (1996; 2002) has taken the work of Stacey forward in considering children's own contribution to the division of labour in child health care. She focuses on the two main domains with which children are concerned, the school and home, and finds that 'at home children's drive towards self-care was valued, since mothers understood their children as competent people who seek independence; at school, staff did not recognise children's competence and instead emphasised their immaturity; staff's over-riding concern was with implementing

the formal school agendas' (Mayall, 2002:17). The importance of the intermediate domain, 'an arena when state/public interests and family/private interests intersect' (Mayall, 2002:11) was emphasised by Stacey and Davies (1983) and later Mayall, as an ambiguous space in which mothers negotiated with health, education and welfare (all patriarchal structures) professionals, on behalf of their children (2002:11).

Chronological age is often presented as key, when considering children's ability to make decisions (the concept of 'Gillick competence' will be discussed later). But as has been pointed out, chronological age and competence are not the same thing (Alderson, 1995; Morrow and Richards, 1996). It has been shown that even children of a young age can make decisions if information is provided and discussed in terms that they can understand. Research into childhood health and illness which adopts an interpretive perspective proves to be fruitful in providing data which has explored the meaning behind social action. Bluebond Langner's (1978) ethnography focuses on the ways in which terminally ill children discover and understand the meaning of their illness. Children are not merely passive recipients of knowledge, they interact with parents and doctors in order to make sense of the information which they are gathering, sometimes unbeknown to adults who are trying to protect them, believing that they would be unable to cope with the truth. Children themselves try to protect their parents from pain and depression; they are rarely given credit for this engagement in 'emotional labour' (Hochschild, 1983; James, 1989). Prout (1992) believes that Bluebond-Langner's approach is limited because her analysis reveals how children on the ward acted, but not why (Prout, 1992:133).

Children's understanding of death is considerably enhanced once they experience a death of a close family member, pet, or their own illness (Judd, 1989). It then becomes less of an abstract concept. Doctor's approach to informing children should be based on a child's understanding; children are given chance to talk candidly about their life threatening illness in order to come to terms with the diagnosis (Bearison, 1991).

The findings of Young et al's (2003) recent research study, published in the British Medical Journal, demonstrate how important clear communication is to young people who have cancer. Young people told how they could feel excluded in consultations where doctors communicated with their parents, and not them. They also were aware that their parents were 'managing' information, in a well-meaning attempt to protect their child's well-being, but this actually had the effect of making them feel marginalised.

Research which considers the difficulties faced by children with a specific chronic illness or disability aids understanding of the kinds of issues faced by the wider group of children with a variety of conditions. In Burton's (1975) research into family's experiences of cystic fibrosis parents often experienced sceptical reactions from doctors who they approached for help, which diminished their self-confidence and belief in knowing that there was 'something wrong'.

Thus many parents experienced a long-drawn-out pre-diagnostic saga of self-doubts, eventual medical interviews, reasonable alternative explanations, ineffective treatments, more self-doubts, despair, more medical interviews and so on (Burton, 1975:25).

A relationship between social class and speed of diagnosis was found in this research. Parents who were articulate, intelligent and determined obtained diagnosis soonest (Burton, 1975:30). Burton notes how, as rates of survival improved, an interest in the whole child, particularly their emotional and social needs, developed. Professional concern then began to include helping children to cope with their illness, as children's reactions to their illness impact on their parents, and parents reactions affect children. This interactive aspect of illness needs to be emphasised. Children may have the same condition, but social and psychological factors also influence the meaning which they give to their experiences.

In contrast, some new health studies with children have benefited from the recent theoretical developments. In the case of surgery (Alderson, 1993) and chronic illness, such as diabetes or renal failure, children have shown that they are not just passive and compliant, but are able to take an active part in discussions regarding treatment. Children are able to look after their own well-being, and play an important role in the division of labour regarding treatment/medication regimens. In addition, children are able to make decisions about aspects of their health that directly concern them, providing they have been given clear information, in terms they will understand (Alderson, 1993). Such decisions may not be congruent with adult choices, but adults should also respect that children make embodied decisions which are relative to their life experience and their own world-view, and may be crucially bound up with their identity.

The ways in which children's illness identity is constructed by others is one of the features of Allison James' (1993) study which explored the boundaries of social identity amongst children between three to nine years old. She was interested in the ways in which children themselves defined who 'belonged', and who did not, and then went on to examine the significance of a sense of 'difference' on children's developing self-identity. James's influential account shows how parents draw on competing discourses of childhood, not only family ideals of 'normality' but medical and educational discourses too, to enable them to understand the meaning of their child's condition. The stereotype of 'normal' childhood is powerful in the way in which it homogenises individual experience. The concepts of 'differently normal' or 'normally different', proposed by James, frame her analysis of parents responses to their child's illness or disability.

James engaged with mothers who had a child with an illness or disability, collecting their accounts of the kind of difficulties involved in caring for such children. The narratives varied, but tended to present 'a radical contrast to the safe, happy and protected childhood which has become sentimentalised in the particularity of its dominant Western ideological form' (James, 1993:36). Children had problems 'participating in their own childhoods'. As previous studies have found, parents' encounters with childhood professionals such as doctors, health visitors and teachers both shape and change parents' perceptions of their child's condition.

Some families attempt to normalise their experiences, and do not see their disabled child as having a significant effect on family life. When discrepancies between

expected and actual child development occur 'parents engage in perceptual and judgmental work to normalise them' (Voysey, 1975:122). Parents are less likely than others to stigmatise their child, partly because continuous interaction ensures that they do not regard their son or daughter as a 'type', and that so-called 'symptoms' would be experienced as unique characteristics to parents. As time progressed, parents came to 'define their child's condition in ways that were congruent with the limitations entailed by medical definitions'(Voysey, 1975:125).

Some of the families in the study by James also stressed the 'normality' of life. Those who conceptualised their child as 'differently normal' accepted the condition, minimized the disruption it caused, and stressed that it did not stop their child from having a normal life. The medical profession had legitimated their child as being different, but within the bounds of normality. These parents accept that variation exists between children's childhoods. Other parents construct their child as essentially different, 'normally different'.

Parents who regard their child as 'normally different' tend to have failed in their bid to gain help from medical and educational services, sometimes because their child's difference is regarded as unexceptional. This can be explained by professionals' tendency to work with a model of 'the child', against which children are measured and found to fall within the broad range. Parents, however, have specific knowledge of and familiarity with their child (James, 1993). Parents who experience disbelief and scepticism from professionals who carry out assessments need to be prepared to persevere, sometimes for years, to have their child's difficulties recognised and legitimated. Unsurprisingly, in order to eventually get

children's needs met some parents may need to emphasise their difference, and their own difficulties in coping with their son or daughter.

The experiences of parents of children with chronic illness or disability have been well documented (Beresford, 1994; Eiser, 1993; Read, 2000). Maintaining a 'normal' family life, where all children in the family feel included, can be difficult when one child needs so much attention. Siblings can try to be understanding, but may also feel resentful that their brother or sister with an illness or disability seems to monopolise their parents/mother's time. Although undoubtedly under pressure, and finding it necessary to negotiate hurdles which other families do not, it should be emphasised that [disabled] children are individuals, and bring with them diverse rewards, stresses, happiness and disappointment, much like any other children (Baldwin and Glendinning, 1981).

### **Methodological Challenges and Residual Problems: is child-centred research really possible?**

Undertaking research with children and young people involves the consideration of many of the moral and ethical issues which are pertinent to all social research, but they become highly significant when carrying out research with a relatively powerless, vulnerable group, such as children. The ability of an individual to give their informed consent to research is essential if research is to be ethical, but what is meant by informed consent? The issue of 'informed consent' is of paramount concern in sociology of childhood literature. At what age children are considered competent enough to make a choice about taking part in social research? Is chronological age a useful measure? Children are constructed as vulnerable and

powerless, and it is parents who are their gatekeepers, often acting protectively towards them. If those taking part in research are under 18, consent is required from both minors and parents, therefore young people cannot speak to researchers if their parents will not allow it. Sociologists of childhood have pointed out that the irony of researching with children is that permission has to be sought from a series of different adults - parents, teachers, doctors, and so on - but not the children themselves (Morrow, 1993; Mayall, 1996; James and Prout, 1990).

Under British law if minors are considered to be 'of sufficient understanding to make an informed decision' (Davie, Upton & Varma, 1996:53) they can be said to be 'Gillick competent', yet Alderson says this can also apply to much younger children than the law recognises as of 'sufficient understanding' (Alderson, 1993). So who decides when a child is competent? In the case of research, Alderson (1995) considers that all school-aged children should be assumed to be competent. 'Competence is usually assessed by checking whether the child is able to make informed, wise and voluntary decisions' (Alderson, 1995:76), based on the provision of clear and relevant information. They should, however, be protected from any harm, mental or physical, which might be a result of research. Researchers should make every effort possible to diminish the power relationship which exists on two levels: researcher/researched and adult/child.

Following recent theoretical and philosophical developments which take as their starting point children's role as active decision-makers, it is recognised that they have a right to participate in all aspects of life, including social research. As a more sophisticated conceptualisation of children has developed, it has become

evident that children are unlikely to respond to certain traditional methods of questioning; this has led to the development of new and innovative methods to be used in research with children. Once children are conceptualised as competent, able, having agency, a group with separate interests from adults, it becomes clear that researchers need to show respect for children's competencies and views by developing a more 'child friendly' methodology. Sociology of childhood literature and new approaches in psychology and particularly social work have led to the development of more appropriate methods, tools and strategies for use with children, which will be explored later in this chapter.

Underpinning debates about the informed consent of children is a concern with adult/child unequal power relationships. Research into children's lives is said to allow the voices of children to be heard, to empower the social group, but does this happen in reality? Can adults truly represent children? Alldred, (1998) discusses how the word 'represent' has two meanings, which are not clearly distinguished in the case of adults researching with children. Claims to 'represent' children may mean 'portray', or 'advocate', or may refer to both. Alldred challenges the assumption that adult researchers act in the best interests of children, and that what children say can be unproblematically represented in research. Relationships between original events, and how children talk about them later are complex (Marks, 1996). There is a dilemma between presenting particular re/presentations of children as a social group, and re-presenting the accounts of the particular children who participated in research. As researchers we need to consider how we publicly represent children's voices, as well as the kinds of methods we employ

(Aldred, 1998:162) if we are serious about trying to diminish adult/child power relationships.

If we seek to understand children, both as a social group and at an individual level, we must use strategies which are inclusive, not those which omit them or make it too difficult for them to participate. The development of innovative methods, which do not rely solely on verbal or written communication, can be advantageous to both the researcher and the children involved, helping to diminish the power relationship and allowing access to the child's world. 'Draw and write' or 'draw and label', as the technique has more recently been termed as it becomes more refined, has become popular with both researchers and children (Bendelow and Oakley, 1993; Oakley, 1995; Bendelow et al, 1998; Lewis and Lindsay, 2000).

Drawing and talking was used by Burton (1975) to allow children to discuss their likes, dislikes, fears and aspirations. They were also asked to choose six pictures, and from this to make up six different stories in response. As a paediatrician, Burton was concerned to evaluate the children's intellectual potential, academic attainment, personality and social functioning through the use of a variety of tests. More recent social research with children accepts that they are competent reporters of their own experience (Christenson and James, 2000; Begley, 2000; Mayall, 1996), treating all children as having a valid contribution to make.

Recent developments in child health research have included an increased use of participatory methods. Images have been used in health education and training to instigate discussion and seek solutions to health issues. Children's pictures, in

conjunction with writing or dialogue, can be a powerful method of exploring the health beliefs of young children which inform health behaviours and influence health status. Williams, Wetton and Moon (1989) undertook the UK Health Education Authority Primary Schools Project, in which children from ages four to twelve were encouraged to reveal their health related perceptions. The technique of investigation employed with the younger children was 'draw and write', which was innovative at the time. The presentation of the final report contains clear visual and written messages which encapsulate the views of the children. 'Draw and write' was very successful in accessing children's views, as it specifically appealed to children, and it has been utilised by many research studies since. (Bendelow and Oakley, 1993; Oakley et al, 1995). The recent upsurge of interest in the use of this method in health research reflects recognition of the need to develop innovative and participatory approaches which enhance our understanding of children and their views of their world. 'Draw and write' was also used in a recent study which investigated young people's beliefs about health, risk and lifestyle (Bendelow et al, 1998).

Shaver, Francis and Barnett (1993) have also shown how using drawings with adults and children can be 'a way to elicit the concerns and understandings' of participants (1993:1). They used a technique which they termed 'drawing and dialogue' (DAD), which involved the participants producing drawings and then giving detailed verbal descriptions of the meaning of the drawing. In this way, the drawing provides a prompt, which leads into conversation. This approach was novel, as participants were asked to think of their own example, an immediate response, rather than respond to a pre-prepared drawing, often used in health

education. In this way, health education which was based on the assessment of needs could be planned.

Barnett, Francis, de Koning, and Shaver (1994) have employed this method in a number of studies involving both adults and children in cross-cultural contexts. In terms of validity and reliability, drawings were analysed in close relationship with the verbal explanations given, particularly as some were highly symbolic images. Having drawn out the main themes, the researchers went back to the participants to confirm that they had understood what they were trying to convey. In a further example, Weinbren and Gill (1998) used drawings and unstructured interviews to explore the health beliefs of children diagnosed with epilepsy, particularly in relation to the 'intangible sense of difference' which the children sometimes felt.

Visual material in sociology is often regarded as supportive of the text, but the ways in which it can 'speak for itself' are generally neglected (Bolton, Pole and Mizen, 2001). Chaplin notes how written text is granted pre-eminence: 'In the positivist era, sociologists used textual strategies to convince readers that the knowledge their accounts purveyed was objective and true' (Chaplin, 1994:277). Sociological texts tend to have a conventional layout, but work which is presented in a novel way, linking images and verbal data, makes viewing and reading more compelling. Visual material has been regarded as subsidiary, yet textual and visual representations should be considered together to enhance analysis. The social and personal relations which lie behind the images may not be evident, but they are usually revealed in the ensuing conversation. The above methodological issues were generated from critiques of positivist philosophy, which also drew attention to

the blurring of distinctions between sociology and chosen areas of study, encouraging reflexivity on the part of researchers, and the seeking out and utilisation of alternative ways of knowing, which drew on the experiences of participants themselves.

Bolton, Pole and Mizen (2001) emphasise that social researchers still rarely encourage participants to produce their own images. In their study of working children, aged between 11-16, participants were invited to photograph their working lives; such primary data would provide access to a visual record *of* their culture, contrasting with sociology which is *about* participant's culture. Such methods can be empowering for young people, as they choose what to select and what to leave out. '[...] Visual methods can complement, augment, confirm and enlarge on other methods' (Bolton et al, 2001:517); they have a 'distinctive contribution to make'.

## **Conclusion**

This chapter has provided an overview of the theoretical debates in childhood studies. The 'dominant framework', the most accepted way of viewing children's lives, has been problematised because it failed to regard children as competent, active participants in the social order. What is more, the dominant framework's sense of 'completion' 'made it such a comfortable truth regime for adults' (Lee, 2001:51). Children's lives are shaped by health, education and welfare policies and practices, but children have agency and are active in making their own decisions and choices.

There exists a limited amount of micro level research about children's own perspectives, supporting macro level research about the social and political context of the increased diagnosis of ADHD. A variety of powerful groups - parents, teachers, health professionals, social workers, government - construct such behaviour as a 'social problem'. Research which tries to address children's own concerns and devise means of getting at their understandings of their social position, moves away from the discredited image of top-down research, towards a less hierarchical relationship. A commitment to including children's contributions in research can be 'both conceptually and methodologically challenging' (Williams and Bendelow, 2000:64); but there are now a variety of approaches and methods which have been developed and used in research with children, including visual methods, which are leading to new ways of understanding child-adult relations. Children can provide detailed information 'if sensitive methodologies, grounded in their own beliefs and concerns, worries and anxieties, are used' (Williams and Bendelow, 2000:57).

The theoretical and methodological advances which have been made provide us with the opportunity to begin to unpack the dominant misconceptions surrounding children and childhood. The concept of 'embodiment' challenges reductionism, and provides a productive means of exploring the lives of the children with which this study is concerned. Narrative and visual contributions help to advance our understanding of the lived reality of young people's experiences. The following chapters will indicate how crucial the inclusion of the 'voices' of children and young people is to the progression of a more informed view of the condition of ADHD.

## **Chapter Three**

### **Attention Deficit Hyperactivity Disorder: Controversies and Debates**

**[...] we have to look at the contemporary ideas about psychiatric disorder, including the ways in which its boundaries are set, the institutions and social relations in which mental health practice is embedded that structure its practice, as well as the social conditions that give rise to psychiatric disorder as it is constituted at that particular time and place (Busfield, 2002:145)**

#### **Introduction**

The previous chapter explored developments in the reconstruction of childhood, particularly in relation to the ways in which children's bodies, their cognitive abilities and behaviour are constructed by adult society. Concerns regarding the future of society lead state regulated institutions, the 'psy complex' (Donzelot, 1980), to investigate signs of deviant childhood behaviour, underpinned by the over-riding concern that widespread anti-social or deviant behaviour could lead to societal breakdown. Current developments in policy suggest that children 'at risk' of mental health problems, offending, and school failure need to be identified early (Sure Start DfES, 1998, Quality Protects DoH, 1998; Every Child Matters, DfES, 2003; National Service Framework DoH, 2004). Preventative projects hope to identify 'at risk' children, and work with the children and their families to help avoid later problems. But is this a constructive way for services to proceed? Or, is it an example of social control? This chapter will focus on current conceptualisations of ADHD, drawing on the well established 'thesis of medicalisation' and critiques thereof to draw attention to the tensions which exist

between differing perspectives of the condition, the advantages and disadvantages of gaining a diagnosis, and the 'care' and 'control' of children and young people.

ADHD is a medical category, underpinned by scientific research but the concept of ADHD is both socially and culturally embedded. ADHD is a social construct, in as much as the meaning of the concept arises from the interaction between individuals and social structures, it does not exist *per se*. The concept of what is and what is not a disease or illness condition is subject to change over time, take for example the medicalisation of alcohol addiction or life-events such as birth and death. Medical sociologists have drawn attention to the negative connotations of medicalisation, but there are occasions where gaining medical recognition can be constructive; legitimisation of experience can have both real and symbolic benefits. There are, however, wider social consequences to having an illness, mental health problem, disability or special educational need - it can be a stigmatising label for life, which can lead to discrimination or inequality.

The concept of bio-psycho-social medicine, a more inclusive model which tends not to focus on purely biological factors, is believed to be a more holistic way of practising medicine, yet critics regard it as all-encompassing, and further evidence of medical expansion (Armstrong, 1983). Bio-psycho-social medicine can cover all aspects of life, including when there is no physical or measurable condition. When controversy exists regarding a condition's status as an illness, this may indicate 'incomplete medicalisation' (Broom and Woodward, 1996:362). The emergence of ADHD has brought to the fore professional differences which exist between health, education and social services in terms of ethos, policy and practice. Educational

and social workers are being asked to accept that biological factors may play a part in emotional and behavioural disorders and learning difficulties, whilst some medical professionals need encouragement to acknowledge the cultural and environmental influences on both the emergence of the concept, and the way in which behaviour is manifested. The approach I have taken in this thesis accepts that there is an *underlying reality to the experience* of children and young people but acknowledges that what has become known as ‘ADHD’ is *socially constructed*. Indeed, Cooper contends that debates about the ‘reality’ of ADHD are ‘deeply rooted in value positions’ (Cooper, 1997:3). Recent government initiatives such as the Sure Start initiative (1998), the Green paper ‘Every Child Matters’ (2003) and the National Service Framework for Children (2004) appear to recognise the need for a coherent, inclusive approach to meeting the needs of children hence the introduction of policy which aims to bring together professionals from a variety of disciplines. Constraints to working in partnership may exist at a political, institutional and individual level.

Critics of the ‘medicalisation thesis’ object to the passivity with which patients are portrayed; lay concepts of health and illness and behaviour are often complex, but can be overlooked (Williams and Calnan, 1996; Williams, 2001). Furthermore, more recently, the ‘health consumer model’ calls claims of increasing medicalisation into question, emphasising the active role which knowledgeable patients are now playing, sometimes resulting in a willingness to challenge medical authority (Haug, 1988). In order to fully comprehend the phenomena of ADHD it is vital that the perspectives of young people and their parents are considered.

## **The genealogy of ADHD**

ADHD is not a new disorder, but the name by which it is known has changed often since it was first described in 1902, by George Still in an article in *The Lancet*. Still noticed that a sub-group of his paediatric patients had poor control of inhibition, more aggression, were restless, fidgety and destructive. These symptoms were attributed to a biological cause (Green, 1995; Munden and Arcelus, 1999; Holowenko, 1999). During the 1950's and 1960's the term Minimal Brain Dysfunction was applied to this group of children, implying that the underlying cause to their difficulties was biological. Also during this time 'hyperkinesis' or 'hyperactivity' was first described. The American Psychiatric Association first referred to 'Attention Deficit Disorder' in the Diagnostic and Statistical Manual of Mental Disorders III (DSM III), in 1980. In DSMIII-R and DSMIV the diagnosis has since been revised. Barkley (1996) amongst others, argues that as lack of inhibitory control appears to be at the centre of the problem, the term should once again be changed to Behavioural Inhibition Disorder.

The most recent edition of the DSM, DSM IV, provides a list of characteristics of ADHD, nine of which relate to inattention and nine to hyperactivity/impulsivity. For a diagnosis to be made, at least six of these must have been present for at least six months, impairing the child's behaviour across school, home and social settings, and these symptoms must have appeared before the age of seven. It is important to list the eighteen characteristics, in order to demonstrate how many can be part of everyone's behaviour and how broad, and culturally-bound the definition is:

**ADHD Criteria from the Diagnostic and Statistical Manual of Mental Disorders, American Psychiatric Association, 1994.**

*Inattention*

- (a) often fails to give close attention to details or makes careless mistakes in schoolwork, work or other activities
- (b) often has difficulty sustaining attention in tasks or play activities
- (c) often does not seem to listen when spoken to directly
- (d) often does not follow through on instructions and fails to finish schoolwork, chores, or duties in the workplace (not due to oppositional behaviour or failure to understand instructions)
- (e) often has difficulty organising tasks and activities
- (f) often avoids, dislikes, or is reluctant to engage in tasks that require sustained mental effort (such as schoolwork or homework)
- (g) often loses things necessary for tasks or activities (e.g. toys, school assignments, pencils, books, or tools)
- (h) is often easily distracted by extraneous stimuli
- (i) is often forgetful in daily activities

*Hyperactivity*

- (a) often fidgets with hands or feet or squirms in seat
- (b) often leaves seat in classroom or in other situation in which remaining seated is expected
- (c) often runs about or climbs excessively in situations in which it is inappropriate (in adolescents or adults, may be limited to subjective feelings of restlessness)
- (d) often has difficulty playing or engaging in leisure activities quietly
- (e) is often 'on the go' or often acts as if 'driven by a motor'
- (f) often talks excessively

*Impulsivity*

- (g) often blurts out answers before questions have been completed
  - (h) often has difficulty awaiting turn
  - (i) often interrupts or intrudes on others (e.g. butts into conversations or games)
- (American Psychiatric Association, 1994, pp83-84)

Within the broad category of ADHD there are three sub-types: ADHD 'predominantly inattentive type', ADHD 'predominantly hyperactive/impulsive type' and ADHD 'combined type'. The first of these has only become included since the publication of DSM III (1980), which recognised that children and adults can have the symptoms of ADHD even when hyperactivity is less prominent or non-existent. Clearly, this has potentially broadened the boundaries of the condition

to incorporate more children.<sup>1</sup> The use of the word ‘often’ in the above criteria leaves the diagnostic decision open to interpretation, and seems to need defining more clearly, as what counts as ‘often’ is subjectively decided. DSMIV classifications are not a-theoretical and value free; both DSMIV and ICD-10 are contemporary cultural documents, although this is rarely acknowledged (Summerfield, 2002). This is particularly significant for children, who find themselves under surveillance, scrutiny and assessment. Moreover, the criteria appear to be very culturally specific, as ‘often on the go’ or ‘often talks excessively’ would actually be advantageous to, say, a majority-world child working as a street seller. It seems that the problematization of certain behaviour exhibited by children and young people is strongly related to the social construction of both childhood and deviant behaviour in our society.

Moreover, there is no specific diagnostic test for ADHD; assessment is made by obtaining a full case history, a complete physical examination (including measures of height, weight, blood pressure, testing of fine and gross motor skills), observing the child’s behaviour, by gathering information from parents and school - both verbally and in the form of rating scales - and by considering other explanations for concerning behaviour, particularly as ADHD can be difficult to distinguish from other related disorders. The condition has a high rate of co-morbidity with other psychiatric and developmental disorders and learning disabilities, such as Autistic Spectrum Disorders, Gilles de la Tourettes Syndrome, dyspraxia, dyslexia, anxiety,

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<sup>1</sup> Each of these categories is incorporated within the term ‘ADHD’ in this thesis, as of the seven children who took part in research interviews only one was considered to have no signs of hyperactivity.

depression, Conduct disorder, and Oppositional defiant disorder (Gillberg et al, 1983; Barkley, 1990).

Psychiatrists, psychologists and paediatricians are supported by the National Institute for Clinical Excellence Guidelines (2001), their own professional guidelines, and DSMIV in assessing children and young people. Careful assessment is of paramount importance. The associated behaviours must be apparent across different settings, and be perceived by medical professionals to have a negative affect upon children's lives in order for a diagnosis of ADHD to be considered. In the UK, this is the work of child psychiatrists, paediatricians and psychologists. The question arises as to whether the criteria can be consistently applied by trained clinicians. Might variations occur according to the context of the behaviour and the subjective opinion of the doctor? How certain can clinicians be that the diagnosis is both accurate and appropriate?

Having outlined the process involved in diagnosing ADHD, this section moves on to demonstrate how the adoption of the particular reference point of 'the medical model' has led to children's emotional and behavioural difficulties being regarded as a medical issue, not a social one. The 'medicalisation of life', a concept introduced by Illich (1975), involves 'defining a problem in medical terms, using medical language to describe a problem, adopting a medical framework to understand a problem, or using a medical intervention to "treat" it' (Conrad, 1992:211). Many of life's normal processes can be medicalised and it has become common for new diseases to be created, particularly in the field of psychiatry. In the case of ADHD there is widespread acceptance of the concept by the scientific

community, despite evidence of an organic cause being largely inconclusive and ambiguous.

Concerns about the appropriateness of medicalising children's behaviour have been raised and the 'reality' and validity of ADHD is often contested by those who are ideologically opposed to the medical definition (Cooper, 1997). The orthodox position on ADHD explains the condition in medical terms, within a medical frame of reference. In order to explain what this means, a definition of the 'biomedical model', widely referred to by those outside the medical profession, is offered:

In terms of medicine, the medical model appears to be a professional orientation which is highly focused on pathology, not normalcy, on sickness, not wellbeing, on the nature and aetiology of the presenting problem itself, not on the individual who has the problem, on dealing with the specific pathology in a centred way, not on the social or ecosystem which surrounds the problem, that is, the patient, his or her family, social and financial circumstances, values and attitudes. (Bailey, 1998:49)

Medicalisation critics have various starting points, but tend to raise similar issues. Critiques of the aspect of social control inherent in medicalisation first emerged in the 1970's (Freidson, 1970; Zola, 1972; Illich, 1976). Zola drew attention to the way in which society's faith in science and reliance on medical experts has led to increased medicalisation. An assumption is made that medicine is 'morally neutral and objective', yet medical practice and decision-making is often based on values, and affected by social, cultural and political forces (Mishler, 1989). The role played by this high status professional group has been called into question by Freidson (1970), who recounts how medicine's increased monopolisation and professional dominance has given it jurisdiction over any state which might qualify as 'health' or 'illness'.

Conrad (1992) examines the different aspects of medicalisation, and maintains that it can take place on three levels: at a conceptual level, where medical vocabulary is used to define a problem; at an institutional level, where a medical approach is adopted by organisations in order to deal with a problem; and at an interactional level, whereby physicians define a problem as medical, give a diagnosis, and provide treatment. In addition, the medical profession is regarded as authoritarian and reductionist in approach; patients are expected to be relatively passive and compliant.

Medicalisation becomes of concern to the wider public when the medical profession is perceived to be exercising social control, via the extension of their remit to areas of life which may previously have been considered social issues. Strong (1979a) draws attention to the role played by a variety of agencies in the discovery and growth of such problems. Lay people can become reliant on professionals and their products, and begin to make demands (Illich, 1975). The term 'medicalisation' is used pejoratively to problematise the medical inclusion of deviant behaviour according to Lupton, as 'to be medicalised is never a desirable state of being' (Lupton, 1997:96). The biomedical model has been criticised for objectifying patients and leaving them disempowered, yet it has been argued that the biomedical model no longer exists in this 'pure' form (Strong, 1979; Williams, 2001), that there have been changes in biomedicine which have not been taken into account by medical sociologists. To be granted a medical diagnosis can also have positive benefits, as will be discussed in later chapters.

Turner (1984;1987) argues that medicine has replaced religion as the dominant moral ideology and social control institution in modern societies. Behaviours which were historically once defined as sinful, and later criminal, are now regarded as evidence of illness. The medical model lifts 'moral condemnation from the individual' (Zola, 1972:490), so that illness or conditions are no longer regarded as evidence of personal failure. However, patients who do not comply with doctors orders can be perceived as irresponsible, and even undeserving of help. Both natural life processes and deviant behaviour have become medicalised. For example, child birth (Ehrenreich and English, 1979; Martin, 1987), menstruation (Laws, 1985), and the menopause are life events which are now the concern of medicine. Similarly, behaviour which may once have been considered deviant is now granted a medical label, such as alcoholism and hyperactivity. Conrad and Schneider (1985) note how hyperactivity, which was once regarded as 'badness' gradually became reconceptualised as 'sickness'. Pawluch (1983), cited in Conrad (1992), notes how the success of public health measures led to improved child health, and ultimately less work for paediatricians. Their traditional territory was expanded with the inclusion of children's troublesome behaviour, which led to the medicalisation of children's psychosocial problems, such as hyperactivity. Halpern (1990) however, contests this claim, arguing that dissatisfaction with the previously routinized nature of paediatric work led to institutional changes, and the changes were not market led. The above examples serve to reinforce that medicine is not an objective enterprise; medical practice acts to reinforce gender, class, ethnicity, and sexual inequalities by promoting a well-defined notion of 'health' and 'normality'.

Those (children) who fall outside the concept of 'normal' and 'healthy' are in danger of being categorised, but on what basis is this categorisation made?

### **Causal 'evidence' of ADHD**

According to critics of the concept of ADHD it has an ill-defined aetiology, as after over thirty years of intense research it is still not possible to categorically assert that ADHD has a biological basis (McCubbin and Cohen, 1999; Baldwin, 2000). No specific gene has been identified as contributing to ADHD, and the 'biochemical abnormality' referred to by proponents is still unknown. Baldwin (2000) asserts, 'Belief in the biopsychiatric perspective by prescribers is a matter of faith, not based on scientific evidence' (2000:456).

Scientific research falls into the categories of cognitive, neuroimaging and genetic, and psychological. Much neurobiological research focuses on genetic and intergenerational family transmission (Biederman et al, 1986; Cantwell, 1975). In Biederman et al's study, ADHD appeared in 31.5% of first-degree relatives of ADHD male children and adolescents, compared to occurring in 5.7% of the relatives of a control group. In studies comparing twins, (Goodman and Stevenson, 1989) and of adopted children (Barkley, 1998a) findings have been suggestive of a genetic link. Hill goes even further when he says 'Genetic studies have established beyond doubt that the components of hyperactivity disorders are inherited and powerfully so' (Hill, 1998:382). Statements such as this have far wider implications when considered in the light of the current emphasis on 'mapping' human genes; it may lead to the suggestion that certain genes should be eliminated,

such as those linked to being 'criminal, 'gay' or 'disabled' (Shakespeare, 1995; Steinberg, 1997).

The implications of genetic research findings on family links are enormous; firstly, if ADHD affects so many of the population, can it really be labelled a disorder? Secondly, the current emphasis on treating individual children must be regarded as mistaken, and a more family systemic approach adopted. Perhaps most importantly, it should be noted that by applying the ADHD illness label to children, the issue is depoliticised:

'By locating the source and the treatment of problems in an individual, other levels of intervention are effectively closed. By the very acceptance of a specific behaviour as an 'illness' and the definition of illness as an undesirable state, the issue becomes not whether to deal with a particular problem, but *how* and *when*.' (Zola, 1972: 500).

If a certain 'problem' appears to be affecting significant numbers of the population, an investigation of socio-economic, cultural and structural factors may provide a wider answer to the issue than a medical diagnosis. However, once the problem is indicated to be within the individual, and treated at an individual level, no further thought is given to how definitions of conditions are constructed within the most dominant available frame of reference, that of medicine. The problem is effectively removed from the public arena and placed in the private realm.

The difference in prevalence rates for ADHD between the US and Britain has been explained variously. It is likely that the use of different diagnostic criteria is largely responsible for the gap (Prendergast et al, 1988; Tannock, 1998). The International Classification of Diseases (ICD-10), published by the World Health Organisation

(1990) has tended to be used in assessment in Europe. It is broadly similar to DSMIV but focuses on hyperactivity rather than inattention, and requires that pervasiveness and persistence are evident, in that behaviours being manifest in just one situation do not constitute grounds for diagnosis (British Psychological Society,1996). Rates of prevalence using ICD-10 are lower as only severely affected children are included; DSM IV has been criticised for being very inclusive (BPS, 1996). It is this difference in classificatory systems which, in part, has led to the disparity in rates of diagnosis; in the UK, as more practitioners adopt the DSM IV criteria, the rates of diagnosis appear to be rising.

It is felt by some that the focus on hyperactivity has been detrimental to some children and young people, who may be experiencing many of the other symptoms of ADHD but remain outside the diagnostic category because they do not have or have grown out of hyperactivity (Kewley, 1997;1999). Kewley (1997) claims that the condition is under-diagnosed and under-treated in the UK. It has also been suggested that UK prevalence rates may be lower because diagnosis remains in the hands of specialists, such as psychiatrists and paediatricians. Additionally, the variation in rates of diagnosis according to region within the UK has been attributed to the search for a diagnosis being akin to a 'postcode lottery'. In other words, the outcome of a consultation may be dependent on where the client lives, which medical professional they see, under which health authority, and whether ADHD is part of usual diagnostic practice. (This was strongly felt to be the case amongst parents and professionals attending the ADDISS (Attention Deficit Disorder Information Services) annual conference in 2000 and 2001). Since the introduction of the National Institute for Clinical Excellence guidelines (2000)

sanctioning the use of medication in children aged six or over clinics are no longer in a position to claim that they do not recognise ADHD.

Prevalence rates for any psychiatric disorder cannot be accurately determined (Barkley, 1990), but in the US five and ten-fold variations from one county to the next are not uncommon (Rappley, Gardiner, and Jetton, 1995; Rees, 1998). Rates of diagnosis also vary in terms of ethnicity and gender. Interestingly, in the US white children are twice as likely to receive a diagnosis of ADHD than Hispanic and black children (Gottlieb, 2002:1296). In a large UK city Minnis et al (2003) found few South Asian families being referred to psychiatric services in a large UK city, yet once referred, a larger proportion of children were diagnosed and treated for ADHD compared to the general population of children. Further research by Minnis and her colleagues is continuing to examine family expectations regarding emotional and behavioural difficulties, considering whether South Asian families have a different conceptualisation of such difficulties. Clearly this is an important area which has so far been under-explored in both the US and UK.

In terms of gender differences ADHD is said to occur in 2-5% of school aged children in England and Wales (National Institute for Clinical Excellence, 2000), with boys outnumbering girls by at least 3:1 (Tannock, 1998) along the whole spectrum of the normal range of intellectual development (Barkley, 1995). Many more girls are being identified as 'predominantly inattentive', but it has been argued that girls with ADHD may suffer in silence; stereotypical female traits may seem emphasised but acceptable in girls with ADHD inattentive type, which is in keeping with gender role expectations and historical and contemporary examples of

women being more readily categorised as mentally ill (Ehrenreich and English, 1979; Russell, 1995) 'Passivity, docility, day-dreaminess and muddle-headedness are traits that society historically assigned to the 'fairer sex''(Cooper and Ideus, 1996:76). Rates of ADHD diagnosis may have risen in the UK as practitioners have become more aware of the condition, less sceptical, increased their knowledge, and gained in confidence when faced with 'evidence' of improved behaviour and relationships in the lives of their young clients post-diagnosis and treatment. Yet the rise in rates of diagnosis is causing concern amongst health, education and social care practitioners and the general public.

### **Why is ADHD of concern?**

Children who have hyperactive behaviour constitute a large proportion of clinical referrals in the UK and the US (Barkley et al, 1992; Taylor, 1987; Holowenko, 1999). ADHD may cause difficulties with development, behaviour and performance, family relationships and social interaction. Often there is a discrepancy between intelligence and performance in certain areas, which can lead to a learning difficulty being identified. For example, some children may be able to verbally express themselves and demonstrate intellectual ability but have difficulty in reading or writing, partly because of difficulty in concentrating or focusing. They can, therefore, appear lazy or disinterested, which draws them to the attention of teachers. 'School severely reduces the opportunities for avoidance of situations where children's social and behavioural difficulties are publicly exposed' (BPS, 2000:26). With an increased emphasis on written evidence of learning in the form of SATS (Standard Assessment Tests) and on-going assessment since the introduction of the National Curriculum, these children can begin to have

difficulties at school. '[...] young people who, for whatever reason, are unable to conform to these expectations are therefore increasingly worried about, pathologised, and interventions designed to remediate their behaviour' (Prior, 1997:18). The combination of poor performance and a poor relationship with teachers may lead to low self-esteem and a feeling of failure, which can be the beginning of a downward spiral towards social and emotional problems. (British Psychological Society 1996; Barkley, 1998).

However, it has to be said that 'there is certainly no inevitability of a negative outcome', as 'outcomes are greatly influenced by the mediating variables of school and family environments' (British Psychological Society, 1996:37). The importance of social and psychological influences on the ways in which being attributed with the diagnosis plays out should not be underestimated, as 'psychosocial factors make an important contribution to the development and prognosis of the behavioural and interpersonal problems of children with hyperactivity' (Woodward, Taylor and Dowdney, 1998:161).

ADHD is frequently misunderstood, with children and parents often blamed for the behaviours. Prior (1997), citing Taylor's (1995) research into attachment disturbances, notes that hyperactive behaviours appear to be more prevalent in families where there is a high degree of disharmony (Taylor, 1995). Taylor et al (1991) found that dysfunctional family relationships did not cause primary hyperactivity but they were relevant in maintaining it which seems to suggest that the way in which mechanisms interact to determine behaviour does need further exploration (Rutter, 1995). These studies point to the need for a comprehensive and

multi-modal assessment of children with behavioural difficulties; overactive or restless behaviour can be exhibited by children who are attempting to adapt to their environment, such as children who have witnessed domestic violence (Vetere and Cooper, 2003). In the case of looked after children who have had numerous placements such behaviour can be regarded as functional (Crittenden, 2002). Research which examines the possibility of family causation generally finds that family and social influences may exacerbate the behaviour associated with ADHD but do not significantly contribute to the occurrence of symptoms (Wodrich, 1994).

Everett and Volgy Everett (1999), who practice as family therapists, emphasise how the presence of ADHD shapes familial interaction. In their experience, the child with ADHD can become the family 'scapegoat', and be blamed as the source of all family conflict. Dealing with behaviour such as constant chatter, noisiness, sleeplessness, arguments with siblings, destruction of personal or valuable items (usually the child does not think they are destroying anything, they were simply taking the video apart to see how it worked) can put a real strain on family relationships, but blaming everything on the child is not the solution, and will certainly help to decrease the child's self-esteem.

Woodward et al (1998) state that parent training can improve the behaviour of hyperactive children, by encouraging proactive and authoritative child management techniques, rather than negative, commanding and controlling styles of parenting. They perceive the problematic behaviours of hyperactive children as possibly presenting 'additional challenges for parents that influence their ability to parent effectively and may well further contribute to the persistence and worsening of

hyperactive behaviour problems' (Woodward et al, 1998). Nigg and Hinshaw's (1998) research also examined the role of parents, focusing on parent 'personality traits' and their association with anti-social behaviours in children with ADHD. Understanding the 'cause' of ADHD is believed to be of importance because for as long as the dominant approach is to accept an underlying biological cause the solution sought will tend to be narrowly focused on medical diagnosis and treatment.

Tensions arise as to whether a diagnosis of ADHD gives a child a stigmatising label for life or, whether such a diagnosis enables access to resources and provides a way of understanding. Could failure to identify and treat a child's difficulties be denying them effective health care? In a recent court case in the US, a Department of Social Services filed child abuse charges against a couple who refused to give their seven year old son medication for ADHD (<http://www.santa.inuk.com> 26.2.03). There are also reported cases of schools refusing to allow young people into lessons or examinations unless they have taken medication. Both of these real-life situations raise important questions in relation to the rights of children and young people in decision-making around the issue of their health and well-being.

In addition to these issues, there is concern that once children are given a psychiatric label, they may become stigmatised, and more likely to stay within the mental health system, with the possibility of receiving further diagnoses or being re-diagnosed once they are an adult psychiatric patient. This is a substantiated fear, as psychiatrists in the adult mental health service have, as yet, little experience of dealing with individuals with ADHD. As ADHD diagnosis is a fairly recent

phenomena in the UK the first 'generation' of patients are now moving onto adult mental health services; it remains to be seen how they are 'treated'.

It is widely recognised that any psychiatric label can lead to children feeling stigmatised; being 'different' becomes apparent to others and children may feel ashamed or embarrassed. Such processes have an influence on children's self-identity and attention will be drawn to the importance of this in later chapters. Proponents of the diagnosis argue that children's difficulties are being recognised, and their rights are being promoted, but should it be necessary for children to be labelled with a mental disorder, or developmental disability, before they can gain access to resources?

The long term political implications of this fine balance between assuring individual rights through labelling and possible political exploitation through labelling has never been fully addressed in ADHD discourse to date (Ideus, 1995:90).

It was once thought that children tended to grow out of ADHD as they became adults, but much research now indicates that this is not always the case. Hellgren (1993) et al followed up 101 children, some of whom were originally diagnosed with DAMP (Deficits in Attention, Motor Control and Perception - this diagnosis is often used in Scandinavian countries) at age 6 or 7, when they were 16 or 17. This was a population based study of 56 children diagnosed with and 45 without. The research focused on the outcome of deficits in attention, motor control and perception for general health in adolescence. The findings indicated a significant excess of fractures and other accidents, and substance abuse, in the DAMP group compared to the control group, plus more motor co-ordination, clumsiness, height and weight problems. For example, 14 of the 56 DAMP group had had accidents

and hospital admissions, whilst only 2 of the 45 control group had. Severe substance abuse was on a ratio of 8:1 (DAMP:control). It is important to stress that my research does not imply that the outcome for children and young people with ADHD is inevitably negative, as mediating environments of school and family have a huge influence on how the disorder is played out. Nevertheless, the issues raised in Hellgren et al's study are pertinent to the experiences of some of the young people included in this study.

### **The 'Treatment of Choice': Methylphenidate**

The main reason for heightened public and professional concern about ADHD has been the rapid rise in the rate of prescription for the most often selected form of treatment, which is Methylphenidate, more commonly known as Ritalin, Equasym, or Concerta. In 1994, prescriptions in the UK numbered 6,000, whereas in 1999 this number had risen to 131,000 (Baldwin, 2000:453). The treatment is a psycho-stimulant medication, licensed for the treatment of children of 6 years old and above in the UK; it is not without side-effects in some children. The question which is often asked is 'Why this dramatic increase?' Some critics link the rise in diagnosed cases of ADHD to the pharmaceutical revolution (Conrad, 1992) which has taken place, and the vested interest of pharmaceutical companies in promoting their products for use in childhood psychiatric behaviour problems (Breggin, 2001). Baldwin and Anderson (2000) draw attention to the rise in prescriptions for Methylphenidate reflecting a 'concerted effort by pharmaceutical companies to expand the market base' (Department of Health, 1998) and this expansion is linked directly to drug company financial incentives and marketing strategies. Wacjman (1991) reminds us that the development of technologies is never neutral; in this

case, the pharmaceutical industry that promotes stimulant treatment is a multi-million dollar industry and has very close links with various US government departments.

A vast amount of research has been carried out into the efficacy and safety of Methlyphenidate (MPH); over 1000 references claim that it 'undoubtedly improves cognition, overactive behaviour, and impulsiveness, effects most obvious in structured, cognitively demanding settings' (Hill, 1998:384). It has been used in the treatment of hyperactivity for over half a century, and whilst it is chemically related to the amphetamines, the low doses at which it is prescribed have a less potent effect on the central nervous system (Barkley, 1990). Five to ten milligrammes taken orally two, possibly three, times per day can lead to decreased hyperactivity, decreased impulsiveness, increased attention span, and more controlled motor activity. In turn, more acceptable behaviour can lead to positive social reactions and relationships. If this is the case, why worry about the children who are taking it?

Concerns arise on many levels: firstly, there are side-effects and adverse drug reactions associated with taking MPH. Novartis, the pharmaceutical company which makes Ritalin, note in their booklet, *'ADHD: Guide to Parents and Guardians'*:

'As with all medicines, the use of Ritalin is associated with a number of unwanted side effects and all children who take Ritalin must have regular check ups. During therapy, the most commonly noted side effects are insomnia, loss of appetite and feelings of nervousness. Occasionally, children may also suffer from unwanted headaches, drowsiness, dizziness or blurred vision.' (Novartis, 2001).

Not all children will experience side effects, but some do, and the solution tends to be to either alter the amount or timing of the dose, or to switch to another medication. In some instances medication is stopped. It is estimated that two thirds of children respond to treatment (Barkley, 1995) and often short term improvement in aggressiveness and impulsivity is observed, but the National Institute of Health stated in 1998 that 'there is no information on long-term treatment' (NIH, 1998). This lack of information regarding the positive long term effects and possible side-effects is of concern. Critics claim that the effect on the central nervous system is considerable; MPH often has 'toxic main effects that suppress spontaneous and social behaviour, with over-focusing on rote activity or a progression toward compulsive and perseverative behaviours. [...] paradoxically, the supposedly desirable behavioural effects (including passivity, attention, reduced spontaneity) *are the primary toxic effects of psychostimulants.*' (Baldwin, 2000:457). Moreover, evidence suggests that 'Withdrawal from the drug commonly leads to rebound nervousness and irritability, exacerbating the very behaviours for which the drug was originally prescribed (Scahill and Lynch, 1994; Whalen and Henker, 1997, cited in McCubbin and Cohen, 1999).

Further concerns include the possibility of addiction to Methylphenidate; this leads parents and advocates to stress that young people need to be persuaded to take their medication, they are not crying out for it. In terms of tolerance, as children grow and put on weight the initial dose may need to be increased in order to remain effective. In addition, Breggin (1998), a long-standing critic of psychiatrists' over-use of medication, claims that in time brain biochemistry actively counteracts

stimulant effects, leading to new complications. It seems that people with ADHD are more likely to use drugs such as alcohol, nicotine and particularly cannabis earlier in life than others without ADHD (Munden and Arcelus, 1999); this practice is sometimes referred to as 'self-medicating'. Biederman et al's (1999) study found that untreated ADHD was a significant risk factor for substance use disorder (SUD) in adolescence, and that there was an 85% reduction in risk for SUD in adolescents who were taking medication for ADHD. In contrast, claims are also made which indicate that young people are likely to 'progress' onto illegal drugs in order to obtain the same effect as from stimulants, or abuse stimulants and that the re-bounce effect is misunderstood (Alderson and Baldwin, 2000). Grave concern exists that research into the long-term effects of Methylphenidate is scant (McCubbin and Cohen, 1999; National Institute of Health, 1998).

In December 1999 the results of the National Institute of Mental Health's Multimodal Treatment Study for ADHD (The MTA Study) were made available. Across six sites around the US and a further site in Canada 96 children, of an average age of 8 years old, having ADHD combined type, were randomised to one of four treatment groups, making a total of 579 recruits. Of these four groups, one group received medication alone (MED) and were seen monthly for monitoring of health and medication. Another group were given a psychosocial treatment programme (BEH), which included parent training classes in behaviour management, child-focused therapy, school based intervention, and parent only training. The next group received a combination of MED and BEH, and the final group acted as a control in the community (CC). The study took place over 14 months.

The results of the study imply that medication alone and medication combined with intensive psychosocial treatment, including parent training were superior to both behavioural psychosocial treatment alone and community control treatment in reducing primary ADHD symptoms (Anastopoulos, 2000:7). The quality of medication management is very important. It is possible that monthly medication management sessions, which consisted of support and advice, monitoring of response and medication, and regular contact with teachers, 'boosted the effect of medication'. COMB (combined) showed advantages over medication alone, as it attended to the multiple learning, behavioural, emotional, social and family problems of children. Those parents who had been involved with the BEH or COMB therapy experienced significant reductions in negative or ineffective parenting practices. The MTA lends support to the advocating of multi-modal treatment programmes for children with ADHD and their families. In the case of COMB, medication preceded BEH, which may have influenced the overall outcome.

However, this study is said to have contained many conceptual and methodological weaknesses, which undermine its scientific validity. According to Breggin's (2003) critique drug treatment did continue for fourteen months, but behavioural treatment was stopped earlier, giving medication the advantage. Also, children were reported to have adverse drug reactions, but these were dismissed by the authors, and no attempt was made to ask the children about these experiences. Adverse drug reactions were actually recorded by teachers and parents, and some - such as loss of spontaneity, or apathy - were mistakenly regarded as improvements.

Breggin regards this study as scientifically unsound. Baldwin also finds it concerning that one of the research team had been provided with funding from six different pharmaceutical companies in the past, and therefore was not independent but had a vested interest in the success of medication as an intervention (Baldwin, 2000). Baldwin claims that the pharmaceutical industry has an interest in medicalising psycho-social problems and has funded such deeply flawed large-scale studies to argue the appropriateness of medication. Outspoken critics, such as Breggin, regard ADHD as a fraud/conspiracy, perpetuated by the pharmaceutical companies, in collaboration with the American Psychiatric Association and the well-known support group CHADD (Children and Adults with ADD).

### **Social implications of diagnosis**

The critiques discussed above which raise concern regarding the use of medication to treat emotional and behavioural problems are particularly interested in the wider political implications; medication, as the central intervention 'is both mechanistic and does not fundamentally challenge practices and procedures at either the individual or systemic level' (Prior, 1997:18). In other words, educational and family systems are not held to be responsible for difficulties in learning or behaviour, and the label of ADHD serves to homogenise difference, and reinforce the focus on individual deficit.

Within the essentially functionalist view adopted by proponents of the ADHD concept, society is perceived as 'given', and individuals are required to function and fit in. Therefore, identifying and treating the condition of ADHD is seen as protecting individual rights and promoting equality of opportunity. Barkley (1990)

and Goldstein and Goldstein (1990) believe that ADHD must be treated in order to allow individuals to comply with the demands of society; untreated they are at risk of long term social failure. Ideus (1995), however, puts forward a powerful case for a sociological analysis of the current situation regarding the concept of ADHD. She asserts that the emergence of the concept is related to 'implicitly held cultural assumptions' (1995:86) which help to define categories of mental illness. Ideus notes that the arbitrariness of ADHD is of particular concern to those who 'fear social or political oppression on the basis of yet one more biological variable in addition to those already historically used for exclusion (race/gender)' (Ideus, 1995:89). There is a need for all those involved to realise the social impact of the diagnosis.

While it is not culturally caused, as suggested in early sociological critiques, it is technically a pathology only in the problematic interaction between a culture's values, demands and expectations for individual demeanour or performance, and that individual's characteristics and abilities (Ideus, 1995: 86).

A further cause for concern is a lack of reporting of adverse drug reactions and side-effects. Children's reports of the above have been discounted (Baldwin, 2000) or ignored, or remain at the level of individual response to medication. As McCubbin and Cohen note, 'The published literature on children's subjective reactions to MPH is sparse'(1999:92). It is therefore difficult to say how many children do have adverse reactions, or experience side-effects, if such data is not collated and patterns identified. Such adverse drug reactions and side-effects can be considered as examples of iatrogenesis (Illich, 1975); these are risks to children's health and well-being brought about by medical intervention. However, there are also risks to children's well-being associated with not offering support when they are finding aspects of educational and social life challenging.

The mass of information with which parents of children diagnosed with ADHD need to become acquainted can be made more accessible by support or self-help groups, often made up of parents who have had to negotiate the health, education and social systems themselves, and been left with unanswered questions. Self-help groups have become established and knowledgeable and are valuable sources of support and information for concerned parents, especially in the early period after diagnosis. Cooper and Ideus (1995:104) claim that '[...] disability labels are no longer synonymous with stigma'; parent advocacy groups can help to empower parents, assisting them in having their child's medical, social and educational needs met. Such groups, however, cannot always be considered to be neutral, as some are actually part funded by donations from the pharmaceutical companies responsible for manufacturing the 'treatment of choice' for ADHD. For example, CHADD (Children and Adults with Attention Deficit Disorder), the largest and most politically active advocacy group, based in the United States, has a web site which reaches an audience world wide. Their fact sheets claim that 'between 70-80% of children with ADHD respond positively to psychostimulant medications', but there can be said to be an underlying political agenda to such claims, as this organisation was directly financed by CIBA-Geigy<sup>2</sup>, the pharmaceutical giant responsible for the manufacture of Methylphenidate (Ritalin), between 1989 and 1996, and in 1995 alone received a total of half a million dollars from drug companies (Breggin, 1998:234), which appears to compromise their representation of children and parents.

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<sup>2</sup> CIBA-Geigy, the manufacturer of Methylphenidate, became NOVARTIS after a \$27 billion merger with Sandoz in 1996.

In the UK, the NICE Guidelines (2000) recommend that clinicians adopt a conservative approach to the use of medication. Where ADHD behaviours are less severe, they advise using behaviour management, educational strategies, and the encouragement of self-instruction, eventually trying medication. Only in the more severe cases should medication be started before other interventions. However, it can be argued that only the more severe cases are making it through to the specialist services and a large number of cases of ADHD are both unrecognised and untreated in the UK (Kewley,1999). In the US with the changes resulting from managed care health insurance companies have been accused of encouraging families to opt for medication, which will be paid for, rather than therapy sessions, which can be more costly (Jensen, 2001). ‘Many children with ADHD confront a steady stream of frustrations and challenges during the week [...] which deeply affect the manner in which they come to view themselves’(1995:9). Therapeutic work which attempts to disrupt the cycle of repeated failures whilst supporting children to make positive behaviour changes, knowing that they are still accepted and valued as a person, is an effective way of working with young people. Self-esteem can be improved if children are encouraged to internalise these messages (Sabian, 1995). Although in the UK it is recognised that long term social, emotional and academic improvements will only come about through the development of self-control/regulation (using self-talk, an internal linguistic strategy, to inhibit), through focusing on resilience, and by helping children to learn social cues and problem-solving, the psychological therapies which teach such skills are not always used before, or indeed in conjunction with, medication. However, there appears to be an over-reliance on medication as treatment for ADHD and non-medical

interventions have been virtually non-existent in the UK (Baldwin, 2000; Baldwin and Anderson, 2000).

### **Validity and utility of the diagnosis.**

The classification of ADHD as a distinct disorder has been problematic, partly because several kinds of disorder are often present together (as mentioned above) and they interact in complex ways, and partly because the condition is regarded as a social construct. Rejection of the medical model, which individualised and marginalised children who displayed behavioural problems, was enshrined in law (Tomlinson, 1982) and 'Given the historical rivalries between the medical and educational professions (Norwich, 1990; Tomlinson, 1982) a tendency has developed amongst educationalists to be suspicious of medical explanations' (Cooper and Ideus, 1995;107) and children's difficulties tend to now be seen as the result of various social, psychological and environmental factors. However, there continue to be a 'range of syndromes, disorders and 'defects' that constitute the population of special educational needs students' (Slee, 2001). Indeed Lloyd and Norris (1999) specifically address the thorny issue of how parents' assertions that their child has the 'right' to be classified as having a medically defined disorder directly challenges the current social perspective on disability and the rejection of the medical model. The label of ADHD is said to put particular medical 'experts' in control and acts to exclude other discourses (Lloyd and Norris, 1999). Different professional cultures, bodies of knowledge, and prevailing ethos exist between medicine and education and the granting of a medical label puts the medical 'experts' in control. Concepts which conflict with the cultural values of teachers,

such as ADHD, are likely to be resisted and rigorously examined, before eventually being accepted, (Cooper and Ideus, 1995:110) perhaps to a degree.

There is a need to pay attention to the socially embedded nature of the phenomena of ADHD (Cooper and Ideus, 1995; McCubbin and Cohen, 1999). What is considered developmentally inappropriate for a child's age may vary cross-culturally, and ADHD can be said to be defined by cultural demands. As stated in the previous chapter, children grow and develop skills at different rates; Goldstein (2001) argues that children with ADHD behaviours seem to develop self-control skills later than children of a comparable age. For example, a child of 12 years old may have the social control skills of a child of 8 years old. This clearly points to the socially constructed nature of the concept, and it is not easy to transfer the concept to other cultures, who may hold alternative views about children and childhood, behaviour, and the role of medicine. Attention needs to focus on '[...] the inherent cultural foundations which have been rendered invisible in the American field...' (Ideus, 1995:91), culture must be acknowledged as central in conceptualising ADHD. On the other hand, studies coming from an educational perspective have been all too eager to discount the possibility of an underlying biological predisposition, and have focused solely on children's environmental and social circumstances. This 'unhelpful polarisation of views' does not contribute to our understanding of ADHD (Cooper, 1997;1999).

Traits associated with ADHD come to be seen as deviant and unacceptable within UK culture, where conformity, commitment and obedience are valued. ADHD characteristics imply resistance to societal norms and values, but by reframing

behaviours in a positive light, a different perspective can be gained. A child who is considered 'easily distracted' could be seen as having a 'high level of environmental awareness'. 'Deviating from the rest of the class' could indicate an independent and individualistic child; 'daydreamers' may actually be bored by the mundane tasks set by school (Hartmann, 1993). Crammond (1994), in a similar vein, perceives ADHD to be merely a different cognitive style. The 'symptoms' of ADHD can be seen as evidence of high creativity and a different way of thinking and working which should be of equal value to any other. Crammond also points out that the traits valued as creativity by American society are very similar to those regarded as pathology within the American Psychiatric Association diagnostic criteria, highlighting the problematic conceptualisation of ADHD as a form of mental illness (Crammond, 1994; Ideus, 1995).

The increased marketisation of education within the UK has led to less time being available firstly, for pupils' active participation in schooling and secondly, for building effective relationships between teachers and pupils (Vulliamy and Webb, 2000; Whitty, 1997; Rustique-Forrester, 2001; Meo and Parker, 2004). With an over reliance on conformity in the school setting the development of critical thinking may be somewhat suppressed (Skrtic, 1991). O'Regan and Cooper (2001) note that there are numerous ways that students with ADHD can be helped within school if school's are prepared to be flexible and use new strategies. Others argue that the kind of teaching practice which benefits children with ADHD is of benefit to all children. 'Grouping children into clusters encourages a more collaborative problem-solving approach, which is more seductive and inherently interesting for

any child, but especially so for the child with attentional problems' who finds a passive style of learning taxing (Starr, 1995:7).

Over time, the validity of the disorder has been questioned. Schrag and Divoky (1976) criticised the aspect of social control which appeared to be inherent in the medicalisation of children's behaviour. Ideus (1995) regards their work, *'The Myth of the Hyperactive Child and other means of child control'* as effectively polarising opinions of those interested in ADHD into two major camps, that of 'reductionism,' viewing ADHD as simply a medical disorder having secondary social implications, or 'idealism', founded on ideological resistance to the diagnosis itself. This parallels debates in medical sociology, where critics of medical imperialism have become accused of 'sociological imperialism' (Strong, 1979a; Williams, 2001). Social scientists have a vested interest in promoting a social view; within debates about the concept and validity of ADHD critics of the orthodox view also have their own agenda. Perhaps their case has been over-stated - are their claims to a privileged ideological position based on empirical evidence?

Cooper criticises environmental theories of causation, saying, '... we must face up to the role that biology plays in human make-up [...] biology is not destiny but we ignore its influence at our peril' (1997:12). Cooper also warns of the risk of rendering the concept of ADHD illegitimate if it is portrayed as a political ideological construct used to label and marginalise children. Fundamental divisions remain in much of the literature surrounding ADHD, with little allowance for a conceptualisation of ADHD as an interplay of both organic and social and cultural factors. Traditional medical research is criticised for seeking a single,

unitary cause instead of acknowledging that biology may be mediated by environment and culture (Cooper, 1997; Sonuga-Barke and Goldfoot, 1995; Woodward, Taylor and Dowdney, 1998) or indeed, in keeping with recent sociological imperatives, '[...] biology is not merely a "constant", rather it is in a state of considerable flux and indeterminacy, influenced in no small part by the sociocultural and material environment' (Williams and Bendelow, 1998:211).

The above debates confirm the need for professionals to 'address the overlapping issues of conceptualisation, identification, prevalence, intervention and prevention of these kinds of difficulties' (BPS, 1996:11). It is very easy for the children on whom the debates focus to become lost in territorial professional rivalry. Although such debates take place at a theoretical level, they have a pervasive influence on professionals, and such differences are evident in practice. Most importantly we need to ask: are children with emotional and behavioural difficulties' needs being met at present? Or would an amalgamation of perspectives, and an emphasis on collaborative working between the various services help to better meet such needs? How might a more bio-psycho-social conceptualisation benefit children?

### **Bio-psycho-social model: 'Joined-up' working**

Most models seek a unitary cause, located within the biological, neurological, and/or genetic substrate - that is, within the individual. [...] the emergence and manifestation of ADHD is likely to arise from multiple interacting factors that cannot be understood in isolation [...] ADHD is a paradigm for a true bio-psycho-social disorder, raising critical questions concerning the relationship between genetic, biological, and environmental factors (Tannock, 1998:65).

The development of a more biopsychosocial approach was promoted by Engel (1977) and has been regarded as positive by many (Cooper, 1997; Tannock, 1998)).

The narrow, biological, organic focus of medicine has been extended to incorporate social and psychological factors. Engel regards this as a new model, and claims it to be more of an holistic approach. Armstrong (1983) however, claims that biomedicine traditionally deals with threats from other disciplines by either marginalising or incorporating them; in the case of social science, although it was marginalised, psychiatry now wishes to incorporate it in order to survive. In this way, the dominance of the biological over the social is maintained. Other explanations for difficulties become regarded as different, yet compatible, rather than alternatives. In short, biopsychosocial medicine is said to be not a new model, but the old one with a gloss. It just encompasses even more areas of life, incorporates the social in order to prevent it being a threat, in effect defusing potential for criticism. Clinicians are then given licence to probe into social and emotional areas of life. Armstrong concludes by advocating that social science pursues a critical examination of biomedicine and its assumptions, and an analysis of new ways of conceptualising illness (1983:1218).

Goodman (1997), in an article entitled '*Who needs child psychiatrists?*' suggests that child psychiatrists have expanded into too many areas in a vain 'attempt to plug the gaps left by Education or Social Service cuts; he advocates that the profession should concentrate on their core medical knowledge and skills. In response to Goodman, Messent (1997) quite rightly points out that childhood problems are complex and overlapping, and not 'neat' or discrete; arguing in favour of multi-disciplinary, flexible teams, he says that such teams 'interconnect to produce a whole that is greater than the sum of it's parts'(1997:20), and Cottrell (1997) agrees that to maintain the skills to deal with complex cases, child

psychiatrists should not overly specialise. There is a danger that over-specialising child psychiatrists may become narrow in their view, and 'look for' their specialist condition in each case.

At present, services are delivered through complex organisational arrangements. As a result of contemporary Government rhetoric 'joined up' working is being encouraged, for which there is often agreement in principle but it is difficult for services to achieve, partly because other professions are suspicious of medicine's imperialist tendencies. It is crucial that the professionals involved are aware of their differing values and philosophies, and that they recognise that they can use their strengths in a complementary way of working. Such professional differences are difficult to manage, but can be very productive. In this study, data collected during fieldwork at a busy Midlands city Child and Adolescent Mental Health Service will highlight the precarious nature of collaborative working, both intra and inter-professionally.

An additional factor affecting support may be differences in the views of professionals and parents of a child's needs. Parents need to be able to challenge decisions in order to promote their child's best interest at times. It is often the case that families under the greatest pressure are the least likely to be able to negotiate with services (Sloper and Turner, 1992). In the case of education, parents may make demands for a Statement of Educational Need but there are finite resources; the more vocal and articulate parents may succeed in their request, but what about the others? In the case of dyslexia, Riddell et al (1992) note that middle class parents more often win additional support.

### **Medical diagnosis: resource or constraint?**

To be given a medical diagnosis of what has seemed for quite some time to be a previously inexplicable set of symptoms can be perceived as helpful. It assists in providing a frame of reference, an explanation, and legitimation. In general, labels can be regarded as unhelpful as they often imply that a value-judgement is being made, but the provision of a label or name can also be helpful in managing a problem. In the case of Autism there is recognition that early intervention gives children the best chance and that late diagnosis exacerbates their difficulties (Hornby et al, 1997). This appears to be the case with ADHD also; assessment should be focused on the individual needs of children as each child is different.

Broom and Woodward (1996) also perceive there to be benefits for patients to have their symptoms legitimated by a medical practitioner, but would argue that medical dominance is not desirable. Medicalising a condition can have a constructive outcome, 'humanity often benefits when some form of distress becomes defined as an illness and is incorporated into the orbit of medicine' (Broom and Woodward, 1996:359). The stigma associated with deviant behaviour can be lifted by the granting of a medical diagnosis; such behaviour becomes legitimised. Medical recognition can be regarded as a resource, not a constraint, to be wrestled from doctors who are sceptical as to the 'reality' of the illness. The quality of life of many people has been improved by medical intervention:

To deny the effectiveness of modern medical procedures such as coronary artery by-pass, renal dialysis, hip replacement, cataract surgery, blood transfusion, the pharmacology of pain relief and the routine control of physical symptoms in restoring or improving the quality of life for those suffering from chronic illness is to deny the

validity of the everyday experiences of the lay public in modern Britain. In stressing the limitations and costs of medical interventions the physical and social contributions of modern medicine are all too frequently ignored (Kelly and Field, 1994:36)

Western medicine does not necessarily detract from the health of individuals; there are numerous examples which can be brought forth in order to demonstrate that medical definition can be advantageous. Lupton (1997) claims that patients can be willing participants in medical dominance, and may actually seek medicalisation. A contemporary example is provided by Kohler-Reissman (1989), who claims that in women's struggle to gain control over their own bodies they have inadvertently strengthened the biomedical model, by seeking help from the medical profession. She points to the medicalisation of menstruation and the construction of premenstrual syndrome to illustrate the paradox; women's reproductive experiences have gained acknowledgement from medicine and been legitimated, whilst at the same time the myth of women being victims of their own biology has been reinforced. This results in gains and losses at the level of individuals, and at a wider macro level. This emphasises the Foucauldian perspective on medicalisation, where power relations in medicine can be collusive, positive and productive (Lupton, 1997). It could be argued that as parents have struggled to gain control over their children they have inadvertently strengthened the biomedical model, by seeking help from the medical profession. Whilst their experiences have been legitimated by the diagnosis of ADHD, the myth of biological reductionism may have been reinforced.

Nevertheless, medicine is difficult to challenge because of the 'competence gap' (Lupton, 1995) which exists, which can lead to patient dependency. Lay beliefs are

not valued, whilst knowledge held by the medical profession is deemed to be that of 'the experts'. This 'professional mystique' encourages public dependency on the profession, and leaves already subordinated social groups vulnerable to manipulation and control by this privileged occupational group (Turner, 1995).

We, the public, have been led to expect too much and have been more than willing partners in the process. We have come almost to believe in magic cures and the waving of wands. The reality is a constant disappointment (Kennedy, 1981:43)

Williams and Calnan (1996) reject the passivity with which patients are portrayed within the medicalisation thesis; '[...] there is a danger of exaggerating the hold which modern medicine has over contemporary experience' (Williams and Calnan, 1996:1611). They maintain that 'the structure of lay thought and perceptions of modern medicine is complex, subtle and sophisticated, and individuals are not simply passive consumers who are duped by medical ideology' (1996:1613). Patients actively engage with medical professionals to define illness, they may reject a diagnosis which they find unacceptable, and they tend to be more sceptical than those associated with the medicalisation thesis perhaps give them credit for. Although Strong's (1979b) study of doctor-parent interaction in a paediatric clinic reveals the specific strategies which doctors employed in order to retain control of the interaction, he also acknowledges that, on occasion, parents were able to negotiate and 'influence the course of action within consultations (1979b:128). Wider social, cultural and economic developments are beginning to undermine the power of the medical profession to define illness. Medical professionals are becoming forced to examine their practices, challenged by lay perspectives, consumerism, constructionism, expectations of society, and changes within the NHS. Yet the challenges to medicine are complex; rather than regarding doctors as

'losing' power to patients, it may be that a new form of medical encounter may be emerging (see Williams, 2003 for a fuller discussion of this issue).

In contemporary medical encounters patients are said to be health consumers, and in this scenario contingent reality emerges from interaction (Bury, 1997). Gabe and Lipshitz-Phillips (1984), in their investigation into patient's use of tranquillisers, also reject the over-generalisation of theories of medical social control, claiming that patients are not simply ideologically controlled victims of the medical profession. They reject the implication that patients passively accept all that doctors say, and suggest instead that patients have a dual consciousness whereby they partly accept and partly oppose dominant ideology. Cooper (1995) would agree; he sees parents shopping around for an acceptable intervention for their child's difficulties. If offered therapeutic work to address behavioural issues, they may choose to pursue a medical diagnosis, which might offer medication as a form of intervention. Cooper draws attention to who is making this consumer choice - parents, rather than children themselves -and in whose interest a medical diagnosis would be.

Cornwell (1984) explored how sub-cultures sometimes reject medical definitions, they have their own lay definitions of illness; they will evaluate the usefulness of a medical diagnosis but may reject medical authority and expertise. Lay concepts of health and illness have their own logic, integrity and complexity, which medics need to understand. They have an important influence on how people evaluate medical care and practice, and have a huge relevance on compliance with medical treatment (Wirsing and Sommerfeld, 1992; Conrad, 1985). In addition, there are

differences between public accounts of illness, in which conventional medical wisdom tends to be reproduced, and private accounts, which give meaning to experiences. An interesting interplay of scientific, medical ideas and those emanating from common-sense understandings, arise from empirical evidence which shows that complicated factors mediate people's experience of medicalisation. According to Williams, 'Lay people, in short, are not passive or active, dependent or autonomous, believers or sceptics. Rather they are a complex mixture of all these things '(2001:147).

A few studies have included the accounts of parents (Cooper, 1999) and individual parents have published accounts of their experience with their ADHD child (Fletcher, 1999; Douglas, 1999). More commonly, adult ADHD 'sufferers' make sense of their lives in hindsight, having received a diagnosis later in life, and some have their own website to dispense advice to others. Less frequently, children and young people themselves are asked about their lived experience. The lay perspective of children and parents is coming to be regarded as essential experiential evidence within social research into illness and disability (Shakespeare et al, 2000); it is crucial that these views are perceived to be as important of those of medical, educational and social work professionals in the ADHD debate. Otherwise medicine will be practised on the basis of assumptions made about the place of children in society, the relative passivity of their designated role, and the expectations which adults have of them, rather than on a body of knowledge which has been actively contributed to by children themselves.

It is important that we look at ADHD more closely because research has shown that it can affect people for life, and may predispose some to educational failure, school exclusion, broken relationships, Conduct Disorder, drug and alcohol abuse. Difficulties with peers and friendships can lead to rejection and isolation, which in turn may lead to the development of aggressive and anti-social behaviour and delinquency (Barkley et al, 1990). Many studies of outcome demonstrate that the symptoms of the original syndrome diminish in adolescence, but low self-esteem, poor school performance and poor peer relations continue to be a problem for children (Weiss and Hechtman, 1993). But is this a direct result of the condition, or a reflection of the ways in which this group of children are treated? Satterfield et al (1981) believe that there is evidence that early, prolonged, multiple intervention may prevent negative self-esteem.

## **Conclusion**

Taking as its starting point the controversial nature of the validity of ADHD, this chapter has explored the differing conceptual and theoretical notions which exist. 'Within child' determinist explanations of emotional and behavioural difficulties serve to focus attention on individual pathology, rather than on the culturally specific expectations of the social system. A medicalised perspective accepts that there is an underlying reality to the experience commonly labelled as ADHD. However, sociological accounts would argue that what we know as ADHD is also socially constructed in that disease categories are produced through social interaction and are in a constant state of revision. The development of a sociological perspective ensures that analysis is focused upon interaction between adults and children, children and their peers, and children and the educational and

family environments. The process by which children's behaviour becomes medicalised is seen to be greatly influenced by discourses of 'health', 'normality' and 'childhood'.

Chapters Five to Seven explore the lived reality of ADHD for young people and their parents, discovering the complex ways in which children and young people develop strategies to care for their own physical and emotional health and well-being and the meaning of the diagnosis of ADHD to them. In some areas of medical practice the medical profession are being challenged by other professions and by 'knowledgeable consumers' but, in the case of ADHD, the medical frame of reference appears to remain dominant. Are diverse professions able to come to a shared perspective and understanding which translates into practice without any one profession having imperialist tendencies? Inevitably, tensions and professional differences exist in the views held by health, education and social service practitioners, but it is essential that the professions work constructively together in order to best meet the needs of children and young people. Within the division of labour in child health care lay/professional, paid/unpaid, adult/child are all perceived as active participants. As has been shown, disparate views exist in the literature regarding ADHD and these are played out in professional practice, yet the British Psychological Society state:

We believe that it is possible for all those involved to work constructively together in responding to the concept of ADHD in a sensitive and sensible way (BPS, 1996:7).

## Chapter Four

### Methodological Choices

**[...] the mythology of ‘hygienic’ research with its accompanying mystification of the researcher and the researched as objective instruments of data production should be replaced by the recognition that personal involvement is more than dangerous bias - it is the condition under which people come to know each other and to admit others into their lives. (Oakley, 1981:58).**

#### Introduction

Having established the methodological and theoretical orientations of my research in the previous chapters, here I discuss the specific methods of enquiry used, the forms of analysis, and the research process. Traditional research accounts have placed great emphasis on research findings and not regarded the ‘messy’ process of doing research as worthy of discussion, but recently others argue that the process should be acknowledged as an integral part of the eventual outcome (Stanley and Wise, 1983; Cotterill and Letherby, 1993; Parker, 1998; Ribbens and Edwards, 1998; Letherby, 2003). By emphasising that knowledge and indeed research accounts are subjectively produced an insight can be provided into some of the theoretical, practical, ethical and methodological issues raised (Roberts, 1981). In this chapter a discussion of the methods adopted is followed with a broader exploration of my role as researcher which includes reflection on the embodied and interactional experience.

During the course of field work both primary and secondary source data were collected, falling into the categories of: in-depth interviews, drawings, observations, a quantitative survey and various documents associated with the diagnosis of ADHD. In addition, popular cultural representations of ADHD were also collected across the four years of the study, in order to allow reflection on the ways in which ADHD is portrayed in society. The study uses mainly qualitative methods of exploration, but the qualitative data have been complemented by the use of a small-scale quantitative survey. It has been argued that quantitative and qualitative methods represent competing and incompatible paradigms; according to Guba, 'we are dealing with an either-or proposition, in which one must pledge allegiance to one paradigm or the other; there is no compromise' (1985:80). Others acknowledge that qualitative and quantitative approaches can explore aspects of social life from different perspectives (Oakley, 1999) and that qualitative and quantitative methods are not mutually exclusive (Bryman, 1988). It is my belief that the combination of methods used in my research led to a more thorough understanding of the issue at hand;

As Burgess (1984a) notes, in ethnographic fieldwork, unlike other methods of research, it is the researchers who are at the heart of the research process, they are the key instrument of social investigation. There is a need to write the researcher into the research process as personal biography and the process of research are inextricably linked. Nurturing reciprocal relationships, and exchanging personal experiences with families, is far removed from the objective data-gathering of traditional mainstream social research (Hughes, 1988; Oakley, 1981; Miller, 1998). Sociological fieldwork is a political, ethical and moral endeavour and being open

about the process allows others to draw on the intricacies of my research experiences (Stanley and Wise, 1983; Letherby, 2003; Coffey, 1999)

This chapter first discusses the process of gaining access to a medical setting, which included satisfying the requirements of a Research Ethics Committee. The rationale behind the sample selection and the chosen methods are next discussed, with a detailed description of the methods of data collection which were used to ascertain the views of children. The latter part of the chapter moves on to explore some of the particular methodological and ethical issues which may arise in this kind of research; it becomes important to reflect on the research process and to recognise how researcher subjectivity is crucially bound up with the way a topic is approached.

### **The research setting: Gaining Access and familiarisation**

Securing access to a Child and Adolescent Mental Health Service (CAMHS) was not as difficult as I had anticipated. I selected the Service on the basis of information provided by parents who were using the support group which was local to this CAMHS. Located in a Midlands city, the overall client group was diverse, in terms of social class, ethnicity, disability, and age range. The sources of help available to children and young people experiencing mental health difficulties included psychiatric and psychological services, drama and art therapy, social skills, anger management, family therapy, occupational therapy, speech and language therapy, amongst others. Such services were provided by a range of professionally trained staff, some of whom had a medical background, and others whose training was grounded in the social sciences. The eclectic mix of

professional cultures at times led to heated debates over issues, but was overall perceived by myself to be productive.

The Consultant Clinical Child Psychologist, who was to act as my initial gatekeeper to the Child and Adolescent Mental Health Service, was extremely interested in the aims of the research, which were primarily to allow children and parents to speak of their experiences. Initially, I asked merely to be put in touch with families with a child with ADHD, but both the Consultant Clinical Child Psychologist and later, the Consultant Child and Adolescent Neuropsychiatrist, who acted as gatekeeper to the respondents, were keen to support the research, and agreed to provide access to their patients, resources and staff members. This was far more than I could have initially hoped for, providing the Research Ethics Committee approved of my proposal and informed consent was gained from parents and guardians.

As my gatekeepers, the consultants had their own agenda. They were engaged in battle with a rather rigid and inflexible health Trust, who did not encourage multi-disciplinary teamwork. The Consultants were introducing innovative practice without the support of the Trust. This could have proved problematic when applying for Research Ethics Committee approval. The Consultants expected the research to be of benefit to the clinic, and supportive of their aims in developing a protocol for practitioners assessing and treating children with ADHD. I was a little anxious that there might be a potential conflict of interests. Were they likely to want to examine, modify or censor any of my data (R. Lee, 1993) or the final report, before submission?

One of the most difficult parts of the research process was overcoming the hurdles of bureaucracy; the proposed research had to satisfy both a Research Ethics Committee and the NHS Trust's Research and Development Committee before approval could be granted. Research protocol guidance was provided by the Research Ethics Committee. Strongly based on a medical model of research, the expectation was that the rationale, hypothesis, objective and anticipated outcome were specified, and my proposal was written accordingly (Appendix I). The committee appeared to have little understanding or appreciation of the subtle nuances of qualitative enquiry and, with this in mind, it was necessary to write for an audience who were more attuned to positivistic methodology, and whose overriding concern was the safe-guarding of patients. It has been suggested that medical ethics' committees lack of familiarity with qualitative methods can lead them to assume that such research may not be rigorous (Darlington and Scott, 2002). The Committee needed to be satisfied that consent would be obtained from both patients and the health professionals involved. In the case of children, it is generally acceptable to obtain parents permission without consulting the child. As this research was theoretically and methodologically underpinned by the sociology of childhood perspective, I did not feel that this was appropriate and at all times obtained the verbal consent of the children involved. There was a frustrating lapse of time after submission as the committee only met every two months.

Once approval had been granted I was keen to begin fieldwork at the CAMHS, but my efforts were once again thwarted as I was informed that the study needed to also gain the approval of the Research and Development Committee of the NHS Trust.

Once the requirements of each were satisfied, I was issued with an Honorary Contract, which gave insurance cover and the fieldwork finally got under way in October 1999.

The period of involvement with the Child and Adolescent Mental Health Service (hereafter referred to as CAMHS) stretched from October 1999 to August 2001. I familiarised myself with the layout of the unit and the staff who worked there, some of whom I had already had contact with. The fieldwork began with a period of non-participant observation at the CAMHS. Parents had usually received notification of my presence in advance, in the form of a letter on CAMHS headed paper plus a Parent/Patient Information Sheet (Appendix II), in accordance with the instructions of the Ethics Committee. The Ethics Committee stipulated that I should be outside the room when the Consultant or doctor asked for the parents' consent for me to observe, so that they did not feel coerced into taking part in the research, and indeed this was adhered to for some weeks, but eventually I found that some parents were told 'I've got a student with me this morning, is it o.k. with you if she sits in?' which left me in an awkward position, not wishing to coerce them into allowing me to observe, but not wishing to appear pedantic with the clinic doctors. In Atkinson's research into medical students' exposure to the reality of clinical medicine, he notes that patients were not made aware of who he was and why he was present, which he also found ethically problematic (Atkinson, 1981).

Fifty five children's consultations were observed over a period of nine months. Some of these were new cases and others were follow-up appointments. In addition, I attended fortnightly team meetings, quarterly strategy meetings,

observation and social skills groups, and took part in in-house training. Watching, recording and analysing these sessions was extremely time-consuming, but vitally important for me to be able to become familiar with the sources of support on offer to children and the ways in which staff worked as a team. As time went on, my name was added to the circulation list for minutes of meetings and new information, I was invited to various staff leaving 'do's' and even the Christmas dinner/dance! Inevitably, being regarded as an 'insider' caused me to question the independence of my research identity, an issue which will be discussed in a later section.

The majority of consultations took place within a particular room; it was square with plain cream walls and an extremely high ceiling, located in the older part of the hospital. Light poured in through one window, the sill of which was at head height; four low chairs were arranged around a small square table, and a further broken chair was in the corner; occasionally paper and pens were provided for children to use. The doctor sat opposite the parent(s) and my location within the room was to the right of the doctor, and furthest away from the door. Notes were made throughout the consultation regarding the diagnostic process, lay/professional interaction, the actions of the children, plus my own reflections and emotional reactions to situations. Although the notes tended to be brief during observations, I took the advice of Lofland and Lofland (1995) and wrote extensive field journal notes each evening. The notes came into the categories identified by Hughes (1988) of observational, theoretical, methodological and personal. Observation was on-going throughout the fieldwork, particularly as the only 'symptoms' of ADHD are displayed through certain types of behaviour. Observational field notes

were kept at every stage in order to enhance the analysis. My attendance at consultations was my first contact with families, some of whom went on to complete a questionnaire to assist the research, and a small number of whom allowed me to enter their homes to talk in more depth about their experiences of ADHD.

### **Study Group Selection**

An 'opt-in' procedure was used to recruit both parents and children. If the outcome of the consultation was that ADHD was suspected, the purpose and aims of the research were explained, and parents asked to complete a questionnaire (Appendix III), returning it in the stamped addressed envelope provided. This allowed parents to make an active decision to become involved in the research. The questionnaire had been carefully designed to include some pre-determined questions, for ease of completion and analysis, and some open-ended questions, encouraging a more detailed response. The personal revelations contained in the latter part of the questionnaire, which asked about parents' hopes and concerns for the child's future, and suggestions as to how the Child and Adolescent Mental Health Service could be of more assistance, were quite surprising. Respondents were open and honest regarding their experiences, and reading some of the heartfelt pleas for help reduced me to tears on more than one occasion. It was touching that even those with limited literacy, who may have found the request for information difficult, gave in-depth, almost cathartic, accounts of their experiences. The similarity in experience was striking, and the questionnaires proved to be a powerful source of data.

Completed questionnaires were received, and individual families contacted by letter, asking them to telephone if they wished to take part in more in-depth interviews. I felt it important to get the child's informed consent, and had produced a small leaflet (sent out with the letter) which explained, in simple terms, who I was, what I was doing, why, and how my research hoped to benefit children (Appendix V). In research with children such a leaflet helps to allay any fears of the unknown, and allows children to make an informed choice about taking part (Alderson, 1997:24). I suggested that parents share with their child the leaflet provided, and talk it through to discover whether they were willing to let me visit them in their home. It was left to families to fully 'opt-in' by telephoning with their decision.

At this point, some families did not call back. The dilemma was whether to ring them and risk harassing, pestering or making them feel guilty if they were unable to help, or not to act, and risk losing potentially rich data? I was resolved to send one further reminder letter; this resulted in one family calling but the others did not reply. I needed to recruit more families and begin the procedure once more, which was time-consuming and frustrating. Although many parents and children had expressed an interest in taking part in the study at the consultation or over the telephone, they did not put themselves forward.

In retrospect, it could be said that I acted too ethically, and after such a favourable response on the first occasion I could have phoned to make an appointment, assuming that they did want to take part. However, I was committed to including

only those families who felt no pressure to take part, and actively volunteered themselves. This does, of course, raise the issue of selective bias; were those families who put themselves forward and were included of a particular type? More articulate? More vocal? Did they have 'an axe to grind'? Did they have more of an interest in their child than other parents? Having considered these issues, I did not find that the characteristics of the sub-sample families differed in any way from the larger study group of 45 or, indeed, from what is known about the prevalence of ADHD in this particular Midlands city. Ultimately, as the fieldwork took longer than anticipated, it felt right that only the 'keen participants' were included. An 'opt-out' method, whereby patients need to actively refuse to take part in research, would not have been appropriate, given that the lives of some of these families already seemed to involve 'policing' by numerous professionals and the research may have been perceived to be yet another type of regulation.

However, handing out the questionnaire face-to-face proved immensely time-consuming, as there was not a discrete 'ADHD clinic' as such. Doctors would see a variety of patients during each day, some with ADHD, others with related conditions, and some with psychiatric conditions unrelated to ADHD. In effect, a whole day might be spent at CAMHS, but only two or three cases of ADHD seen. To counter this issue, the consultant suggested sending a questionnaire plus covering letter, signed by himself endorsing the research, to all of those on the client list not yet contacted. This appeared to be a form of 'cold-calling', which I found ethically problematic as it might not give families a clear enough picture of the process which involvement in the research would entail, it did not involve a face-to-face introduction to the researcher, and could be construed as coercive.

However, in light of the time-consuming nature of my previous attempts I made the decision to try this method.

The work involved in this exercise was quite phenomenal. Firstly, the CAMHS photocopier was only able to copy one page at a time; secondly, I was surprised to find that a central database of names and addresses did not exist, one had never been created, and all information was stored in paper records rather than on computer. It seemed significant to me that CAMHS appeared to be in a technological vacuum, as part of the severely under-funded and neglected mental health arm of the NHS. I referred to a cardex system to find the information, and hand wrote each envelope. It was close to Christmas and I was determined to complete the job before the clinic closed for the vacation, so the questionnaires were despatched on December 22. I had not, however, considered that the request to complete a questionnaire was not going to be given priority this close to Christmas. Needless to say, the response rate in January was pretty poor, at 11%.

With a further reminder, the final questionnaire response rate increased to 40% ( $n = 45$ ), which is clearly not high in social science terms, but my respondent gatekeeper at CAMHS was very pleased with the outcome as he was anticipating a far lower rate of response. Of those that did not complete the questionnaire, six wrote or telephoned to explain their reasons. From this information I was able to suggest that non-respondents did not differ significantly from respondents, with reference to social class and geographical distribution. Overall the reason given for not wanting to take part in the research was parental desire to protect their child from intrusive questions, and to avoid drawing their child's attention to their

diagnosis. One woman who gave these reasons also felt unable to answer questions about her child's early life as she had become his adoptive mother when he was aged five. This led me to reflect on the design of my questionnaire, perhaps it could have been less prescriptive, allowing for variation in different forms of family experience.

The questionnaires were anonymous, asking only the first name of the children and their age; in hindsight information appertaining to the postcode would have been helpful, allowing me to plot a geographical distribution across the city in question and to make reference to diagnostic clusters in my analysis. On the other hand, it may have made the children identifiable, so parents may have been more reluctant to give information.

From the returned questionnaires seven families were selected to follow through for a period of 12 months<sup>3</sup>. Having explained earlier in this chapter that an 'opt in' approach was used, an additional aspect of my criteria was that the children would be 'pure ADHD' cases, in other words, that ADHD would be their primary and only diagnosis. In up to 50% of children with ADHD it is possible that another developmental or learning difficulty is present, referred to as co-morbidity, and I felt that this would complicate things, to the extent that I would not be comparing

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<sup>3</sup> Appendix I indicates that I intended to follow up 15-20 children but I had not anticipated how long it would take to recruit families. In order to still be able to visit children three times during the fieldwork period the sub-sample was reduced to 7.

like with like. I could not, however, guard against children in the sample receiving further diagnoses at a later date, which did in fact happen in one case<sup>4</sup>.

All of those selected were families I had met and observed at CAMHS and I visited their home three times during the year. Here I provide some detail of the social characteristics of the sample families. The children were aged from 6 to 16, six of whom were boys and one girl. The gender of the survey respondents' children with an ADHD diagnosis was overwhelmingly male, at 86.7%, 6.7% were female and a further 6.7% were classed as anonymous as parents had omitted to answer the question concerning gender.

Within the survey responses 95.5% of respondents were white British, and of the sample of seven children five were white British, one was black British and one North American. The marital status of parents within the small sample included four reconstituted families, one single parent and two biologically related two parent families. Families of all types were seen at the child and adolescent mental health unit, including foster families, and families where a grandparent or aunt was head of the household. In terms of the survey, the majority of families who responded contained two biological parents - 47%, then reconstituted (parent and step-parent) 27%, then lone mothers 20%, and lone fathers 4.0%. I interviewed seven mothers, two fathers and two step-fathers and seven children who had the diagnosis of ADHD, and also recorded data relating to conversations which I had with individuals during the time spent at CAMHS.

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<sup>4</sup> One young person, Sean (aged 12), was diagnosed with mild Tourette's Syndrome, during the course of the research. Although this was noted in his records the doctor concerned did not disclose

The parents within the sub-sample (those who were interviewed) worked in a variety of blue and white collar occupations such as: civil engineer, child minder, sales representative, LGV driver, security guard, nurse, care worker, social worker, secretary. Three families owned their own home, one was in private rented accommodation and three rented their home from the local authority. Information on housing tenure obtained from the survey respondents showed that 53% were owner occupiers, those that rented from the Local Authority numbered 20%, also 20% rented from a Housing Association, and tenants in private rented accommodation numbered 7% (Please refer to Appendix IV for further biographical details of the respondents).

Three of the children had been recently diagnosed (during the course of the research), and they were the youngest children, Michael at 6, Jack at 9, and Marcus at 10<sup>5</sup>. Three of the others had been in contact with the service for more than three years, including a period of time before being diagnosed with ADHD, and one, Ross, received a diagnosis whilst living in the United States. While I had initially hoped to carry out one interview with parents, and three with their child, it became clear that each time I entered a home parents would update me on recent events, at length, and did not comprehend that in this research, the views of their child were to be given priority.

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it to Sean as he felt it would cause undue anxiety.

<sup>5</sup> The names of all respondents have been changed and a pseudonym used in order to protect identity.

Data-gathering sessions with children took place within the family home, in a variety of rooms. In theory, parents had no objection to me speaking to their child alone and usually ensured that everyone else vacated the space in which we were to work. In reality, however, there were often interruptions from parents during the one-to-one session. For example, whilst a young person was talking to me about her difficulties and painting a picture of her hopes for the future her mother came into the kitchen to activate the washing machine and to boil the kettle to make coffee. Both of these noises impacted on the tape recording but, more importantly, illustrated how adults often do not respect children and young people's right to privacy and confidentiality. On other occasions parents interrupted children, corrected their 'version of events' and dominated joint discussions. It seems that the ethical commitment to 'listen to the voices of children' can often be difficult to achieve when other adults with whom children are in a relationship of power do not hold the same values.

The purpose of using qualitative methods has been to highlight the meanings which respondents give to their actions; the meanings which parents give to their health-seeking behaviour, which professionals give to their practice and delivery of services, and which children give to their experience of being diagnosed with a condition known as ADHD. There were some commonalities of experience, and similar traits demonstrated by children with ADHD, but diverse social and environmental circumstances meant that each family had a very individual and unique experience.

### **In-depth Qualitative Sessions: parents**

There are many methods which could have been chosen, but a technique derived from narrative was considered to be the best way of understanding the meanings which family members gave to their experiences. The process of people's lives is highlighted with life-history methods, 'by enabling people to talk about their lives in their own words' (Humphrey, 1993:168). Ribbens (1993), writing about her research with women, says that in-depth, unstructured interviews, based on the narrative technique, were chosen because narrative is a way of encouraging rich, in-depth data, and 'an appropriate vehicle for exploring women's experiences in ways that may be hidden from view in more 'traditional' academic formats' (Ribbens, 1993). Feminist writing has shown that personal experience should not be excluded as 'subjective and emotional'; analysis of personal relationships relates directly to wider social processes (Stanley, 1990). According to Humphrey (1993: 167), all lives are lived within 'enclosing contexts'; narratives reflect both common social structural influences and individual responses and action. Although it would prove difficult to separate 'fact' from a respondent's representation of their life events, this is not a necessity in this type of research, which considers the personal accounts of people to be valid in their own right. This method allowed the respondents to define what *they* considered relevant to help me understand what it was like to be the parent of a child with ADHD or, indeed, a child with such a diagnosis.

Each of the parental interviews began with the same request, 'Tell me about your experience of your child's ADHD, in your own words'. I was interested in their child's lifecourse, significant events and crises, the support received from services

and informal networks and, most importantly, their feelings regarding the above. One striking feature of the sessions was the noticeably different chronology of accounts of life events; some started from birth and worked their way through to the present, others, particularly those in crisis, focused on the present situation before reflecting on past events. Often what seemed irrelevant and unconnected to the research came, at a much later stage, to link with crucial aspects of their experience of ADHD and gave me 'useful new insights' (Alderson and Goodey, 1998:6). Kleinman (1988) notes that the process of telling stories about the past in the present will impact on participants' organisation and understanding of their experience. It is important to acknowledge, as Letherby (2003:90) reminds us, 'that respondents are active in the process of reflection and construction', and the narrator weaves her/his story with those of "significant others", allowing insight into the lives of others.

It was of interest to discover how children and parents' on-going lives and identities are affected differently by ADHD. Hyden (1997:53) contends that 'Narratives offer an opportunity to knit together the split ends of time, to construct a new context and to fit the illness disruption into a temporal framework', which is very different from a biomedical approach. Past events were retold in the light of previous and present experiences. It is important to note here that whilst I appreciate the narrative quality of the accounts, for the purpose of this research all qualitative data has been analysed on a thematic basis.

All interviews were tape-recorded, with permission from each respondent, and written consent obtained. The interviews were transcribed in their entirety for later

analysis. Both the data gathering sessions and the transcription were extremely time consuming, and required careful interpretation (Alderson, 1995). To ensure confidentiality, all tapes and transcripts were labelled anonymously and kept in a locked filing cabinet at my home, to which no one else had access.

### **In-depth qualitative sessions: children**

Children and young people with ADHD cannot be considered a homogeneous group. As Begley (2000:103) found, in her research with young people with Downs Syndrome, there are variations in capabilities, comprehension and language skills. This, in turn, has implications for the chosen ways of asking questions. One of the aims of this project is to give children a voice, but, as Alderson succinctly states: “‘Giving children a voice’ is a popular slogan, but children have voices, it is adults who need to listen’ (Alderson, 2000:133).

As discussed in Chapter Two, visual imagery is a useful way of exploring subjective experience (Shaver, Francis and Barnett, 1993), and can be a very useful tool in research with children (Oakley and Bendelow et al, 1995; Pridmore and Bendelow, 1995; Bendelow, Williams and Oakley, 1996). On meeting the family for the second time at the clinic a two hour session was booked, to be held in their home, which involved encouraging the children to draw pictures in response to my enquiries, labelling them if possible, and the emerging themes then led me into narrative interview.

In planning for the sessions with children I selected from a variety of sources across different disciplines, namely social work, psychology, art therapy, and sociology.

The idea of creating a 'life story' book, something personal which children could keep, came from reviewing these various resources. 'This is Me!' by Harmin (1978) provided ideas for the first page of the book, which allows children to identify themselves and mention their family, homes, schools and place of birth. Harmin's was an extensive book, suited to the important therapeutic task of working through emotions with the help of a trusted professional. I felt that the depth and scope went beyond the level of emotional exploration which was feasible in this project. 'Talking Pictures' by Philip (1989) however, was aimed at giving children the opportunity to draw in order to encourage them to talk about themselves. Philip advocated the use of this tool to help children to communicate, to elicit information and to perhaps help them understand their situation. Philip contends that it is a myth that communication with children is 'best left to the experts'. Alderson (2000) might tend to agree, as she does not believe that talking to children requires special or different skills; the same considerations should be made when talking to anyone of any age.

Qualitative research takes a rainbow approach, exploring the differences in each child and circumstance, enlarging understanding and empathy (Alderson, 2000:83).

In research with children, it is vitally important to be aware of the dynamics of power involved in the research process; in all adult/child interactions there is a power imbalance. I did not wish, therefore, to be regarded as yet another adult who wanted to probe and question children. I felt, therefore, that I needed to emotionally invest in the research relationship, and not be merely 'a data-gathering machine' (Oakley, 1981). On arrival at the family home, I would ask the child if they had seen and read the leaflet which had been designed for them (Appendix V)

and I would then talk through my intentions. Two children commented on how much they liked the leaflet; one liked the cartoon image on the cover, and another said 'It's good because it explains things so that kids can understand' (Emma, 10).

Children in the study upon which this thesis is based knew that they were free to withdraw at any time and that their access to services, such as the Child and Adolescent Mental Health Service, would not be affected in any way. Consent was sought at each session, as I felt it important to confirm that the young people involved still felt comfortable about taking part. (A more detailed exploration of ethical and moral issues will be discussed later). I made it clear that any child could decline to continue being part of the research at any time, and although no-one actually said that they did not want to see me again, certain children had their own way of letting me know that they would rather be doing something other than talking to me. One boy, Marcus, went to great lengths, entertaining me for over an hour with his parents' wedding album and video tapes of himself as a baby, to avoid my questions about his understanding and experience of ADHD. But it was important to let the children interact as they wished, in order to establish a rapport. As Hazel notes, the researcher needs to cross the 'cultural and communicative divide which has characterised the paternal adult-child relationship' (Hazel, 1995:2). Ultimately, this is research *for* not *on* children, and these diversions were still teaching me about the children's perception of themselves and their family. It also meant that every meeting with each child was entirely different, and would prove difficult to standardise.

There was clearly a need for us to get to know each other in the first session. The aims of the project were shared, and it was explained how they could contribute if they felt it was something they would like to do. The children were asked to draw a picture of themselves, either on their own or with their family. They often sought guidance and asked for reassurance; the majority of first responses to this request were: 'I'm rubbish at drawing', but clearly most did actually enjoy being given the opportunity to draw. Christensen and James (2000) note that such questioning relates to the hierarchical relationships of adults and children; children are particularly used to having their competence judged by teachers. I explained that the standard was not important, and that they could use a variety of mediums to present their work - felt-tips, coloured pencils, crayons, paints. Michael, the youngest child in the study, unproblematically used the coloured felt-tips to illustrate his drawings; the three oldest boys (Chris, Sean and Ross) chose to use pencil only at each of the three sessions. They appeared to have internalised the notion that they were not skilled artists and had limited ability in this area, therefore using pencil made as small a mark as possible on the paper, and could be erased if not up to their standards. This may relate to the increasing marginalisation of art in favour of more academic subjects since the introduction of the National Curriculum or may be that art is something that many people find difficult.

We talked at this stage about family, friends, and school, all of which figured largely in their likes and dislikes (Figure 1). The following activity was a 'Feelings Flag', designed by myself, but heavily influenced by Hobday and Ollier's (1999) 'My Feelings Pie' activity. I drew a flag with eight sections and labelled each with

an emotion. The children were encouraged to think of situations when they may have experienced this emotion, what kind of events in their lives made them feel this way. Although the categories were pre-determined, the children self-defined the situations which led them to experience emotions such as 'anger' or 'pride'. Two separate 'Feelings Flags' were used to represent the range of emotions, and although I did not refer to one as 'negative' and the other as 'positive' it might be common to regard them as such. It is recognised that emotions are not dichotomous, 'good' or 'bad', all are necessary for balanced well-being. The flag containing less pleasant emotions was always introduced first, in case it raised issues which may have caused upset. I took care to end each of these sessions on a positive note. This exercise tended to require a lot of concentration; the children were often pensive and deep in thought as they wrote down their examples. One boy asked for clarification of 'optimistic' before he could think of an example.

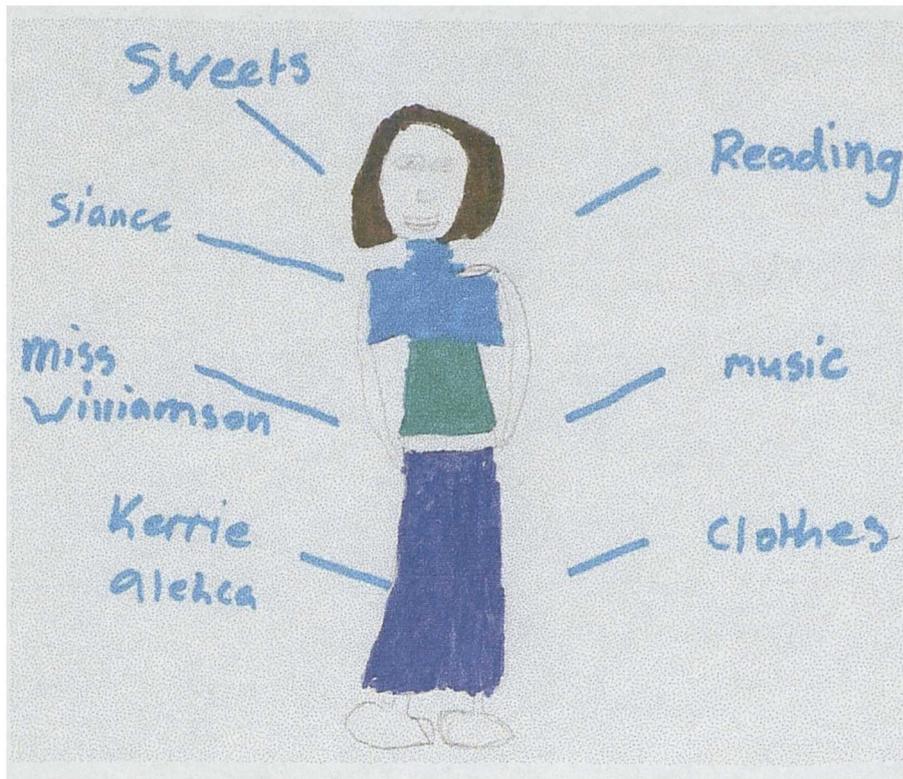


Figure 1: Emma's self-portrait and things that she likes

After catching up on events since the last visit, session two began with 'My life snake'. Giving children a life snake to represent their life, from birth to the present allowed them to define the events and memories which were significant to them. Children had no difficulty in recalling events, the snakes' curves allowed for a natural development of ideas and I felt a request for a linear list may not have produced the same intuitive recall. The memories which were regarded as important to the children were not necessarily the kind of memories which adults or parents would have considered to be significant. Memories such as 'my dog got put down' (Sean), 'got ran over' (Emma), 'when my mum and dad split up' (Emma/Sean) and 'when someone hit me and I just stood there [rather than retaliate]' (Chris). They did not simply write, but as they sat and thought they showed amusement or shock as their memories emerged. They especially delighted

in giving me the graphic details of any accidents or injuries (a feature common to most of the accounts). It was hoped that this request would elicit details directly relevant to ADHD and, indeed, certain children did refer to this (Figure 2).

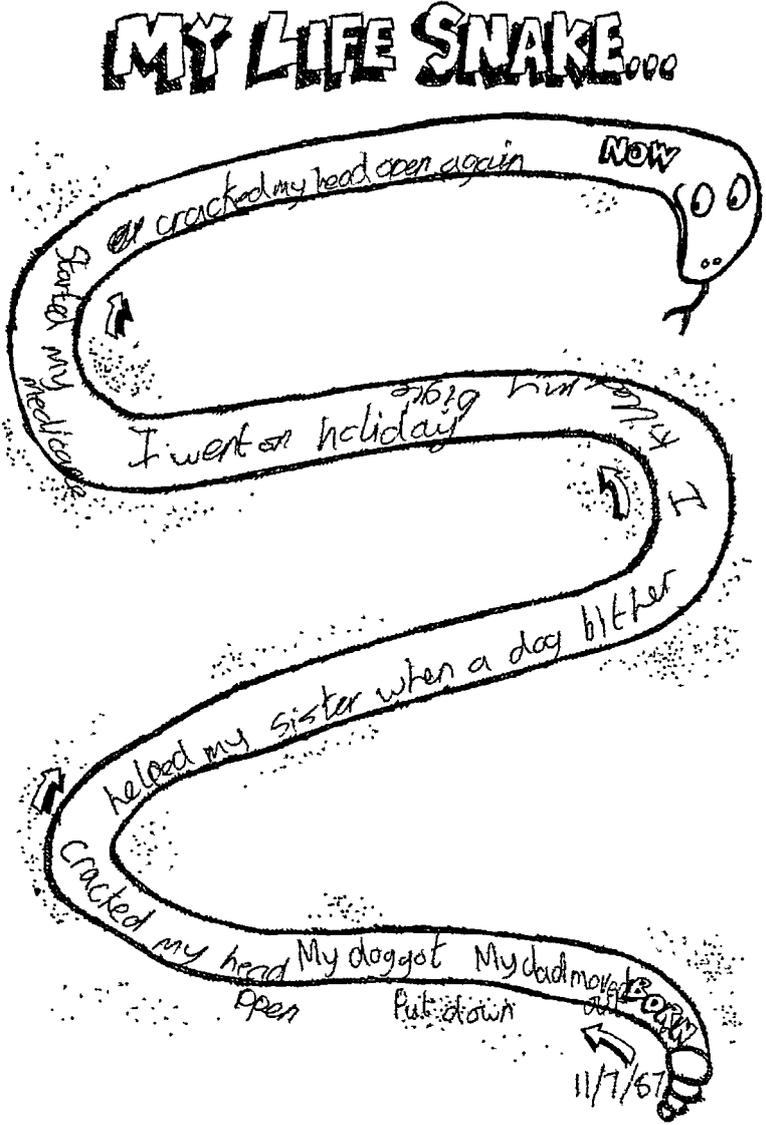


Figure 2: Sean's 'My life snake', memories from birth to now

This part of the session led onto asking those who had experience of taking stimulant medication (six of the seven) how they felt about it. They talked to me, but the pictures which they produced to illustrate how life is different since

diagnosis and medication spoke more clearly and directly than words ever could. Nevertheless, I did clarify with each child what their picture depicted, so that the interpretation was in their hands, not mine. On leaving, I explained that the next visit would be the last, and that they could give me anything which they would like to see included in their book at that time.

Each final interview ended with an opportunity to think about the future. The conceptual form of a ladder was used as it contained the embedded notion of aspiration - a ladder is there to be climbed. Here, children communicated the changes which they would like to see, hopes and plans for both the immediate and long-term future, ambitions and futuristic fantasies. Some of these closing statements were amongst the most poignant, but in general they tended to reflect the concerns and dreams of the majority of young people. It is hoped that this research has considered ADHD as an aspect of their lives, rather than the entirety of their lives. Similarly, although there were commonalities in the children's experiences of ADHD, their experiences of childhood were quite diverse. As Roberts (2000) notes, the irony of promoting inclusion for such children can mean inclusion in 'research entirely focused on precisely those issues which exclude them. Disabled children and young people are more than their impairment' (2000:236).

These children often regard themselves as 'failing' in many aspects of their lives, so in thinking about the way I would carry out this research, I felt very strongly that I should develop ways of communicating which would allow children to competently engage and make an extremely valuable contribution to the ADHD

knowledge base. Child-centred and impossible to standardise, it was anticipated that each of the sessions would be different, depending on the unique response of the child, and this was very true. Each book was a unique combination of drawings, pictorial and written activities, photographs, certificates and awards, medals and memorabilia. Being engaged in activities of interest did help to build relationships between myself and the children, but, as in life, some connections were deeper than others. The use of drawing and labelling as a method proved to be quite positive and certainly suitable for children with a need for constant stimulation. Both drawing and writing were used as a key to unlocking children's feelings and emotions, which they may have been unable or unwilling to talk about. Art is a valuable research method as images often emerge which would be subconsciously censored in dialogue. The success of the method relied on me being flexible, and making the activities accessible, sometimes fun, and as least like school work as possible and also on the children and young people giving me their time and being open to sharing their experiences.

Building on my previous experience of research with children, I knew it would be difficult to leave the field once a rapport and relationship had been established, but staying in touch with the children and their parents and caring about their progress made for a gradual withdrawal, rather than a complete break, and this I did by sending Christmas cards with a personal message, a card addressed to the child to thank them for their help with the research and, occasionally, by telephone.

### **Analysis: a process which leads to the emergence of theory**

In this section, I give a detailed account of the way in which the research analysis was carried out. So many methods texts tell you what to do, but not how to do it, failing to mention that the highlighter pens, post-it notes, and mind-maps pinned to walls around one's home are crucial to the creative process. For some time I believed that there must be an easier, neater way, it seemed ridiculous that the more I explored the themes, the more complex they became. Eventually I came to appreciate that the messiness, and feeling of 'drowning in data' was the essence of empirical research.

A similar form of analysis was used with all qualitative data. Tape recordings of interviews with parents and young people were fully transcribed, and transcripts were read to determine areas of interest - themes - which were then underlined using coloured pen. A further examination of the transcripts revealed there to be different aspects to these broad themes. For instance, the broad theme of 'education' was referred to by every participant, but various issues to do with education were emphasised. These included academic performance, social relationships, support, responsibility. These sub-categories were then loosely coded, as 'eduac', 'edusoc', 'edusupp', and 'eduresp' and then applied to the transcripts. Each of these codes contained further sub-themes, and related in different ways to each other. For instance, 'eduresp' included school taking responsibility for young people's well-being, for their medication, and for making provision to support their learning needs, the latter of which then linked to the other category of 'edusupp'. In this way, new codes continued to be generated, and refined.

I then noted the frequency with which each appeared in the transcripts, and devised a coding frame, listing the places where reference to each could be found in the data. This was quite time-consuming, but was a worthwhile exercise, as it gave me an at-a-glance frame of reference, a way of identifying patterns. Concepts which consistently emerged were drawn out and focused upon, for example, explanations for 'difference' in parents transcripts. There were some themes which perhaps only one person may have mentioned, for example, racism. This would lead me to question why it had been raised by this person, but not by others. I theorised that it was not perceived as an issue directly relevant to the other participants, who were not from minority ethnic groups, but was an additional concern for the woman who mentioned it, the mother of a 10 year old boy with ADHD, both being African-Caribbean. In turn, this led me to reflect on the ways in which the ADHD label is mediated by differentials of social class, ethnicity and gender, which very much affect the way the condition plays out. In this case, the boy could find himself doubly discriminated against because he has ADHD and is black. I then attempted to contextualise this finding by linking it to an existing body of literature. I found that literature exists which explores the issue of black, disabled identity, but not specifically a black, ADHD identity, as it appears that few children from minority ethnic groups are diagnosed with ADHD. According to a recent US survey which investigated ethnic attitudes to ADHD, 53% of African American parents would not seek treatment for their child because they were concerned that their child may be labelled (<http://www.concerta.net/vcrc/newswatch>, 2.4.03).

My approach, loosely based on grounded theory (Glaser and Strauss, 1967), allowed for theory to emerge from the research, to be generated from the 'empirical world'. By examining the range of data, looking for similarities and diversity of opinion, theories were generated, and tested against the transcripts. This same process of analysis was used to examine the observational field notes collected whilst at CAMHS, generating additional categories which included lay/professional interaction, examples of good practice, including reflexive practice, factors which constrained or facilitated inter-professional collaboration. In the early stages of analysis I did consider using a computer package to analyse the qualitative data but I had already invested quite some time in analysing the survey responses with the use of SPSS and, having sought advice from supervisors, decided to press ahead with detailed manual analysis.

Children's drawings were analysed alongside their verbal explanations; the art work was studied, and themes which were common were explored. Additional themes were constantly emerging; pinning copies of the drawings around the walls of my study meant that I became familiar with them, particularly with the kinds of issues and events that troubled children. It is important to emphasise once again that the drawings were not interpreted and used to make judgements about the children, since I am neither qualified to evaluate children, nor familiar enough with their particular familial context to make any assumptions. My interest lies in presenting a variety of forms of data, and exploring the relationships between each.

As indicated above, the survey data were analysed with the use of SPSS, a quantitative data analysis package. The data collected relate to almost half of the

population of families who have a child diagnosed with ADHD in this particular Midlands city, therefore I feel relatively confident in suggesting that it is representative of the experience of many families. All cases on the CAMHS client list were mailed the questionnaire, all were given an equal chance to respond. The questionnaire asked mainly closed questions, providing a small range of possible responses which required a tick. Two of the questions also pre-determined the range of responses, by asking respondents to tick the relevant box, numbered from 0 - 3, or select an attitudinal response from a list of 4 possible answers. The questionnaire also featured some open questions; those located on the last page drew some very detailed responses. These more qualitative responses contained similar themes, and I decided that five codes would be used to summarise the responses. Although the uniqueness of each answer was lost in this process, I was still able to use this rich data elsewhere in the analysis. It was, however, advantageous to be able to see patterns in the responses, and quantify data relating to the structural differentials of the respondents. I found it beneficial to devise a code book so that I was not reliant on memory when coding individual questionnaires. Once all forms of data were coded it became clear that some themes identified cut across each of the sources - fieldwork notes, interview transcripts, drawings and documents. Kelly (2002) comments, '[...] I think about mixed methods as enabling different kinds of telling' (Kelly, 2002:133).

In addition, and with parental permission (where necessary), I examined treatment diaries, clinic records, school reports, media representations of ADHD, and any other documents which seemed relevant once in the field. This has added weight to the argument that ADHD is constructed differently across a variety of settings, with

various terms used to describe both the behaviour and needs of children and little consensus in approach to the management of children's difficulties.

### **Reflections on the research process**

As Letherby (2003) argues 'researchers multiple identities as people are as relevant to the research process and product as the personhood of the respondents'. I begin my reflections on the research process with this auto/biographical 'story' to indicate the ways in which drawing on my own experiences brought me closer to understanding the experiences of my respondents, both parents and children. The inclusion of my auto/biographical account helps to situate myself in the research.

*Once my period of ESRC funding had finished, I found part-time work in a nursery as a Special Needs Assistant in order to support my final year. The nursery was located in an economically deprived area, and drew its clientele from largely unemployed and low income families. The majority of families self-referred, but a significant number were referred by Social Services or health visitors as preventive care measures or as the follow up to a Child Protection issue, as in cases of domestic violence, physical or sexual abuse, or neglect. The children were from ethnically and culturally diverse backgrounds, which adequately reflected the geographical area in which the nursery was based. The nursery employed a range of experienced staff, including teachers, nursery officers, part-time bilingual support staff, family workers and a special needs team; my role was within the special needs team. Committed to promoting integrated services for children and families, the staff were particularly keen to value the contribution to the child's learning made by parents and carers and acknowledged that the majority of learning takes place or is reinforced within the home.*

*Within the nursery, children were given a large amount of autonomy; there were only 3 structured periods in a day - morning and afternoon 'group time' sessions, lasting around 20 minutes, and lunchtime - the rest of the day free play was encouraged. This suited most children; they might first have breakfast, then choose to play in the sand for around 20 minutes, moving on to the water play (remembering their apron) for a further 15 minutes, going outside to socialise, ride the bikes, and play games, then perhaps make a glue model before stopping for lunch.*

*Casey, the child I was supporting, would burst through the door, either throw her coat on the floor or run to the breakfast table with her hat and coat on, greet staff by running at them and head-butting their groin, wrapping her arms around their*

*bottom, dash off to play in the water, without her apron (!), still clutching her heavily buttered toast, grabbing toys from other children (who had been playing quietly in the water), become angry and aggressive, drop to the floor and attempt to bite me when I tried to calm her and take her back to the table where she could finish her toast. She would continue throughout the day to career from one activity to another, never spending more than approximately 5 minutes in one area (apart from when playing in water, which could occupy her for 20 minutes or so), leaving unfinished paintings, puzzles and pictures wherever she went. Should I turn my back momentarily when supervising her, she'd be gone, having run past me without me seeing, into another hair-raising situation. Given that for the past five years, all my 'hard work' had been undertaken at a computer, sat in a chair and studying, this level of physical activity certainly proved a challenge.*

*Casey was a four year old girl with a variety of difficulties. She and her three older siblings had been taken into care by Social Services as they were being neglected. Her maternal aunt had fostered all four of the children, but also had four children of her own, which meant that eight children under 11 lived in the household. Casey was extremely adept at ensuring her needs were met by any available adult, often using tactics of manipulation or wearing one down; she was single minded and bright, although her attention span was so limited that she was unable to demonstrate this much of the time. She demanded attention, immediate gratification and reward. She had little sense of danger and took risks daily, which often led to accidents involving bumps and bruises. She ran on tiptoes at all times, never walked, and had great difficulty listening to adult's advice or instructions. This sometimes meant that she learnt 'the hard way'; on one occasion when I had repeatedly told her not to touch a bee, and explained why, she was surprised and upset when she 'stroked' it and it stung her. Casey also had the capacity to show a great deal of affection.*

I include this personal narrative in order to reflect on how this hands-on experience of looking after a pre-school child with such restless behaviour shaped and influenced the direction of my thesis. Until this point I had largely regarded the problem of children's behavioural difficulties as socially constructed, in the sense that in other cultures and in other historical periods such behaviours may not have been regarded as problematic. This experience, however, led me to critically assess my thoughts and I came to the understanding that although I would advocate that the acceptance of 'different' styles of learning and cognition could be accepted if certain structural changes were made to society, in reality, and in the meantime, a certain level of conformity is necessary in order for children to feel a sense of

personal achievement. Children who are having extreme difficulty in understanding social rules and norms find themselves on the receiving end of much negative attention, both from adults and their peers. This, in turn, leads them to feel rejected and lacking in self-worth.

In this case, Casey's difficult family background was likely to have contributed to her restless behaviour, but may not have been the direct cause as her maternal aunt described Casey's mother as behaving in a very similar way when she was a child. In my relationship with Casey I felt that I was on a 'personal crusade' to calm her, to help her to relate to others, and to encourage trust; I thought I could be the one to do this. I had a strong emotional bond with her despite not always liking the way she treated me (particularly spitting at me and biting me); it was the most physically and emotionally exhausting job I had ever undertaken and I learnt a great deal about my own limitations and had cause to reflect on the way in which I had parented my own two children and the way I had conceptualised ADHD to date.

In the course of this research I have reflected on a number of ethical and methodological issues. Turner (1984) drew awareness to the lack of attention paid by social science to the body; it remains implicit rather than explicit in fieldwork accounts. For example, it has been said that that the effect which gender identity has on the research process has largely escaped the attention of many male sociologists (Hearn, 1993). Coffey (1999) maintains that recognising the concept of research as embodied helps us to understand the personal and practical in fieldwork. Fieldwork cannot be separated from our sense of self, biography and identity; daily experience is inevitably embodied. 'The interaction, language and

discipline of the body form the very essence of fieldwork' (Coffey, 1999:60). The current turn in qualitative research - the use of narrative, discourse, life-stories, biographical research, the inclusion of voices - can be conceptualised as a glamorous form of social research, according to Garner (2000). But social researchers ensure that it is not perceived as a 'soft option', remaining methodologically rigorous, adopting safeguards regarding confidentiality, and informed consent, and relating to child participants as one human being to another, all of which is emotionally, spiritually and morally challenging, in a way which some forms of quantitative research are thought not to be. This view of quantitative methods, however, has been challenged; Katz-Rothman, (1986) and Kelly et al, (1994) point out that analysing the responses included in questionnaires can provoke an emotional response from researchers. In my study I also found that reading about parents' concerns, fears and hopes for their child with ADHD often led me to feel distressed and sad, as discussed above.

Gaining access to the homes of this fairly marginalised group was relatively unproblematic. No matter how carefully informed consent (written from parents and verbal from children) was obtained, it may still be that I have unknowingly taken advantage and exploited people in some way. At the time of the fieldwork I was genuinely concerned with the plight of each child, but once away from the field, other priorities took over - namely, transcription, analysis, selection of 'useful' data, further reading, and the process of writing; Parker (1998) refers to this as 'researcher distance'. Although I still wondered how each child was coping, from time to time, I was also concerned with my own personal goal of tying findings, theory and practice together in a coherent legible way, in order to achieve

a PhD. Garner (2000) points out that social researchers insulate themselves within university departments, adopt a virtuous position, and craft a story from participant's words. It is important to acknowledge that the researcher has control over the data (Ribbens, 1989; Cotterill, 1992; Letherby, 2003); behaving ethically is not just a matter for the field. In Standing's research with low income lone mothers she was particularly concerned that social researchers should write their research in a language which is acceptable to the academic community but does not alienate the people who took part in the research, ensuring that we do not reinforce and contribute to inequalities of power (Standing, 1998). It became crucially important to me that the parents, young people and health professionals involved in this research should be able to recognise their experiences within these pages and, just as importantly, that the language used was not unnecessarily complex, remaining accessible to them.

Contradictions are produced when moving between fieldwork and the academic world (Birch, 1998). The social relationships formed in the field are very different, and somehow make academia seem 'unreal'; life as a qualitative social researcher is about *real people*. Lofland and Lofland (1995:51) acknowledge that researchers 'often struggle with the personally painful question of whether to throw in the towel on doing research and give themselves over entirely to 'helping' or to remain in the field as a chronicler of difficulties'. This was also a dilemma for me; I emotionally invested in the lives of the children I had been visiting and wanted to take on a more practical, proactive role which may have assisted them in life. Listening to the taped interviews and analysing the drawings kept the children's 'voices' alive and reminded me that in writing up their stories I was helping to raise

awareness of the real life people behind the ADHD label. The ways in which particularly qualitative social research can impact on the researcher (and vice versa) are further discussed later in this chapter.

Ultimately, the children who took part in this research had rights of ownership over their drawings; the trust of the children could have been lost if they had become defaced, damaged or lost and in this way I could relate all too well to concerns regarding the transfer of the 'ownership of data' passing from the researched to the researcher (Graham, 1984; Price, 1996). I am responsible for sharing these images, with the children's permission, so that others can gain an understanding of those who created them. Furthermore, the issue of anonymity when using drawings as data needs to be considered. As Malchiodi (1998) notes, drawing styles are often unique, and although biographical information and names can be altered to protect children's identities, children's privacy cannot be fully protected as the uniqueness of art expressions cannot easily be changed. This is of crucial importance in the work of therapists like Malchiodi, dealing with incredibly sensitive issues, but must also be considered by social researchers who intend to make public the work which children have shared with them.

Overt/Covert research: where do you draw the line?

As suggested above, during the fieldwork period my role was more complex than anticipated, graduating from observer, to participant observer, to active participant in the ADHD team (regarded as having a valid contribution to make), and later to

confidante/listening ear of children and parents. In common with other research, several roles were developed during my investigations.

The shift or drift from observer to participant seemed to begin when offered a place in which to work on the days I attended CAMHS. The space occupied at the mental health unit was a cluttered desk in the corner of an office shared by two doctors, Dr Turner and Dr Watson, and a Senior House Officer. In my presence, they openly discussed cases, decisions made, their requests for further training, the absence of protocols, collegial differences of opinion, and the precariousness of their position in the current climate, where those associated with ADHD were demonised. I could only assume that I was not regarded as an 'outsider', although they would not expect that the 'work' I appeared to be doing involved memorising and recording these conversations. This raised an ethical dilemma for me.

In Dingwall's (1980) research into health visitor training, he was confronted by students who noticed him recording 'backstage' events and conversations, which they did not see as relevant to his research. He explained that he was locating their training within their overall life trajectory, but respondents had assumed that their chats with him were 'conversational lubrication between researched events rather than as research relevant in themselves' (Dingwall, 1980: 882). Similarly, in Porter's (1995) ethnographic study the participants were aware that although his role was staff nurse in an intensive care unit, he was simultaneously a social researcher, but his method was not entirely overt:

While I was quite open about the fact that I was examining interaction between nurses and doctors, I did not emphasise that I was interested in how this related to issues such as racism [...] I felt that by highlighting

these issues I would be in danger of driving their manifestation underground (Porter, 1995: 24).

If I had declared that I was examining how individual assessment related to a philosophy of care, or doctors own gendered value systems, it is likely that the health care professionals would have altered their behaviour to present a more politically correct face or blocked access once they realised that they were part of the research. This, in turn, could have been a loss to the advancement of medical sociological knowledge. I strived to protect the identities of those involved, and there is likely to be a substantial gap of around four years between the end of fieldwork and publication, and a considerable change in personnel at the CAMHS.

It happens that participants everywhere do and say many things they would prefer to forget or prefer not to have known, or at least not widely known. In the process of writing up his notes the observer necessarily violates these participant preferences. (Lofland, 1971:108).

When studying those in power, some deceit can be justified, and data can be collected covertly if it is the only way of gaining insight into professional cultural practices. According to Bulmer (1982) 'complete concealment of the research [...] may rarely if ever be justified, but the converse - that total openness is in all circumstances desirable or possible - does not follow' (Bulmer, 1982:235-6) As Burgess (1984) notes, participant observation provides an opportunity to 'collect the different versions of events', and to compare them with other accounts and one's own observations. There is no clear distinction between covert and overt research, the two are not mutually exclusive.

## Researcher Role

Adopting a role or identity that meshes with the values and behaviour of the group being studied, without seriously compromising one's own values is an important part of ethnographic research; qualitative researchers must know how to effectively present the 'self' in the research setting in order to 'fit in'. It was necessary to create the right impression and so I dressed in a smart, professional manner whilst at the clinic in a similar way to the staff, including doctors, who did not wear white coats. I dressed more casually when visiting families at home and carried a fake-fur bag in the shape of a cartoon character rather than a briefcase. 'Dressing down' was one of the ways I consciously used my embodied self to reduce power relations, enabling respondents, particularly children, to feel more comfortable. Following Goffman, Hammersley and Atkinson (1995) refer to this process as 'impression management'; researchers engage in managing their identity in order to form and maintain relationships in the field and this is varied according to the audience. Researchers strive to be accepted by the people involved in their study but providing people with the opportunity to talk about their experiences can lead to a deeper involvement in their lives than first anticipated.

Gans (1962) suggests that 'the fieldworker is under pressure from those he (*sic*) studies to involve himself'; showing empathy and building rapport can encourage participants to begin to include the researcher in family discussions, disagreements and concerns. This total acceptance of the researcher can become problematic, putting them in a moral and ethical predicament, as well as possibly 'contaminating' the data. For example, in answering a question put by one party they would have to be careful not to offend another. Although this may be so, it is

not acceptable to avoid engaging in and answering such questions. In Oakley's (1981) research into women's experiences of pregnancy and childbirth she received requests for information, questions about the research, and a small percentage asked for Oakley's advice on particular matters. Oakley felt that she was asking a lot of these women to participate in research, during a stressful time in their lives, therefore she did not consider it unreasonable to answer their questions to her, and did not follow the text book advice, which was generally to deflect any questions in order to avoid bias or any personal, emotional involvement with participants. More recently others have argued that the in-depth, participatory interview may not always be appropriate to particular issues or respondent groups and can even be exploitative (Finch, 1984; Kelly et al, 1994; Letherby, 2003)

It follows that the boundaries between the researcher role and one's personal life are not clearly demarcated when conducting this kind of research. How can I say where they lie when parents ask me questions about my personal life - where I live, how many children I have, whether I am married - and ask for my advice on matters concerning their child's health and education? In her ethnographic study of step-families, Hughes (1991) comments on the complexity of fieldwork relationships, particularly in the setting of the familial home. She found the nature of fieldwork relationships with families to be influenced by individual personality, family lifestyles, and their disposition to incorporating a 'stranger' into their home. Attention has been drawn to the similarities between research and counselling and like Hughes (1991), I was 'seen as a resource with a sympathetic ear' (1991:44). I felt that I was providing a source of support, and on occasion parents asked me directly to provide information;

I discovered, early on in the research, that disclosing that I was the mother of a girl of 10 and boy of 9 could actually be a disadvantage. In one of the first interviews, I let slip that I had some behaviour issues with my son, and the mother I was interviewing looked quite excited /relieved when she asked, 'Oh, he's got ADHD too? You'll know all about living with it then!' I couldn't help but feel that when I said 'Oh no, my son hasn't got it', the implication was 'there's nothing wrong with *my* son, he's quite normal'. In Chrisler's (1996) research with women engaged in a weight loss programme she found that 'a veil seemed to descend' between her and the respondents when she revealed that she had never had a 'weight problem' (Chrisler, 1996:95).

On another level, being a mother did help, especially as my children were of similar age to those I met. It made me more sensitive to the complexities of the job of mothering and helped to guard against the tendency to judge their parenting ability. I understood the difficulties regarding getting children up in the mornings, encouraging them to go to bed in the evenings, battles over homework, and so forth and was able to imagine that these family difficulties would be magnified with a child with ADHD. For these parents to tell someone without parenting experience (social or biological) how they 'completely lost it', shouted, screamed and almost hit their child, might have had a different impact than telling another parent, who is almost bound to have had a similar experience in their relationship with their child.

As A. James reminds us:

Biography is intimately and inevitably entwined with the research process; it cannot be left conveniently 'at home' while the professional assumes the leading role (James, 1993:13)

Yet experience is much more complex than is sometimes presented and, as Letherby (2003) argues, identification with respondents is not always possible or even desirable. An integral, yet often unrecognised part of the role of researcher is 'emotional labour' (Hochschild, 1983; James, 1989; Ramsay, 1996). Listening to distressed women or children, feeling their anger, resentment, frustration, anxiety, is a difficult task. On one occasion, the mother of a six year old boy became very tearful in my presence as she recounted how her thirteen year old nephew had been killed just a few weeks previously in a 'joy-riding' accident; others in the car were also killed or seriously injured. She told how her nephew had always been a child who took risks, acted on impulse, found it difficult to focus, but was very likeable. These were all qualities which she could see in her own son and she was anxious and fearful that if he was not given additional support now, at an early age, he would 'end up like his cousin'. Her son was feeling the loss of his cousin, and drew a picture of himself and his cousin whilst we were talking. I found listening to this account really distressing. I was reminded that I read about the incident in the local newspaper and may have made assumptions about the young people involved and their parents' values and parenting skills. This was a profound realisation that these were real people, with real and complex lives, doing their utmost to help their child, but often being faced with insurmountable obstacles and receiving little or no outside support. The emotions which I felt included shock, helplessness, empathy and frustration, but I felt it necessary to 'manage' (Hochschild, 1983) my feelings, to still appear professional. Emotion work, it has been argued, is an inevitable part of fieldwork (Young and Lee, 1996) and emotional labour can be as exhausting as physical labour. Each situation - every consultation, every interview session - is

different therefore, each time was like the first and required an intense emotional engagement from myself as the researcher. As N. James (1989:29) says:

Emotional labour requires a flexibility of response to different circumstances and different people's needs and requests that cannot be timetabled and routinised as easily as physical tasks are.

Stanley and Wise (1983) were amongst the first to show that self-reflexivity is a major part of successful research. Researchers simultaneously draw on previous theoretical ideas and experiences, develop and construct new theoretical ideas and re-create themselves in the process. Research practice can be regarded as an emotional, personal journey (Mauthner and Doucet, 1998; Coffey, 1999; Letherby, 2003). Acknowledging the embodied nature of social research is regarded as crucial:

Not only is fieldwork concerned with the spatial location of bodies (the fieldworker and other social actors). It is also concerned with the interaction, regulation, management and use of the body in everyday social life. Fieldwork includes the observance and analysis of the body as an embodiment of culture. At the same time our engagement with the field is both intellectual and physical. We cannot divorce our scholarly endeavours from the bodily reality of being in the field (Coffey, 1999:68)

Adopting principles which are grounded in a feminist discourse on the nature and process of social research affects both the way in which data is gathered and the type of data being gathered. In particular, the self is located as gendered, embodied, and emotional, 'discounting the myth that social research can ever be neutral and hygienic' (Coffey, 1999:12). Our own 'sociological identity' transforms and unfolds as part of the process of the research. Many feminist researchers (Kelly, 1988; Reinharz, 1983; Ribbens and Edwards, 1998) encourage focusing on human responses to research, and not ignoring our own feelings,

responses and experiences. In turn, a better understanding of social reality will be possible.

To illustrate this, the autobiographical account included at the beginning of this chapter encapsulates many of the issues discussed within this thesis. It also demonstrates how my public/academic work as a researcher has been directly influenced and shaped by my personal/private experiences as a woman, a mother and a worker. The experience of caring for Casey gave me many insights into the kinds of issues which parents of children who have the diagnosis of ADHD might face and of the difficulty these children have in adhering to socially required norms. Theoretical deliberations alone fail to capture the reality of living with such challenging behaviour, both for parents and for the children themselves.

## **Conclusion**

This chapter gives a complete account of the research process, which includes issues of access, selecting a sample, the chosen methods, and the complex ethical and methodological issues involved. Having reflexively conducted, interpreted and written up my research, this detailed account will serve as a backdrop to the following chapters, in which the research findings are presented. The voices of children and parents, the lay perspective in the ADHD debate, is the central focus of the research, but I also had a rare opportunity to interact with health care professionals, and appreciate their views of diagnostic practice in the social and political climate of the time. The themes which emerged from the data analysis are presented in Chapter's Five to Seven. These include analysis of the data and linkage to the overall theoretical framework.

## Chapter Five

### Non-conforming behaviour: 'Personal trouble or Public issue?'

#### Introduction

**The way in which an individual interprets or understands their disorders will depend, not upon individual whim or fancy, but significantly upon the classifications of illness which are available within a culture and by reference to general cultural values concerning appropriate behaviour (Turner, 1995:207).**

Family life is heavily influenced by prevailing discourses regarding appropriate parenting, 'normal' childhood, and the requirement for children to be under the 'control' of parents. The opening quote highlights the precarious nature of illness conditions, such as ADHD, which are based on observations of unacceptable, inappropriate, deviant behaviour which flouts social norms. Zola (1972) contends that medicalising a social problem leads it to be located within the individual, and therefore effectively depoliticizes the issue; we then seek to change the individual rather than looking for causes and solutions to complex social problems in the social system (Conrad, 1975). Alternatively, it can also be argued that the behaviour of children is a private matter for families and should be handled by families; but by conceptualising aspects of children's behaviour as a medical condition, namely ADHD, the matter becomes one of public concern, the 'personal trouble' becomes a 'public issue' (Mills, 1959). In a somewhat contradictory manner the illness label of ADHD tends to homogenise difference, whilst reinforcing the focus on individual deficit.

A variety of factors influence the process involved in identifying a child as 'different' to others, including parents' understandings of 'normal' and 'different' children, the explanations offered for 'difference' when drawing on lay and 'expert' knowledge, and the ways in which dominant discourses (medical or other) influence the course of action taken by parents. As such, the moral, social and political concerns around diagnosis form a backdrop to the data presented in this chapter and provide the context in which to locate the actions of parents and health professionals.

Awareness of ADHD has undoubtedly increased over recent years, and is still growing, but this chapter suggests that ADHD has not always been so readily identified. Health care providers have become more confident in their practice as a result of increased public awareness, experience, and the development of professional guidelines and protocol. Influences which have shaped the beliefs and practices of both parents and health professionals will be explored below in order to reveal the commonality of experience of families, whilst drawing attention to some of the mediating factors which differentially structure the experiences.

Whilst the data presented in the early part of the chapter seem to suggest that health professionals may not have taken the concerns of parents seriously, therefore dismissing lay knowledge, information gathered whilst carrying out observations at a CAMHS will show that the decision-making process was largely influenced by temporal, social and political concerns around the delivery of health care to children. The data also explicitly illustrates the ways in which parents' encounters

with professionals, family and friends, shaped and influenced their perception of their child.

The chapter focuses firstly on the views of parents and then those of professionals. Children's views are not represented in this chapter in order to replicate the way in which their voices have largely been omitted from debates about their non-conforming behaviour. Findings presented in Chapter Six and Seven will illustrate that the need to include their active contributions is long overdue.

### **'Normal' or 'Different'?**

As indicated in Chapter Two, a heavy, unquestioning reliance on the theories of developmentalism and socialisation has led to a kind of 'common knowledge' regarding children. 'Normal children are the goal, judged according to physical, developmental and social criteria' (Mayall, 1996:51). Underpinning parents' concepts of 'normal' development is the traditional positivist belief in 'the' child as a universal phenomenon. Parents generally have a view of babies and children as being relatively passive, and pliable. The expectation is that 'normal' children are healthy, unproblematic, compliant, reach developmental milestones when expected to, and are not challenging or frustrating. Parents in this study recounted how they 'knew' their child was not like others as they did not behave like the stereotypical 'normal' baby or child, a situation which caused various degrees of distress within different family and social contexts.

This knowledge of what babies and small children should be like and should do at various stages was reflected in some of the responses given by parents responding

to the questionnaire, such as '*He never seemed contented, didn't sleep for long*', '*He was hard to keep entertained, cried excessively*' and '*Behind on the milestones, never slept very much, aggressive*'. Memories of the early years spent with their child were often vivid. In the interview situation, parents could recount in detail the impact of having a child who was very active, insatiable, and rarely slept for long:

Because she was my first as well it was difficult for me, but I knew she was different, I knew she was, right from 10 months, definitely, because erm well she put her foot on the bar of the buggy, she didn't have the shoulder straps, just the waist ones, and did a backwards somersault and hung out the buggy, and that was 10 months. And she walked, well she didn't walk, she ran, she took two walking steps and that was it, she didn't crawl, just ran. Same as talking, she didn't really babble, just straight into talking. And she didn't play with toys at all really. Then about 12 months she learnt that if she put her foot high enough up she could get out of the playpen, climb on the side, and decided that it was better fun to hoof the soil out of plants and things than play with toys. And then when she was at nursery, that's when I had to really try and get something done, but they weren't having it then, even though it was the same doctor's that I went back to, a different doctor I must admit, but same practice. Because what she did, we used to have to barricade the house up because she could get out, there was an alarm, a chain, there were two locks, and this one morning, at 4 in the morning, the milkman knocked the door with her, and she was only a nursery child! What she'd done, she'd got up, gone out, it was winter and she had just socks, shorts and a t-shirt, and they reckon she was on her way to nursery, because that's where they found her (Mrs Ling, Emma's mother).

Given the prominence of common sense theories of child development and socialisation, it is perhaps not surprising that the parents in this study perceived their children to be in some way 'different'. They defined 'difference' in terms of expected norms. Comparisons were made to other children of the same age; to siblings when they were the age of the child in question; to what parents had been told about themselves as children, and to available textbooks and articles regarding early childhood. Some parents, 20% ( $n = 9$ ) felt that their child was in some way

different from birth, but the majority of parents 62.2% ( $n = 28$ ) maintained that it was during the pre-school years that they became aware of their child's more unusual behaviour.

Of the mothers who felt intuitively that their young child was 'different', some sought to confirm this by conferring with other mothers, in their lay, informal networks, before approaching health care professionals. It was much later, often years, before their intuition was affirmed and legitimated by medical professionals. This experience is supported by other research which has shown that parents are often the first to suspect that there is something concerning about their child's development, but the issues raised are not always taken seriously (Audit Commission, 1994; Baldwin and Carlisle, 1994).

Amongst the broader study group, in most cases, the family GP took parents' concerns seriously (53%,  $n = 24$ ) and was sympathetic. Some parents who responded to the survey felt that their GP was unhelpful (11%) and 16% claimed that their GP implied their parenting was at fault. Both general practitioners and health visitors appeared to be working with a different definition of health than some parents. Thus, some professionals regarded children as unproblematic, given that they fell within the broad category expected of children of a similar age when measures of height, weight, and developmental targets were taken into account. Parents, however, held a wider definition of health and normality which encompassed the social acceptability of their child (Buswell, 1980). An important question for them was, 'Do my family and friends perceive my child to be normal?'

As mentioned earlier, a principal topic in James' (1993) research was whether parents perceived their child to be 'normally different' or 'differently normal'. Of the parents involved in my study only one of the seven could be said to regard their son, Marcus, as 'differently normal' in that the medical profession had legitimated his difficulties by granting a diagnosis of ADHD, but his parents minimized the disruption caused by regarding him as a regular ten year old boy who happens to have some difficulties which have been described as ADHD. Other parents in the study were more inclined to regard their children as 'normally different', in that the majority of poor behaviour was blamed on ADHD, in other words, the child was the condition.

Occasionally, over time, members of the extended family did express concerns regarding children. Michael's mother felt that her own mother perceived him to differ in some way from her other seventeen grandchildren:

'[...] she's (Michael's grandmother) known all along - she's always said to me 'There's something more to Michael than what...you know. [...] she's always known, she's always known, and she's very good with him' (Mrs Summers, Michael's mother).

Throughout the research it was generally mothers, rather than fathers or both parents, who recounted their intimate involvement with their children. Although questionnaires were sent to mothers and fathers, or mothers and their partner, and a request was made for each to complete the forms separately, it appears from the responses that the task was left to mothers. Similarly, although the fathers or step-fathers of six of the seven children inhabited the house where interviews took place, most implicitly withdrew themselves from the research. Both Chris's father

and Michael's step-father were present at every interview, but other fathers appeared to regard talking about their child's difficulties as part of the domestic sphere for which mothers are responsible. Such a gendered division of labour was apparent when Marcus' step-father was asked by his wife (in my presence) to take part in an interview he replied, 'I thought she'd come to speak to you', and left the task to his partner. Previous researchers have noted that when 'parents' are mentioned in relation to caring for children, it quite often means 'mothers' (Read, 2000; Mayall, 1996).

At the stage of raised concern and anxiety it was mothers who were especially inclined to take advice from family when making their decision whether to take the matter further, and perhaps consult a doctor. Decisions were influenced by the kind of support mothers were hoping to receive from doctors. Emma's mother describes how she became aware of a condition which seemed to tie in with her six year old daughter's behaviour:

It was quite strange really because my mum had seen something in a magazine about an ADHD child and she said, 'That's Emma all over', and then the same day as that came in the post it was about ADHD on one of the chat shows in the morning and everybody was phoning me saying, 'That's Emma, that's Emma, don't you think that's Emma?' and I'm like, 'Well I'm trying to watch it, but I can't!' (Mrs Ling)

Other parents told of news stories, dramas and documentaries such as *'Kid in the Corner'* (screened by Channel 4 in 1999) and *'Driving Mum Crazy'* (also Channel 4, 2002) which were specifically about families who had a child with ADHD, sometimes being able to see their child's behaviour as relative, claiming 'Thank God he's not as bad as that' (Mrs Summers). Parents who took part in the broader survey were asked, 'From which source did you first hear of ADHD?'. The most

popular response was '*through the media*'. Much of the media coverage of ADHD was sensationalist, partial or uninformed (Prior, 1997) so the implications of this were that parents often did not have a full understanding of ADHD before coming into contact with the health service.

Solberg (1990; 1996) notes how in other cultures the chronological age of a child can be less of a defining factor than in Western European culture. Age was a theme which was common in the accounts of parents in my study; it was extensively referred to as a defining category. Parents had certain expectations of children as they reached a particular age or milestone, and if children did not measure up or fulfil expectations they may be deemed to be 'immature' or 'behind', irresponsible, or not to be trusted.

At first you put it down to 'Oh well, he's only three', then only four, or only five, but you get to six and you can't keep putting it down to age. They act very immature, I mean, it sounds silly to call an eight year old immature, because they are, but it's too young - you'd expect that behaviour at about four, and that would be acceptable, but of course as they get older it gets more and more worrying (Mrs Hardy, Danny's mother).

Well, the headmistress has observed him and she says he's more immature and his behaviour is more babyish than the rest of the class; he wants attention all the time and they can't give him the one to one he needs (Mrs Summers, Michael's mother).

These children are defined as different and are unlike 'the' child. However, it can be argued that the 'normal' universal child against which these children are measured does not exist (James and Prout, 1990; Mayall, 1996) therefore parents and professionals alike are making comparisons with an elusive ideal. Disparities exist between the social experiences and expectations of children cross-culturally

(Solberg, 1990; Hallden, 1992; Qvortrup, 1994). In Chapter Two I referred to studies which demonstrate the specific nature of childhood in this culture in comparison to other countries. Experiential knowledge rather than chronological age are regarded as more important and cultural demands define what kind of behaviour is developmentally appropriate. The following section notes how parents look for ways of understanding, they need to know why their child is 'different' to other children.

### **Explanations for 'difference'/ways of understanding**

As Hyden (1997) contends, forms of lay knowledge and beliefs and medical expertise are difficult to disentangle. Parents in this study appeared to employ both systems of understanding in order to construct a meaningful account of events. It was common for parents to think that 'it was just a phase he was going through' when, as babies, children were 'unhappy, never settled, very demanding', and as toddlers 'never slept, always on the go'. Others who reported knowing that their child was 'different' from an early age often attempted to explain this 'difference' using disparate discourses which were drawn upon in order to make sense of the experience of having a child who differed from the norm.

Explanations linked to gender were most commonly used in the earlier part of the child's life. Parental concerns were allayed when family members would imply that the behaviour was normal for a child of a certain gender. Michael's mother reported his uncles to have often said 'Oh he's alright, he's just a normal child - he's a boy!' A minority of survey respondents concurred, as one parent said, 'Typical boy, into everything, completely different to our daughter, I thought it was

the norm'. The views expressed indicated a specifically western conceptualisation of masculine behaviour (Mac an Ghail, 1994). In their embodiment of gender boys are expected to dominate space (Young, 1989), climbing, running and being loud. School can be a physically restricting environment for boys (Mayall, 1996) and they are often to be seen 'acting out' within the classroom, demanding and getting more teacher time than girls (Epstein et al, 1998).

Differences were also explained in terms of individual characteristics. Thus, comments such as 'No two children are the same', or 'It was his personality' revealed a certain open-mindedness and a resistance to see the differences as a problem. Parents did not expect each of their children to develop or respond to discipline in exactly the same way, they were prepared to accept that children are individuals with varied temperaments. The children in question often seemed to have an unusual world-view, a need to question and discover, a dissatisfaction with monotonous daily life, and a desire for almost constant stimulation and these were sometimes regarded as positive qualities. It is important to acknowledge that 'normal' and 'different' are relational concepts; what is regarded as not normal must be different, but difference need not necessarily be viewed negatively. Crammond (1994) cited in Chapter Two regards the traits associated with ADHD as evidence of high creativity and a different cognitive style which can be viewed as beneficial attributes and, if channelled appropriately, can lead to positive outcomes.

As one mother's understanding of ADHD has developed, she now feels that hereditary factors have a part to play because she can relate her son's experience to her own:

It's funny, because we speak about it often, and I believe I have it, when I look back now, *absol-utely*. I was just talking to my mum yesterday and I said, you know, it's little things like I remember sitting in my English class and I was looking at the teacher and he was talking, but nothing. I'm looking at him, I'm thinking, I can hear him but nothing's going in, not a word. And after that you know you're scared to say anything, because you're worried, you think is it my hearing?  
(Mrs Adams, Ross's mother)

This mother's evolving familiarity with the characteristics associated with ADHD has helped to reframe her understanding of her personal experience of education as well as building genuine empathy for her son, who appears to be bright and articulate, but has difficulty in committing ideas and information to paper. Of the smaller study group of parents, five parents demonstrated similar empathy with their child, because they also remembered struggling at school. Particular reference was made to the similarity of their school reports, as Marcus's mum said when she showed me her final school report, 'You'll see in there, I tell you, a carbon copy! "Marion has the ability to do well but is easily distracted", etc!' In Marion's case, her negative experience of the education system, 'in the stream just above special needs', contrasted with her obvious ability (she has a degree and works as a qualified social worker). As a result she now emphasises the importance of educational qualifications, yet this is tempered by her utmost faith and belief in her son's ability to do well in life with or without academic success.

The mothers of Ross and Jack had also been told by family members that their own behaviour as children was not dissimilar to their sons, so they were prepared to

accept the possibility of a genetic link. This chain of belief begins with lay understandings and is reinforced by science, in that similar tendencies between adult and child are often regarded as inherited. Children identified as hyperactive are more likely to have parents with a history of hyperactivity and impulsivity (British Psychological Society, 1996). Both Ross's father and his younger brother were diagnosed with Tourette's Syndrome, which has overlaps with ADHD (Kewley, 1999; Munden and Arcelus, 1999). According to Mrs Clarke, Chris's maternal uncle was said to have behaved very much like Chris when younger:

I've got a brother who was a dreamer - another thing with ADHD - failed all his 'O' levels, but he had an interview at Warwick University and they liked him and said he could start there, do day release, and he became the youngest ever chief laboratory assistant. He went on from there and did a degree, and went on and did his PhD and now he's a fantastically paid geneticist/micro biologist in America - but he did it all in later life (Mrs Clarke, Chris's mother).

Recognising this possible connection, Chris's mum continues to emphasise the importance of Chris doing well at school, and spends a large proportion of her time trying to ensure that the school staff are aware of his disability and particular needs and are making the relevant provision.

Sean's mother is aware of features of ADHD in both her own behaviour and that of his father. Her view of the situation is an interesting one:

GB: And do you think his dad has much of an understanding about Sean's condition?

I think that's the problem, I don't know how much he understands of it really, he's a bit volatile himself, with ADHD being supposedly inherited I suspect that Sean's dad and me probably have an element in there somewhere, there are things that I recognise in both of us. Perhaps all these sort of odd balls getting together are all people with

this problem then they have children who have the problem and it's like completely crazy families! [we both laugh] Perhaps crazy's not quite the word to use! (Ms Jones)

In this excerpt Sean's mother expresses a sense of inevitability about people who are 'different' to the 'norm' yet similar to each other being drawn together to go on to reproduce children who will also have difficulties. Sean's older brother and sister did not experience the same difficulties, but inheritance is also accepted within these discourses as a complicated, non-linear matter.

Michael's mother also attempted to explain his experience in terms of genetic, hereditary characteristics but her account also shows the importance of social and environmental influences:

And also he's very forward in everything, in walking, apart from his speech, his speech was slower. When we'd go out with other children the same age he'd be the one to fall over, be clumsy, he'd be more energetic, and they'd go for an afternoon nap, whereas Michael would still be on the go, so I knew he was different, but also from his natural father as well, cos he was violent, and it wasn't because of drink, it wasn't drink related at all, no, I don't know what was wrong with him, his childhood - speaking to his mum, he used to go for his mum and her way of coping was to lock him in a room and she used to beat him with a stick, so whether that made him the way he was towards me (...) so I can't hate him for it because he obviously had the same as Michael only it wasn't identified. (Mrs Summers)

This woman's experience of having a child with aggressive tendencies is made meaningful when she recalls his father's violent outbursts. Although she seems to imply that there is 'obviously' a genetic link, she also acknowledges that being beaten with a stick may have made Michael's father *more* violent, and likely to repeat the pattern in his relationship with his wife. This example provides an interesting account of the complex inter-relationship of both biological and social

factors used by parents in their explanations of ADHD, suggesting that what is known as ADHD arises from an inter-relationship of biological, social and psychological factors. The British Psychological Society recognise that 'a range of different psychological mechanisms and biological causes can account for behaviours described as impulsive, overactive or inattentive' and therefore account needs to be taken of 'the interplay between environmental and individual factors at all levels of analysis' (1996:61).

The search for a specific cause was also apparent in parental explanations which referred to social factors. It was acknowledged that children's life experiences may have had an influence on their behaviour, as shown in the following comments garnered from survey respondents: *'Myself and his birth father split when he was eighteen months old'* and *'He was abused by his birth mother and foster parents'*. Some parents wondered if their child's position in the family could have influenced their behaviour - being the youngest, or an 'only child' led some parents to wonder if their child was spoilt with attention and therefore sought it. It appeared that although position in a family is biologically determined, parents worked from a social understanding of the meaning of birth position, often referring to lay perceptions of what it means to be an eldest, a middle or a youngest child.

When families sought help from health or welfare professionals, enquiries were usually made into their social circumstances. Death or divorce in the family, domestic violence, parental separation, the possibility of bullying, were all investigated. Emotional and behavioural problems could certainly stem from such traumatic incidents but within the contexts of investigations parents were at pains

to state that whilst such events may have influenced or exacerbated the problem behaviour it had actually been noticed some time previously, often at a pre-school age. Woodward, Taylor and Dowdney (1998) found that psychosocial factors are of importance in influencing the severity of difficulties in children with hyperactivity. This seems to suggest that a full and sensitive exploration of all possible contributory factors should be carried out.

Many parents expressed a sense of guilt or self blame, if they felt their child's behaviour could have been caused or made worse by their own actions. Sometimes they felt that they were lacking in the competence and skill required to deal with this particular child's behaviour, even when they felt confident in their parenting of other children in the family. In common with mothers of disabled children (Read, 2000; James, 1993) mothers asked themselves what they had done wrong or differently during the pregnancy, birth, and formative years. This feeling of responsibility and guilt sometimes caused parents to alter their way of relating to their child, as indicated in the following quote:

We looked closely at our parenting skills - he was our eldest child and we felt we were not handling him well. (Questionnaire response, Mother of boy, aged 15)

This child's mother was a Special Educational Needs Co-ordinator within the primary setting and his father a secondary school teacher; they looked towards environmental and social factors for an explanation for his behaviour as their own professional training had emphasised these as influential. It was not until their son was fourteen years old that they began to acknowledge that biological factors might also play a part in his behaviour, and he was assessed, diagnosed and treated for

ADHD. This viewpoint is echoed by many other professionals in their respective fields, in that explanations for behaviour are expected to have either purely social causes or purely biological. This is unhelpful in the conceptualisation of ADHD. Evidence seems to suggest that ADHD does not arise from purely social or environmental factors, although both can exacerbate the condition (Barkley, 1990).

Chris's parents also blamed their own parenting skills, and as Chris had no siblings they were unable to make lateral comparisons within their family, yet they could compare him with the uncle mentioned above. After many years of feeling blamed for Chris's behaviour, his mother reminds herself that the success of her childminding ability seems to absolve her of blame and therefore guilt:

I keep saying to my husband, I spend more time with these children I look after than their own parents do, so if it was me surely all those children - or some of them - would be like it too, and they are not, they are just not (Mrs Clarke, Chris's mum).

Parents at times seemed to regard children as a reflection of themselves; when their behaviour seemed to be the antithesis of that of their parents this was felt to be personally shameful. As demonstrated in the examples provided, gradually, over a period of time, parents began to turn to medicine in their search for an explanation for the difficulties which they were experiencing with their children. Medical vocabulary began to be used to define the behaviours. The increasing media profile led to raised interest in the topic of ADHD. Armstrong (1983) notes that one of the consequences of the growth of medical knowledge in the twentieth century was the proliferation of different types of 'child', differentiated into categories of perceptual difference from some notional model of the 'normal' child.

### **Prevailing attitudes - 'I blame the parents':**

Parents are subject to external monitoring and surveillance from professionals, practitioners, the community, friends and family. They struggle to hold onto the belief in their ability to be a 'good' parent, sometimes despite parenting other children successfully. Parents often felt inadequate, cheated of a normal loving relationship and the chance to ensure that their child was happy and secure. Parents find themselves publicly accountable for their children, and they generally accept the expectation that they are required to be 'in control'. Children who appear to behave inappropriately, or not respond to discipline, lead to parents' competence being called into question by educators, social workers and legislators. Parents are expected to oversee their children's passage through the pre-determined developmental stages and ensure proper socialisation (Elias, 1994). The traditional division of labour frequently leaves mother's responsible for the welfare of their children. Mothers were the principal carers in my study, and they provided rich descriptions of their experiences of their children. Michael's mother expresses how frustrated she felt when other adults showed little understanding of the difficulties she faced:

But it's also when I go to collect him from school and I've got the bobby (*sic*) in the pushchair and I'm trying to control him with one hand and steer the pushchair with the other, cos he's all over the place and there's main roads everywhere, and if I don't he runs straight out into the main road - he's run straight in front of a car and luckily it's stopped and not come out, but you know, then I get a mouthful of abuse from 'em. But if I hold on tight to him he gets mad and starts shouting for me to get off, and I'm trying to control this pram and I sometimes just feel like going 'Aaaahhhhhhh!!'(Mrs Summers, Michael's mother)

For several of the mothers, being judged by others and regarded as somehow to blame for their children's behaviour caused real distress. It led them to feel ashamed and embarrassed. They encountered discrimination and bigotry within the lay community, and from some professionals. Often opinions expressed by members of the family, friends and people within their community contained the implication that their parenting skills left a lot to be desired:

The nurses I work with have seen Danny on form, rolling around the floor etcetera, and the younger ones were very scathing, 'He wants a good slap', 'She wants to keep him under control', sort of thing (Mrs Hardy, Danny's mother).

In Miller's research with women in the process of becoming mothers she notes how it is not easy for them to give an account of their experience if it does not resonate with the public story of motherhood (Miller, 1998). In my study mothers were aware that their experiences and feelings about their child did not always reflect those of other mothers but they relished the opportunity to share their experiences with me and were keen that, through my work, public recognition of their stressful family life might be gained. Even undertaking a routine activity, such as the weekly food shopping, could be a major source of stress for mothers, when children were constantly touching the array of brightly coloured goods, sliding across supermarket floors, and running away. Bus journeys were especially problematic, given the wait for the bus to arrive, the seating arrangement, and the reaction of the public to a seemingly 'uncontrollable' child. The insensitive reactions of fellow passengers often led to frustration and embarrassment:

When he was five you could tuck him under your arm, but when he got to that age you couldn't take him on the bus anywhere, he'd be running up and down the aisles, up the stairs, ringing the bell, climbing under them and over them [people]. What do you do? When everyone's looking at you thinking, and saying, 'Can't you control that child' and

the answer to that was, short of putting him in a straitjacket and hanging him on a hook 'no'!! (Ms Jones, Sean's mother)

Parents were criticised on various levels - for being too liberal and not using corporal punishment, for being too disciplinarian and not engaging in discussion, or for being inconsistent. Mothers took the public responsibility of mothering seriously, so to have 'no control' over one's children was strongly felt by parents to be the harshest criticism as 'socialisation in the name of private and public moral norms requires women to control their children' (Mayall, 1996:34). Danny's mother felt that such negative reactions could be particular to British culture; she explains how, whilst on holiday in Spain, her son behaved in a way which was unacceptable to some people, but accepted by local people:

[...] it was a buffet style serve yourself, and you went up to the chef for your meat. Now, any other five year old child would have done as they were told and sat down and let me serve them - not Danny - he wants to go round the table and of course making a decision takes absolutely ages so I just ignored it in the end, and people were sighing and tutting and staring at me to do something. But do you know what? The people who were behaving like that were our nationality, the other guests simply leaned over and helped themselves and carried on, [...] then he'd be running round in bars and places but the continentals just moved their drinks and let him get on with it, saying to me, 'No worry, he's just a boy!' (Mrs Hardy, Danny's mother)

Derogatory comments regarding children's disruptive behaviour often had a strong emotional impact, to the extent that broader aspects of family life were affected. Those that shared the home, such as siblings, were often affected by the inequitable amount of time parents spent on dealing with the 'difficult' child. <sup>6</sup>Mothers especially felt that their other children were in some way

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<sup>6</sup> The voices of siblings do not feature in this study but their experience of living with a sister or brother with ADHD is a further neglected area of research. Studies which explore the impact of disability on the lives of siblings are becoming more usual (see Stalker and Connor, 2004).

being neglected, or missing out on positive family experiences. Relationships with some friends and family were tense, as visits to their homes could frequently result in a trail of destruction - broken toys, ornaments, arguments and fights. Danny's parents' friends had stipulated that they would only visit if Danny was in bed. Others found that their social lives declined because few friends were understanding. In some cases, socialising was extremely limited because of the activity levels of their child with ADHD:

We won't go anywhere because of his behaviour, but that's not fair on Aaron [younger brother]) but I don't want to say to someone 'Can you have Michael while we take Aaron out?' because then Michael will think 'Why can't I go?' Sometimes I've left Michael behind [with family], and I've felt guilty but I've had to because I'd like to enjoy the day myself for once (Mrs Summers, Michael's mum).

Social contact became minimal at the very same time the family's need for support was greatly increased. In some cases, the physical and psychological well-being of mothers was affected. A small number of mothers indicated that the sense of guilt and blame, coupled with the sheer exhaustion of daily life with an energetic child, led them to seek professional help for clinical depression:

I think what happens is that it's something that disrupts the entire family and it's not surprising that at some stages we come across as completely dysfunctional because, in a way, that's how it makes everything. You're at your wits end knowing what to do to cope with it. [...] I was treated for depression, most certainly, I don't know about *thought* that the men in white coats might come, I was *hoping* the men in white coats would come and take me away because it was just too, too, exhausting, mentally and physically exhausting. (Ms Jones, Sean's mother)

A number of questionnaire respondents also mentioned having depression (this information was given in different places throughout the questionnaire), although it was not indicated whether this was a clinical diagnosis.

Maternal depression was sometimes a factor which confused health professionals in their assessment of the child. Judgements were made regarding the mother's ability to parent, it was often assumed by health care professionals that her depression was the cause of the parent-child relationship difficulties, but, as one mother put it, 'What is the point in treating the symptom, it is basic medicine to try and find the cause' (Mrs Hardy), implying that dealing with her child's difficult behaviour had caused her to become depressed. In a study by Edwards et al (1995) families of children with ADHD were found to have difficulties with marital discord, higher levels of stress and feelings of parental incompetence; it was not, however, possible to determine to what extent parents experience these problems because of the way their children are behaving or whether the depression was there anywhere.

Brown and Harris (1978) and Graham (1984) found that women have been assumed to be depressed without reference to the influence of their social circumstances. Read (2000) reviews literature which draws attention to the damaging misconceptions regarding disabled children and their families, in which it is implied that dysfunctional parents cause disability. Managing the behaviour of a disabled child can lead to dysfunction where there was organisation, and ill health where parents were well before.

It is possible that dominant definitions of 'motherhood' may have influenced the responses of health professionals; mothers who spoke of not liking their child, or of a lack of bond or intimate relationship, may have been seen to be 'ill', as mothering is expected to come 'naturally' to women (Ribbens, 1998; Miller, 1998; Letherby,

2002; 2003). There seemed to be little appreciation that children's temperament and expression of needs largely shape and structure the relationship between mother and child in an interactive way. The mothers in my research often felt alone with their problem, misunderstood and rejected by society.

The external monitoring to which mothers are subjected can be internalised and become self-monitoring; influenced by ideologies of motherhood and the uncritical acceptance of child development advice, mothers became critical of themselves. They were committed to making the lives of their children fruitful and enjoyable yet their feelings towards their child were sometimes complex and ambivalent. The concept of the 'good' mother has a normative, moral status, and implies inherent qualities. A 'good mother' will be caring, responsive, patient, understanding, and will always put the needs of her children and partner before her own needs; women who do not adhere to such norms are regarded as deviant mothers by wider society (Ribbens, 1993).

[...] parenting is being privatised with parents being held much more responsible for their children socially and economically (O'Neill, 1994, cited in Alderson (2000).

Of central importance in the data above are ways in which mothers are positioned as responsible for their child's behaviour at all times and the 'subtle communications' (Ribbens, 1998:35) which indicated that either mothers or their child were deviating from societal expectations of appropriate behaviour. There was also evidence of occasions when direct and explicit comments had been made to mothers and sometimes the child themselves. Powerful ideologies of motherhood, and childhood, influenced the responses of family, friends and the

wider public. Letherby (2002) notes that motherhood is valued in our society, although not structurally supported. Contradiction exists as although the behaviour of children might be regarded as a family matter, and mothers certainly felt that they were alone with their difficulties and it was of no concern to anyone outside the private sphere, the comments made by various people outside the family indicate a public concern with the matter. Jenks (1996) would argue that this stems from a concern for the future generation. With the gradual turn towards medicine in order to seek an answer to their child's inappropriate behaviour, it can be argued that the matter evolved from a private to a public issue.

### **Parents search for recognition: why won't they just listen?**

Chapter Three explored debates around the medicalisation of social issues. Misconception regarding ADHD abounded during the 1990's, and was partly linked to sensationalised media reporting and disagreement regarding the cause of and treatment for ADHD. Many health and welfare professionals who parents had encountered were either unaware of ADHD or misinformed. Chris (15), Sean (12), Emma (12) and Frank's (12) parents had experienced their search for help as a struggle. Various agencies were approached, but a positive response was rare, with families becoming part of long waiting lists. Zola (1972) claims that by accepting a specific behaviour as an 'illness', defined as an undesirable state, the issue becomes not whether to deal with it but how and when. Once the concept of ADHD had become established it was widely used and recognised. To conceptualise the behaviour of children in this way led to help and treatment rather than rejection and punishment. Conrad and Schneider (1980) and Conrad (1992) note how with the gradual development of a medical frame of reference parents

begin to seek a medical answer; this is regarded as medicalisation at the conceptual level.

Parents who had sought help for their child previous to 1999 had waited a long time for an appointment with CAMHS, and many had been dissatisfied with the outcome of their visit. This is borne out in the questionnaire responses in that 33.3% ( $n = 15$ ) were cases of re-referral. These were generally parents who had persisted in wanting a further opinion. The situation by the time of the fieldwork had greatly altered, and parents were having more success in getting their GP to refer them to a specialist service for a full assessment. ADHD had become a frame of reference with which people were familiar, partly due to a raised media profile and a prolific output of research in the US context. The parents of Jack (9) and Michael (6), and others with children in the younger age group, were able to report that their concerns were acknowledged and the route to diagnosis was less problematic, with an average waiting time for first appointment with CAMHS being three to four months. By drawing on the data gathered during observations at a CAMHS, it is possible to shed some light on the various responses received by parents to reveal not an inefficient service, or evidence of poor practice, but a complex service, which is the result of several inter-related factors. Different professional perspectives, agendas, and access to knowledge led to a sometimes incoherent response to need.

### **Moral, social and political concerns around the delivery of child health care**

The lack of knowledge and inconsistency of response in previous years is not altogether surprising, given the ambivalence and tensions which I observed within

the specialist CAMHS. Aspects of the service have indeed improved, but some issues remain of concern.

Although parents may have perceived practitioners to be apportioning blame when questions were asked about family background, home circumstances, and parenting strategies, it was necessary to discount the kinds of events which may have led to the emergence of the described behaviours. Some parents resisted an authoritative attempt at surveillance. They had waited a long time for an appointment with CAMHS and had one chance to be taken seriously. Those who realised that the subjective opinion of the practitioner was of importance in this encounter were careful about the way in which they presented themselves. Goffman (1963) makes reference to the bodily production of social hierarchy, drawing attention to the ways in which individuals manage their bodies in public places. Goffman's use of front-stage/back-stage metaphors to emphasise how people engage in strategic forms of interaction could be applied to the behaviour of some of the parents in my study.

The way in which questions were asked, and case histories were taken, was influenced by the professional background and personal philosophy of the practitioner concerned. Within CAMHS, various professionals were part of the service responsible for assessing children with behavioural difficulties, under the remit of the 'general allocation' of cases. Therefore, disparate philosophies underpinned the conceptualisation of children's difficulties, and led staff to emphasise different aspects as influential in contributing to any difficulties. For example, social workers and psychologists would be keen to explore social and

environmental influences, and perhaps a little reluctant to acknowledge biological factors. Psychiatry acknowledges a social influence, especially if symptoms have a recent onset, but seeks an underlying pathology. The conceptualisation of a problem influences how it is dealt with. The existence of a more specialised ADHD service since 1999 had provided a 'route' for referrals but had the existence of the service led to a rise in the number of children receiving a diagnosis of ADHD?

Within the course of my observations at CAMHS, members of the 'ADHD team' were not averse to openly discussing their concerns about the diagnostic process and the way in which the Service was being/had been run. In November 1999, at a quarterly strategy meeting, Doctor Watson expressed feelings of remorse for having worked for the CAMHS for several years, but not dealt adequately with children with behavioural difficulties in the past. A colleague, Dr Turner, agreed that ADHD was not 'being looked for' in the past in the way that it was now and commented 'if only we'd known then what we know now'. The consultant team leader assured both that they had not let anyone down, but done their best with the knowledge available at the time. The staff were referring to a period when the consultant in post previously, with overall responsibility, felt that he was not knowledgeable or qualified enough to diagnose ADHD, and was unable to support his staff in doing so. Therefore, ADHD was not officially recognised or diagnosed in this Health Authority, and medication was not available. There were children in the city who did have a diagnosis, but this had been gained either from an outside health authority or through private practice.

Many of these earlier cases had since been seen and diagnosed, but only if parents had remained persistent and insisted on being seen by the service again. I could not help but wonder what happened to the parents who were completely demoralised by their experience, and did not pursue their concerns. Have their children continued to be regarded as 'naughty'? Do low expectations of 'disadvantaged' children lead to a fatalistic acceptance of such behaviour, rather than investigation? Some disadvantaged parents may not have the 'economic, social and cultural capital' (Bourdieu, 1986) to persist in their struggle to gain recognition of their child's difficulties - more immediate social factors, such as bus fares to get to appointments, may be of more critical importance.

In a further example of discussion regarding the future development of the Service Doctor Turner revealed her concern for clients reaching the age of 16, who would need to move onto adult psychiatric services by the end of the school year. As clients of adult psychiatric services they would receive either a six month or annual review, rather than quarterly. The doctor's concern stemmed from her perception that there was a lack of knowledge and experience of ADHD amongst psychiatrists in the adult service. She raised her concerns at a meeting of the ADHD team; she was particularly worried that young people would react to the stigma of attending a psychiatric unit, and the implications of seeing themselves as having a mental illness rather than a behavioural problem. The team leader, Doctor Mills, acknowledged that the situation was not ideal, and that there were unknown factors as cases had not so far been passed across to adult services, but he also advised doctors to have faith that others 'can manage our kids', saying 'let's not get

precious about it'. Doctor Turner continued to stress that it would be good to develop links with adult psychiatry, and to be kept informed of the young person's progress<sup>7</sup>. Organisations are often portrayed as unemotional places and men working within them as not emotional enough (Hearn, 1993); it is possible that Dr Mills may have been working hard to maintain the appearance of 'non-emotionality', perhaps compartmentalizing his emotions. Hearn argues that more powerful men often control the emotion labour of women who themselves may manage the emotions of clients or patients (1993:160). Recent developments in mental health services have drawn attention to the need for child and adult mental health services to work together to ensure a smooth transition for young people. The Mental Health Policy Implementation Guide (2001) requires staff in a number of agencies to work together to support young people with mental health difficulties, to make the transition to adult services less stressful and more positive.

Although in this study parents who had brought their child for assessment were sometimes angry and disappointed that ADHD had not been diagnosed sooner, they were unaware that health care professionals in previous years were unsupported by the lead clinician and the health Trust in making diagnoses of ADHD. The appointment of a new consultant in 1999 led to a change in practice and additional resources which better met the needs of families. This also led to a sharp rise in the number of children diagnosed with ADHD in the city; only six children had a diagnosis when the consultant came to his post, and within ten months this had risen to one hundred and twenty two (observation of meeting 11.1.00). At the time

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<sup>7</sup> A short while later the first case was referred to Adult Mental Health Services. When Dr Turner enquired how the 16 year old young man had managed the transition she was informed that he had

of the fieldwork a similar sharp rise in diagnosis in another Midlands city CAMHS had led to the suspension of a consultant psychiatrist and the start of an investigation (the subject of the aforementioned *Panorama* programme). In this way, the broader social and political context had an impact on practice. The media attention and public debate it generated led clinicians to ask questions of their own practice and introduce safe-guards such as clearer record-keeping and written protocols. The above examples demonstrate that ‘expert’ medical knowledge is socially constructed; doctors are operating in a wider social and political context than generally acknowledged.

The above discussion clearly relates to debates which have taken place between evidence based and value based medicine. Evidence based practice implies that scientific research should be more highly regarded than values based medicine, practised by experienced clinicians, yet ‘[...] applying general knowledge to particular cases depends on skills to which “craft” or implicit knowledge is as important as the explicit knowledge which evidence-based practice supplies’ (Fulford, Murray, Dickenson, 2002). In the health care encounter different kinds of knowledge are being drawn upon by professionals and lay people; emotion, intuition and lived experience should not be excluded as invalid or non-rational as each plays a part in creating a whole picture of ADHD.

These examples of reflection on practice which I observed serve to illustrate the paradigm shift in medicine, particularly psychiatry; as both Strong (1979a) and

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since been re-diagnosed. This served to increase concern about psychiatrists working for adult services’ knowledge regarding ADHD.

Williams (2001) point out, it can no longer be assumed to resemble the biomedical caricature still referred to by many social researchers. Granting medical diagnosis can appear to be an objective, value-free enterprise, yet various factors are of influence, such as the personal morality of the health care professional, the underpinning ethos of the team, and the political stance of the health institution. The above examples indicate the nature of the relationship between lay and expert knowledge both within the clinical setting and within individual practitioners. It was the case within my research that at times health care workers experienced conflict between their own professionally based views and their moral position. Health care professionals reflected on their position of power and the impact which their decisions had on families; this gave an insight into the complexity of health care practitioners' perceived moral and social responsibilities; it was not just a job which they did with objective detachment, they were emotionally involved. Over time, there were other such examples of professional conscience, although a gendered division, not uncommon to research on emotions in other organisations (Hearn, 1993; Fineman, 1993) was present.

Inevitably, undertaking work in emotionally charged situations had an impact on these doctors. Some chose to air their anxieties, regrets, frustration, and fears, whilst others did not relay their emotional experiences to their colleagues. A gendered division was apparent, in that Dr Watson and Dr Turner, both women, were more likely to discuss issues other than the 'facts' of cases at team meetings. Doctor Mills, the male consultant, appeared to be more self-assured; he had more expertise and experience in the area of ADHD, and had a wide knowledge of the research base upon which claims regarding the validity of the ADHD concept and

the efficacy of medication were based. He regularly stated that he felt confident that children in need of help were being assessed and treated. He did not publicly reflect on his practice in the way that Doctors Watson and Turner did. This may, of course, relate more directly to his position in the medical hierarchy, and less to the differential of gender or it could be that each reinforces the other. Stacey (1988), Davies (1995) and Witz, (1994) have all given an insight into the gendered division of labour in medicine and the dynamics of gender in institutions in the health care field (Davies, 2002).

The implicit influence of differing professional ethos should not be overlooked, as each of the three principal doctors had come to their role via different routes. The ADHD team leader (consultant) was a neuropsychiatrist, Dr Turner a family therapist, and Dr Watson a former GP, which may also help to explain their differing approaches to understanding the problems with which families were referred. Scientific underpinnings give the impression that medical (psychiatric) practice is neutral and objective, that by using the same diagnostic criteria the outcome of assessments carried out by different members of the ADHD team would be the same. It fails to acknowledge that medical practice is value-based, and ultimately subject to the individual judgement of clinicians, assisted by the diagnostic criteria.

## **Discussion**

Among the parent respondents in this study 'difference' is primarily explained in biological terms, as genetic, hereditary or in-born; at a pre-diagnostic stage parents still take social factors into account, such as the influence of their style of

parenting, but find that they are inadequate in explaining the behaviour, which has often been noticed from pre-school age and sometimes from birth. With the passage of time, it is no longer possible to separate the various strands of lay belief and medical influence contained in parents' accounts:

Parents sought professional opinion, which they then amalgamated along with the rest of the lay knowledge which they possessed. '[...] respondents' stories moved back and forth between lay concerns and perceptions, and a growing familiarity with medically-based ideas' (Bury, 2000:269).

Interestingly, it would appear that at the earliest stages of diagnosis health professionals and parents were operating with varying concepts of 'normal' and 'different'. Providing children were within the defined range of normal development and behaviour, professionals would try to allay parents' concerns and fears, reassuring them that their child was not unusual. Parents, however, had a particularistic, intimate knowledge of their own child, which included a notion of social acceptability, and consequently felt that their child did not fit with their personal concept of a normal, healthy child, which had been shaped by available discourses (Buswell, 1980; James, 1993). The narrative reconstruction of biographical events - namely, the symptoms, the event, the diagnosis and the ways of coping - cannot be regarded unproblematically as 'simply a matter of recall or report'; it is an interpretive process which draws on particular discourses of childhood (James, 1993:41). James comments that parents in her study 'offered stories which were well-rehearsed' and that 'the past had been extensively recounted, reworked and gone over' (James, 1993:39).

Accounts given by parents in this study serve to illustrate the differential status which was afforded experiential knowledge in comparison to that of the medical 'expert' (Cornwell, 1984; Stacey, 1988; Williams and Calnan, 1996; Hyden, 1997). In the years previous to 1999, parents' accounts of their child's difficulties, based on their intimate knowledge of their child, were, overall, dismissed by health and social care professionals. In some cases they were regarded as over-reacting, or their parenting skills questioned. In most cases, it was a number of months, and in some cases years, before children's behaviour was finally acknowledged to be characteristic of hyperactivity or ADHD. This research raises questions about the value and status of knowledge, the kind of 'expert' knowledge drawn upon by professionals, in this case particularly health care workers, and the kinds of knowledge possessed by the lay population. The socially constructed nature of medical knowledge is also apparent in the account given of observations at the CAMHS. It is to these related points that I will now turn.

The health care professionals observed at CAMHS were wary in their practice, they were careful about the wording of information regarding the condition, and careful to leave the option to receive medication for children in the hands of parents. The dominant view of the medical profession 'constructs clinical decision-making as a precise, certain and scientific practice' (Hatt, 1998), yet there may be an acknowledgement of 'medical uncertainty' in clinical practice. The empirical data presented serves to illustrate that health care professionals felt that they had a burden of responsibility to both their clients and their profession. They could be held accountable if mistakes were made, which was of concern to them, but the data also indicate a moral conscience. Furthermore, decision-making was at times

shown to be based on ethical values. These particular clinicians were not completely detached or disengaged, they appeared to be emotionally involved in their work, showing empathy towards parents and children and young people themselves. Such empirical examples demonstrate that doctors engage in 'emotional labour' (Hochschild, 1989; James, 1989) in their work with families.

It is possible that what has been regarded by parents as inefficient service, or poor practice, where parents believed that the professionals to whom they turned for help did not listen to their account of their child's difficulties, choosing to reframe or dismiss their concerns, arose from a lack of awareness, a lack of resources, and a lack of Health Authority commitment to diagnosing ADHD. In previous research studies parents also received a sceptical reaction to their accounts of their children's difficulties (Burton, 1975; James, 1993). Parents' success in being given a diagnosis of ADHD for their child as a point of reference was largely dependent on approaching an individual who had knowledge of the condition, at the right time, coupled with their own perseverance and determination.

Difficulties with behaviour can be constructed in various ways; the biomedical discourse is but one way of understanding the kind of behaviours which the respondents in this study have described. With the most dominant frame of reference being medical, it is not surprising that children's difficulties or differences were conceptualised in medical terms. The biomedical discourse constructs the 'problem' as a mental health issue and provides a 'miracle' treatment; the discourse is reinforced because medical experts provide a quick fix solution. In addition, parents begin to feel absolved of blame; other discourses

which take a more systemic approach to understanding require families to acknowledge that interaction within the family home may play a key role in exacerbating or alleviating children's behaviour.

## **Conclusion**

I have argued that the issue of children's deviant or inappropriate behaviour, which was thought by many to be a matter of individual personality, to be contained within the family, gradually became a public issue when a diagnosis of ADHD was made. At this point the 'psy complex' (Donzelot, 1980) became involved and the child became part of a cohort of children so diagnosed. Following medical diagnosis the stereotype of the 'ADHD kid' became associated with the child. Viewed using Mills' (1958:187) concept of personal troubles/public issues the respondents' 'personal tragedy' then becomes a very public issue and what an individual 'feels to be personal troubles are very often also problems shared by others, and more importantly, not capable of solution by any one individual but only by modifications of the structure of the groups in which he lives and sometimes the structure of the entire society'.

Attention is here drawn to the following tension: medical diagnosis according to Zola (1972) and Conrad (1992) tends to result in the behaviour of children being regarded as a 'private' matter, which leads to the issue becoming depoliticized. Yet the private matter of a child behaving inappropriately becomes a public issue as the child becomes part of the system of medical surveillance. Simultaneously both a private trouble and a public issue, a medical frame of reference has become more dominant, and parents are looking towards medicine for an answer to children's

non-conformist, lively, and often challenging behaviour. The following chapter asks why this might be the case: what are the benefits of diagnosis? And, equally importantly, what are the disadvantages associated with such a label?

## Chapter Six

### ADHD Diagnosis: 'Lifeline' or 'Label'?

#### Introduction

Having outlined the steps which parents took in order to find an explanation for their child's inappropriate behaviour this chapter moves on to explore both parent's and children's active response to finding out that the explanation for children's difficulties lay in the condition of ADHD. I will explore the social, emotional and material consequences and benefits of medical diagnosis. The majority of parents who had experienced dealings with the medical profession as a 'battle' may have perceived a diagnosis of ADHD for their child as the end goal, but often they found that their struggle with authority was not over, as they were required to advocate for their child's educational and social rights and needs. There are, however, less positive aspects to receiving a medical label, including the stigma which may be attached to being seen as 'different'. The accounts presented here, gathered from parents and children, highlight the tension which surrounds the issue of medical diagnosis and the prescription of psychostimulant medication. So in what ways did receiving a diagnosis of ADHD make a difference to the lives of children, young people and their families?

#### **Ambivalence and tension: stories of lifeline**

##### Initial reactions to diagnosis

The importance of being listened to, taken seriously and believed, was evident in the accounts of parents. When I asked Marcus' mother how she had felt since he

was diagnosed with ADHD she answered: 'Relieved. Relieved to know it's not my parenting skills, not my fault'. As Voysey notes, in cases of a clear diagnosis and certain prognosis '[...] diagnosis is typically experienced as a 'relief' after earlier ambiguity' (Voysey, 1975:120). Both Sean and Marcus' mothers had been single parents for much of their son's lives, and indicated that they keenly felt judged for having such a 'badly behaved' child; the diagnosis of ADHD was seen to provide absolution:

I felt I needed to talk to somebody about it, those who knew about this behaviour, and for me to say "Well, he's not the naughty child that you always thought he was, he's got a diagnosis" (Mrs Baldwin, Marcus' mother).

Because of where we lived - a poor area, a council house, a single parent - they assumed that it was those problems, coming from a 'disadvantaged background' rather than a problem with a name [...] it was just sheer luck finding a doctor who knew something about it [ADHD] (Ms Jones, Sean's mother).

The diagnosis helped parents to order the events of their child's life. It all made sense once they were informed that their child had a condition. Of parents who took part in the survey 87% agreed that 'parents tend to blame themselves'. The provision of a frame of reference helped to explain their child's 'different' life experience, and to confirm parents' intuition. Bury (1997) also draws attention to the importance of 'disease categories' to lay people (1997:121); an illness label provides identification and gives meaning to their experience. Michael's mum also experienced relief, tinged with anxiety, when she was told that her son met the criteria for ADHD, she thought 'Yes, he has got something! But the other half of me says, "Oh God! Not medication!"' Michael's mother had great difficulty

accepting that her son might need 'drugs'. She had heard only negative things about stimulant medication:

I don't want him on the Ritalin because he has good days, and I don't want to give him tablets when he's good, because Ritalin you have to give it them every day, you can't just give it them on the bad days, I mean I wish you could but you can't (Michael's mum).

Michael was the only child of the in-depth interview sample of seven who was not, and had not been, taking medication. His parents had almost relented on several occasions, and felt extremely pressurised by Michael's school:

Yeah, in all the reports, you see, it's got "Parents have chosen not to put him on Ritalin", it's like they're holding back on properly assessing his needs because they think if he goes on Ritalin they won't have to pay so much out for his education (Michael's mum).

This mother perceived there to be political and economic issues at the heart of the delay in providing a statement of educational need for Michael. However, the effect of Michael's boisterous, defiant behaviour on the family eventually reached crisis point, and his mother and step-father made the decision to ask for medication at Michael's next check-up. A week before this appointment, the BBC screened a 'Panorama' programme entitled 'Kids on Pills' (10.4.00) which indicated that many children with ADHD came from one parent families, that the concept of ADHD was an excuse for inadequate parenting, and that using medication to change children's behaviour was totally inappropriate. Insufficient attention was given to any benefits for children and parents which treatment provided. The programme incensed parents who I was in contact with who had struggled for years to have their child's condition recognised, and did 'a lot of soul searching' before reluctantly agreeing to try medication, and it increased anxiety amongst parents who were currently considering whether their child needed medication.

Much of what parents knew about ADHD at the time of diagnosis had been gathered from stories in the media. There was no doubt that the media portrayal of ADHD children was often unfavourable, headlines such as *'T.V focus on the children from hell'* (Coventry Evening Telegraph, 29.11.99), *'More children to get 'kiddie cocaine' drug'* (Metro, 28.2.00), and *'Ritalin made my son a demon'* (The Observer, 9.4.00) had a major influence on parents, friends and family, the public and children themselves. The way in which ADHD was portrayed by both newspapers, magazines, and some television programmes often relied on inaccurate descriptions of ADHD, sensationalised reporting regarding the effects of medication, and negative imagery of glum, despairing parents and over-active, destructive children. Much reporting actually questioned the existence of the condition and was highly critical of the use of medication. Newspapers tend to focus on personalised, specific instances of 'suffering' parents, and highlight research findings which often cannot be substantiated, or are only applicable to the US situation. Such sensationalist journalism at the time of the field work served to demonise both the children diagnosed with ADHD and the medication most often used in treatment, which fuelled parents' anxieties. The subject of ADHD is sometimes topical, other times not so; the year 2000 brought a prolific number of articles on the condition which possibly supports Jenks' (1996) view that the coming of the millenium heightened concerns about the future generation. ADHD does, however, seem to be less prevalent in the news since the National Institute of Clinical Excellence approved of the use of Methylphenidate in children of 6 and above. (Nov 2000).

It was in this climate that Michael's parents attended their appointment. His mum told the doctor that it had taken her a long time to make up her mind about medication, and that she was coming here today to ask if Michael could be prescribed Ritalin, until she saw the Panorama programme, and now she thinks 'No way!', as she was worried about 'changing his personality'. The doctor talked through the concerns and fears which the programme had raised, giving clarification on some of the issues, and confirming that information on long-term use of Methylphenidate is lacking, but that regular check-ups should ensure that any changes in health would be noticed early. Whilst this conversation was occurring Michael was drawing a picture of an intricate machine (Figure 3); he turned to his step-dad and asked him to entitle it 'Michael's Best Machine to Discover Things Out'

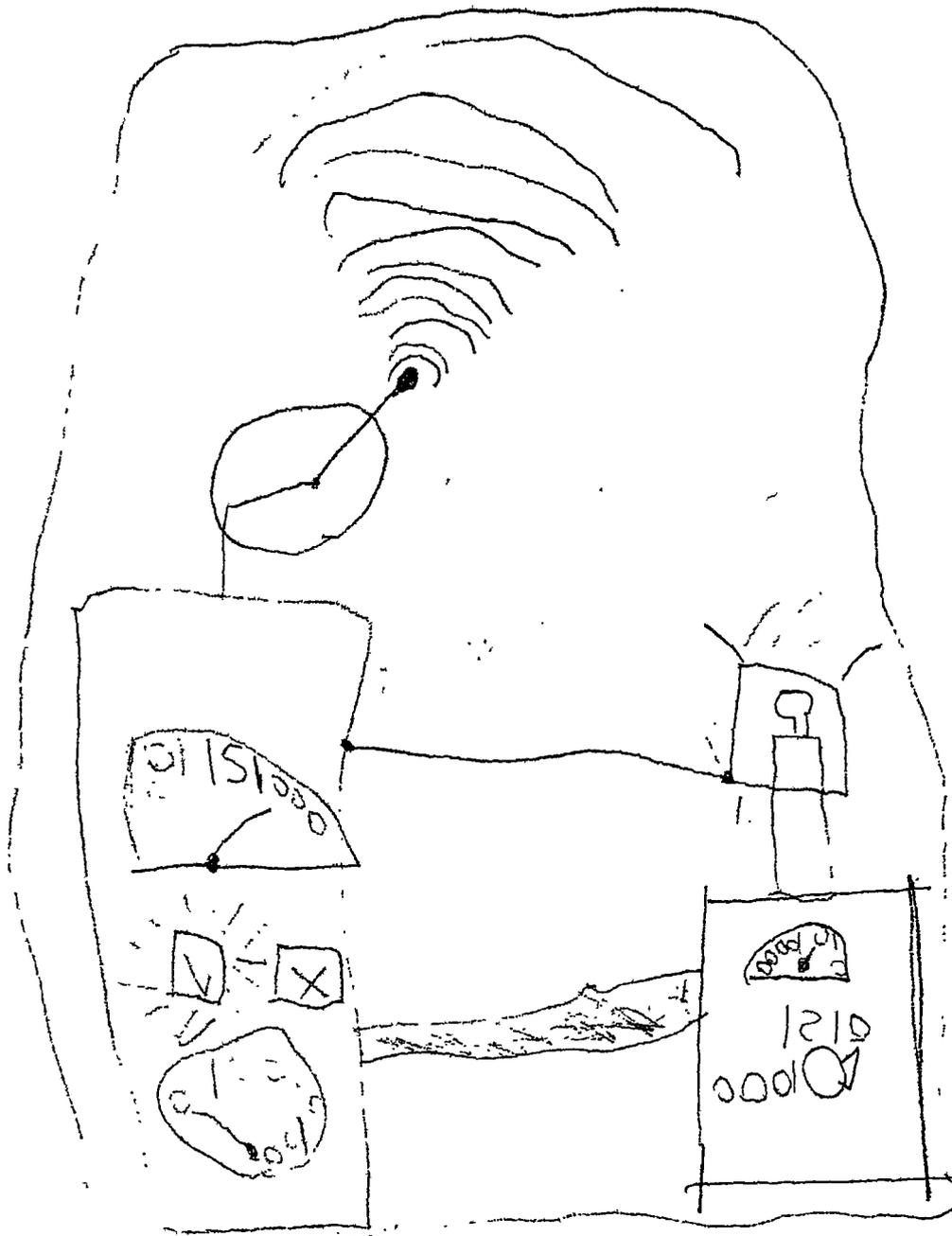


Figure 3: Michael's Best Machine to Discover Things Out

The doctor asked him what the machine did, but he could not possibly have anticipated the answer:

You press that button [pointing] if you want to know what's wrong with someone and 'ch-ch-ch' it prints out at the bottom the answer!

The doctor laughed, and commented that he would be out of a job if it were ever invented, but seemed impressed by Michael's imagination and creative skills. Michael's actions clearly indicated that he was aware of the reason for his visit to the clinic, and was perhaps feeling a little anxious about the outcome of the meeting. Conversation between the adults continued, but meanwhile Michael had discovered the broken chair discarded in the corner of the room. I heard him ponder aloud, 'Mmm, I wonder if I can fix this?' Swiftly he dived underneath the chair, saying 'A-ha' when he noticed two large loose screws and looked around for a tool with which to tighten them. He alighted on the doctor's tendon hammer, and began to use it to tighten the screws. My research diary entry says:

I marvelled at this 'no nonsense' matter-of-fact approach to a practical task; countless adults use that room every day, and simply push that chair into the corner as it is 'broken'. It took a six year old boy with ADHD to solve the matter and return the chair's utility! (17.4.00, Research Diary 3)

The above examples serve to highlight the complexity of the assessment situation; such children may have difficulty concentrating on academic work, but it seems that they often possess skills, qualities and insight which are not always valued in our society. When Michael's energy is channelled into a practical pursuit he is able to achieve success, but within the school environment, his achievements are regarded as limited. To give a further example, Marcus also had difficulty with reading and writing and had been assessed as having a reading age of 6 although he was 10 years old but within the home environment he was more able than both of his parents to repair broken electrical equipment, to wire the video to the sound system, and to build complicated models with Connex or Meccano. Analysis of the survey data which I collected revealed that 100% of parents agreed that 'parents

can become so worn down that they lose sight of their child's positive characteristics'. This seems to indicate that assessment of difficulties is complex because the children themselves are so complex.

Clinicians themselves were aware of these contradictions, and take the assessment process very seriously. Any discrepancy between reports of behaviour at home (completed by parents) and at school (completed by teachers) were investigated by arranging for a health care worker to visit school and anonymously observe children's behaviour. If their behaviour was not found to fit the assessment criteria, this would be reported to the team and further investigation of the 'situational' behaviour would take place. Children whose activity and attention levels were appropriate in school, but not home, or vice versa, would not be diagnosed with ADHD, as 'situational' inappropriate behaviour would be more likely to indicate external, situational influences. Clinicians were aware that in some cases parents' own needs were unmet, that they were parenting negatively perhaps because they had been negatively parented, and that additional social factors impacted on children's behaviour. Difficult as it might be (sometimes provoking a hostile reaction from parents), it was important to fully explore the influence of familial factors on children's behaviour. On three occasions, in my presence, children revealed that parents fought, threw things, swore, and used physical punishment on their children. One child aged seven was smacked across the top of his head during the consultation because his mother was unhappy that he had told us his parents had 'a slipper, and they smack you if you create' (7.2.00, Research Diary 2). The doctors I observed asked a limited number of questions regarding the social situation of parents and, to varying degrees, of children; the behaviour of children

was still the focus of their investigation and as such the criteria provided by DSMIV continued to frame their approach.

Unfortunately, where children were not found to have ADHD families were not always offered alternative assistance as referral to other parts of CAMHS' service was not automatic. Although some were referred within the service to the multi-disciplinary resources team for behaviour management or family therapy parents were not always willing to examine their own practices or to regard the difficulties as a family matter rather than the 'problem' of their child.

### **Parental adjustment to the diagnosis**

In common with other research which has sought to examine the meaning of diagnosis to lay people (Scambler and Hopkins, 1990; Anderson and Bury, 1988; Weinbren and Gill, 1998) parental responses were a mixture of relief, vindication, and sorrow and concern. Quite often the diagnostic assessment threw into critical relief parents' hopes for their child's future; whilst they may have previously felt that with effective guidance and input their child would ultimately outgrow some of the concerning behaviours once they became an adult they were now faced with the knowledge that the condition of ADHD would have a long term impact . Analysis of the questionnaire responses revealed parents' concerns to fall into five broad categories. Concern for: social relationships, educational failure, emotional/mental health, crime/trouble, and effect on the family, sometimes worrying also about stigma and discrimination:

I worry how this will effect my son in his teenage years and his working life. Will he grow out of it? Or will it effect (*sic*) him all his life? Will

it effect (*sic*) future relationships? Will he pass it on to any future children he may have? (Questionnaire sample, Mother of boy, aged 10)

Well ever since I heard about ADHD back of my mind I think about his future. When we are not there who is going to be there for him? That's going to stay with me till I die. Who is to blame for the curse of ADHD? (Questionnaire sample, Mother of boy, aged 8)

Parents were also concerned that labelling might lead to self-fulfilling prophecy:

I am not particularly ambitious for my daughter. I would be happy if she was happy in life. She has low expectations of herself. (Questionnaire sample, Father of girl, aged 14)

Across all research data, many parents were particularly anxious regarding the transition from primary to secondary school (Key Stage II to III). As well as worrying that their child would get into trouble, they were also concerned that s/he may be a target for bullies; some also felt that secondary school teachers would not be as understanding as those located in primary schools. The accounts revealed sadness regarding the future prospects of young people; one parent described how they were concerned:

That the family falls apart, that we are becoming dysfunctional, that my son ends up in youth detention centre, that nobody loves him, that he turns to crime/hard drugs, influenced by the wrong sort (Mother of boy, aged 12)

Marcus' mother was concerned that racist attitudes might influence how her son was treated. Before hearing that Marcus had ADHD his mum was extremely concerned that her son would be perceived as 'another Black, disruptive, under-achieving child, who would be channelled into sports'. After the diagnosis she was anxious about the label of ADHD, 'I was worried whether they'd even accept him [when applying to secondary school] or would he have to go to special school'.

This further illustrates the potential for compounded stigma when both disability and ethnicity interact.

Diagnosis was usually followed by a period of adjustment. Parents told how they began to treat their child with enhanced understanding. 'We have become more understanding, and try to put ourselves in his shoes' (Questionnaire response, Mother of boy, aged 8). Parents tried to understand that their child sometimes could not help the way they behaved, especially not thinking before acting, therefore not foreseeing consequences. Thus, the discovery that their child was not wilfully 'naughty' often would affect the way in which parents interacted with their child. Some fathers (including step-fathers) were less sympathetic than their partner and had to remind themselves that the child was not deliberately trying to annoy them.

I wouldn't say I'm less understanding, but in a sense I'm less patient. I mean, I see certain things are down to ADHD, but certain things I see are not necessarily, and I don't put them down to that, and so I'm less patient, and my wife thinks I'm being unsympathetic, or hard, but I'm not trying to be hard or harsh I just feel that there are times when Marcus isn't kept in line (Marcus' step-father).

Mothers tried to be more patient but they often had an ambivalent relationship towards their son or daughter with ADHD. Mixed feelings were expressed, such as, they found their children to be disruptive of family and school routines, boisterous, demanding, self-centred, sometimes aggressive, disobedient and generally challenging. More positively mothers felt their children with ADHD to be unique, loving, caring, active and lively, liable to be noticed therefore not likely to be ignored, fun-loving, and able to make friends easily. Caring for them could be both physically and emotionally exhausting as they needed almost constant supervision, yet often a special bond developed. Some mothers, aware of the

vulnerability of their child, felt the need to protect them against negative comments - Marcus, Michael, Adam, Sean and Ross's mothers; the mothers of Chris and Emma tended to collude with authority, wanting obedience from their child, perhaps not always convinced that their child was making enough effort to stay on task and out of trouble.

On occasion, other members of the family, both siblings and fathers, felt slightly excluded, perhaps misunderstanding why the mother seemed so close to her child with ADHD when they appeared to cause so many difficulties for the family. For example, Sean's mother described how his sister was often frustrated with the way that Sean's behaviour dominated family life, leaving very little time for her to spend with her daughter. At other times the child with ADHD was blamed for all the problems and difficulties within the family and became a scapegoat (Everett and Volgy-Everett, 1999). For example, Emma's brothers and sisters were so used to Emma being referred to in only negative terms that they were able to be quite disruptive, argumentative and to ignore their mother's requests, knowing that their mother would blame Emma for their poor behaviour, saying that she 'set a bad example'.

A gendered division of labour in child health care, touched on in the previous chapter, was evident throughout the research, with mothers being regarded as primarily responsible for their children's health. Much of the work done by women comprises the physical and emotional labour of caring for people and caring about them (Stacey, 1980; Doyal, 1983; Graham, 1984b) particularly when a child has a

disability or additional needs (Read, 2000; James, 1993). Mothers also work to civilise, regulate and construct children's bodies and minds (Mayall, 1996).

### **Doctor's dilemmas**

One of the benefits of receiving a diagnosis of ADHD for their child was that families were provided with a point of contact. Doctors were fully aware that the diagnosis may have come as a shock to some parents, or that they may not have thought of questions which they would like to ask until later, so they always made sure that parents knew that they could phone to ask questions or for reassurance. All health professionals at this time were under pressure from the Health Authority management to see more patients in order to reduce waiting lists. Raised awareness of ADHD amongst the general public had led to an increased workload amongst the CAMHS team who were trained to identify ADHD, although they were keen to maintain an efficient assessment service, keeping the waiting list to a maximum of three months if possible, and appointment times to approximately thirty minutes. Some of the team felt that management did not appreciate the amount of time which health care professionals spent dealing with parental concerns over the telephone. One of the team estimated that 50 per cent of their time was spent in face-to-face consultations, the rest on phone calls and administration. Of the phone calls from parents, many were urgent and fell into the 'I'm gonna strangle him!' category. For most of these parents the psychiatric service was their first port of call in a crisis. Members of the CAMHS team became embroiled in family situations and had difficulty distancing themselves in cases where they knew families had very little support. Occasionally, it was felt that CAMHS were treating individual children when strategies to help the whole

family may have been of more benefit. A minority of families were described as 'needy' or having a tendency to 'catastrophize'.

'Continuity of care' was an aspect of CAMHS support which was highly valued by parents. It was important to parents that an individual had detailed knowledge of the circumstances of their case as they wanted to form a relationship with a doctor. Constantly changing personnel was a source of frustration to those parents who experienced it; some described having to relay their case history to somebody new at each follow-up appointment, largely due to the half yearly turnaround of Senior House Officers. The more experienced doctors tended to keep the more socially and medically complex cases.

Doctors were in an unenviable position, torn between their commitment to assess and treat children on the waiting list - who might be experiencing difficulties at school and at home - and their wish to help families whose particular circumstances were known to them. At the time of the fieldwork, there was increasing concern amongst staff about the introduction of a computerised appointment system, which it was felt would take no account of the time spent informally helping. These concerns were voiced at a fortnightly team meeting, at which the Team Leader advised staff to offer 'consistent' but not 'constant' support to parents who were experiencing difficulties with their child. He clarified that such families might be seen more often, perhaps every two months rather than three, but stressed that they should ultimately be directed to other services, indicating that professional boundaries needed to be reinforced.

In general, it was felt that a gap existed in the service provided to parents and their children. One doctor said that 'Parents have enough information on theories and research on what ADHD is, but would really welcome some practical help and support' (Dr Turner). Unfortunately, some of the staff who would have been the most appropriate choice to deliver support such as behaviour management were 'quite hostile to the ADHD diagnosis' (Dr Mills, team leader), in particular the use of medication in treatment, and working relationships between the professions of psychology, social work, therapy and psychiatry within CAMHS were, at times, strained. It appeared that the other professions were resisting being 'co-opted' by psychiatry, which they felt focused too narrowly on individual pathology, without paying enough attention to family history and social environment. Cooper (1997) draws attention to the value positions of professions and regards the resistance of medical imperialism as an attempt to maintain professional boundaries; he suggests that the apparent neutrality of biomedical and scientific knowledge needs to be challenged.

### **ADHD diagnosis as a 'resource'**

#### **Practical benefits of the diagnosis of ADHD**

Diagnosis of ADHD, sometimes after a lengthy search for a reason for difficult behaviour, was regarded by parents as a 'resource', in the true sense of the word. The definition of 'resource' in the Oxford English Dictionary is 'something to which one can turn for help or support or to achieve one's purpose' (1999). It seemed that the help which the diagnosis offered was, firstly, to provide an explanation for their child's 'difference', secondly, to provide absolution from

blame for both parents and children and, thirdly, to provide a commonality of experience, the feeling that they were not alone.

Parents were asked what kind of help they would like CAMHS to provide in the future; responses ranged from practical help, education, liaising with other agencies, increasing public awareness, to emotional support. Some parents commented on the high standard of service which they had so far received:

CAMHS has been my lifeline. We would not have survived without them, but I wish the diagnosis had been quicker in coming. (Questionnaire response, Mother of boy, aged 15, diagnosed with ADHD at 13)

Others spoke of their hopes of what CAMHS might provide:

I know my son is a very bright child and like any mother I want him to achieve, but my dream is that he will eventually learn to love himself for what and who he is, and what I would like the Services to do would be to help him achieve this, so instead of just his physical health, they would teach him and us how to control and focus his gift into something positive (Questionnaire response, Mother of boy, aged 10)

I would like CAMHS to educate teachers, social workers etc., so that the problems of these children and their families are not made worse by the ill-conceived notions some professionals have of them. Also, apart from the medication, some help for parents, children, teachers etc. in developing strategies for dealing with individual problems (Questionnaire response, Mother of boy, aged 12)

Once children were given a recognised diagnosis, treatment could be provided, usually in the form of Methylphenidate (Ritalin). Some children also had access to other forms of support within CAMHS, including psychological therapy, anger management, social skills training and help with organisational skills, and sometimes educational support within school. The data showed that having a point

of contact was vitally important to the parents; to be able to share their concerns with a medical professional helped to alleviate stressful situations. Health care professionals provided a 'listening ear', and gave advice as to when to seek help from other services, such as Social Services. In line with Broom and Woodward's (1996) position, this serves to highlight the benefits of medical recognition of a problem. It also emphasises the importance of the role of the doctor or health care professional as 'gatekeeper' to additional resources; when parents are seeking medical recognition, there is more at stake than the prescription of a label for their child. The way in which a child's problem is defined by the medical profession influences the way other services perceive the child's needs.

Diagnosis of ADHD does not automatically lead to access to resources, apart from medical care. Children can further benefit from a Statement of Educational Need, if they are considered to have any learning difficulty, and parents are eligible to apply for Disability Living Allowance, which can make a difference to lives of families. Parents, for example, could use the DLA to pay for outside activities for their child, such as swimming or cycling awareness, which would be stimulating and rewarding for the child, and give parents a short amount of respite.

Parents of children with learning difficulties had often approached their child's school to ask for their child's educational needs to be assessed. Eligibility for special education rests on assessing children's deficits or differences, but only a small percentage of children with special educational needs receive a Statement to safeguard their rights (For a fuller discussion of the merits and limitations of Statements of Educational Need see Florian, 2002; Audit Commission, 2002).

Although 71% ( $n = 32$ ) of parents who responded to the survey stated that their child had been classed as having special needs, only a minority, 29% ( $n = 13$ ) had a Statement. The educational needs of children who have ADHD are diverse and complex, and not always easy to accurately assess.

Other forms of support which some parents accessed included social services, local and national support groups, and the behavioural support service, but the statutory services tended to offer only short-term support and relied on parents (usually mothers) being persistent, whilst running the risk of being perceived as a 'pushy mother' (Read, 2000). This was unfortunate as it made a very real difference to the life of the whole family if, for example, their extremely hyperactive child was looked after and they were given respite even for a brief period of time. It sometimes allowed parents to give time and attention to their other children, who may have felt neglected, or simply to relax and regain some strength. The voluntary support groups, in contrast, were always available to provide emotional support, over the telephone or internet, and parents perceived them to play a valuable role.

Services are delivered through complex organisational arrangements, and the processes involved in applying for support can be confusing. As highlighted in previous research (Read, 2000; Baldwin and Glendinning, 1981), each of the forms of support mentioned above have to be applied for, and are 'needs assessed', they are not received automatically. Parents were required to act as advocates, to actively promote their child's needs. Dealing with service providers is demanding, frustrating, and tiring (Read, 2000), and fighting for their child's rights and needs

required personal conviction on the part of parents; some had more 'social, economic and cultural capital' (Bourdieu, 1986) than others, to assist them in the negotiations. For example, parents who were articulate, assertive without being aggressive, had access to a telephone during office hours, could take time off work to attend various appointments and had knowledge of their child's rights and entitlements were more able to negotiate than parents who were lacking in any of the above. Thus, although families may have had the best interests of their child at heart they were not always in a position to have their voice heard as, sometimes due to demand on resources, the professions whom they approached often attempted to deter requests for assistance. It was noted that unequal power relationships existed between mothers and health, social and educational practitioners who acted as gatekeepers to the services.

When resources provided by health, education and welfare services were successfully accessed this was counted as a 'real' difference by these parents. Had their child not come under a medical remit, and not received a 'diagnosis', parents would have not been entitled to claim Disability Living Allowance, and would be unlikely to be offered any of the other sources of support mentioned above. In this way a medical diagnosis was regarded as a resource and conferred positive, beneficial qualities. Parents felt that various sources of support, both formal and informal, were now more available to them. There were also advantages to diagnosis which were less tangible, but nevertheless still valued by the parents and, to a degree, young people themselves.

### Diagnosis: 'Symbolic' meaning

Examples provided earlier show how the diagnosis of ADHD had both practical and social consequences, but also a deeper, 'symbolic' significance (Bury, 1997). The uncertainty which prevailed in the period prior to diagnosis led the parents to be highly anxious as to the cause of the behaviour of their child. Such behaviour had also called into question the parents' moral character, so the meaning of diagnosis was highly significant as it reduced blame and provided an explanation, a frame of reference. The parents had recounted their personal narratives and had a successful outcome. At a symbolic level, if their children's behaviour had been perceived as 'different' to other children of a similar chronological age, regarded as being of concern, and assigned to a medical category, parents felt that they had been vindicated, and their child's difficulties legitimated by medical professionals. As is evident from the data, these parents still felt some responsibility for their child's ADHD, but they no longer blamed their own parenting skills, and were more likely to blame their genetic make-up.

It has been argued that sociologists have placed too much emphasis on the aspect of social control regarded as inherent in medicalisation, whilst ignoring the real clinical and symbolic benefits of medicalisation (Gerhardt, 1989). Other studies have found that individuals who have experiences of difficulties which may previously have been perceived to be socially caused, or non-existent, such as premenstrual tension or Chronic Fatigue Syndrome (CFS), have benefited when given a medical definition (Kohler-Reissman, 1989; Broom and Woodward, 1996). Gaining legitimation from the medical profession can be of help in a variety of social relationships (Broom and Woodward, 1996). Benefits can be gained from

placing problems within the medical remit (Treichler, 1990). The diagnosis of ADHD gave parents within my study both a legitimated framework from which to understand their child's behaviour and the opportunity to apply for practical help. Turning now to focus on the outcome of the treatment intervention which is most often offered to children diagnosed with ADHD in the UK, Methylphenidate, the effects of treatment mentioned by both parents and children themselves will be explored.

Although the granting of a medical diagnosis may have led to reduced stigma for children and their parents Conrad and Schneider (1980) argue that the medical patient submits to a subordinate relationship with an official agent of control, namely the medical profession. In addition, as the cause of the problem is seen to be in an individual rather than endemic to society the solution appears to be to change individual children rather than change the way society treats children and the expectations which we have of them. In this way medicalisation 'diverts our attention from the family or school and from seriously entertaining the idea that the 'problem' could be in the structure of the social system' (Conrad, 1980: 250). Medical diagnosis can also create disempowering expectancies leading to a self-fulfilling prophecy. For example, if a young person is regarded as having 'special needs' or being a 'challenged learner' or 'having' ADHD they may begin to respond as such so that the label person begins to fit the label (Becker, 1963).

#### **Accounts of treatment with psychostimulant medication**

For both parents and children, it was sometimes difficult to disentangle the effects of receiving a diagnosis of ADHD from the effects of the prescribed treatment,

mostly Methylphenidate (Ritalin); the two are regarded almost as synonymous, which can be problematic. My initial meeting with Sean's mother began with her account of the events which led to Sean's diagnosis, aged almost ten, two years previously. The description of his early childhood was similar to those of the other children involved in this study, but Sean's behaviour had become more worrying as he had got older:

He was diagnosed when he was ten, he was just coming up to the last year of junior school. It was quite a long, hard struggle and I think if I hadn't known something about ADHD it probably never would have been diagnosed. By that stage he'd really got incredibly difficult, he was on the verge of being excluded (from school) permanently, he'd been brought home by the police - he'd actually broken somebody's windscreen by dropping concrete from a bridge, then attacked them with a golf club when they got out to remonstrate. He was just under ten; they said if he'd been ten he'd have been charged, so he was quite lucky on that one (Sean's mum).

Three months later, on my second visit to the family home, Sean himself spoke about the incidents he often found himself involved in. He told me that about two years ago he used to hang out on the train track with his friends, and throw stones at the trains (Figure 4). Although he mainly shrugged his shoulders and did not reply when I asked whether it made any difference to have taken the medication, he eventually said:

Before I used to have loads of fights, lob things to try and hit the teacher. But in football if I take my tablet I concentrate more, but if I don't, I just try and skin everyone, I don't care about anyone else.

Exploring this in more depth, I discovered that whilst taking medication Sean is more aware of the other members of the team, and passes the ball as a team player, rather than is 'ball greedy', trying to score without assistance from his team. This may seem to be a minor point, but it does in fact illustrate the way in which

medication helps young people to be less self-centred, and to appreciate the view point of other significant individuals in their lives. I asked Sean if he could draw an example of something he may have done before he was taking medication, and something which represents the change in his behaviour since taking medication.

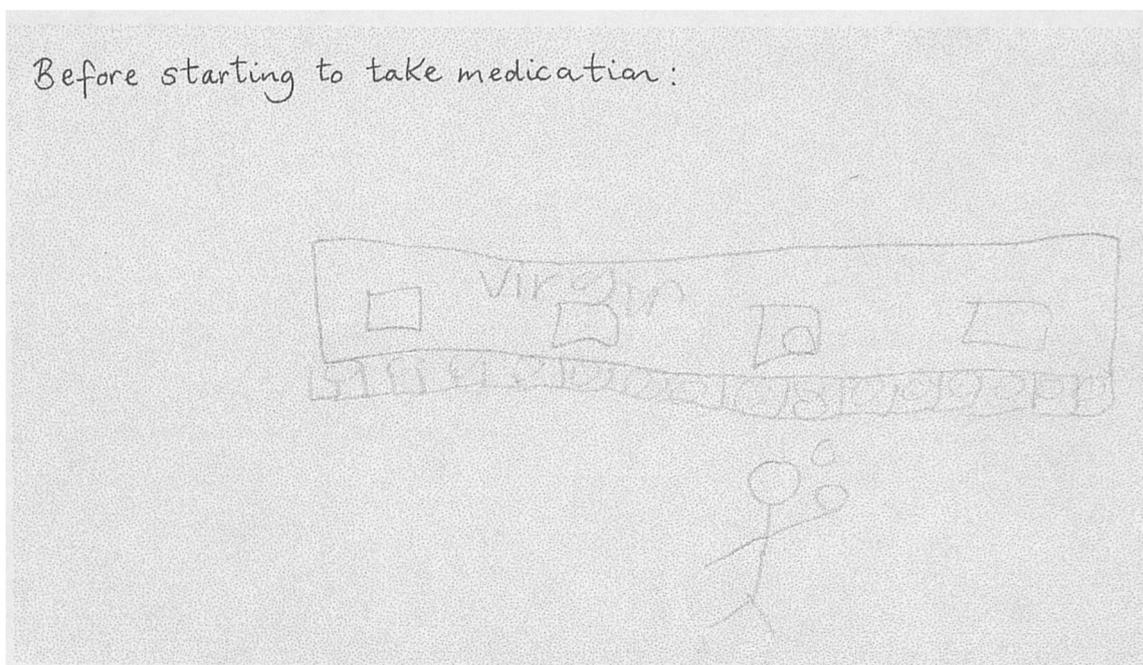


Figure 4: Sean throwing stones at a train, before receiving treatment for ADHD

Figure 4: Sean throwing stones at a train, before receiving treatment for ADHD

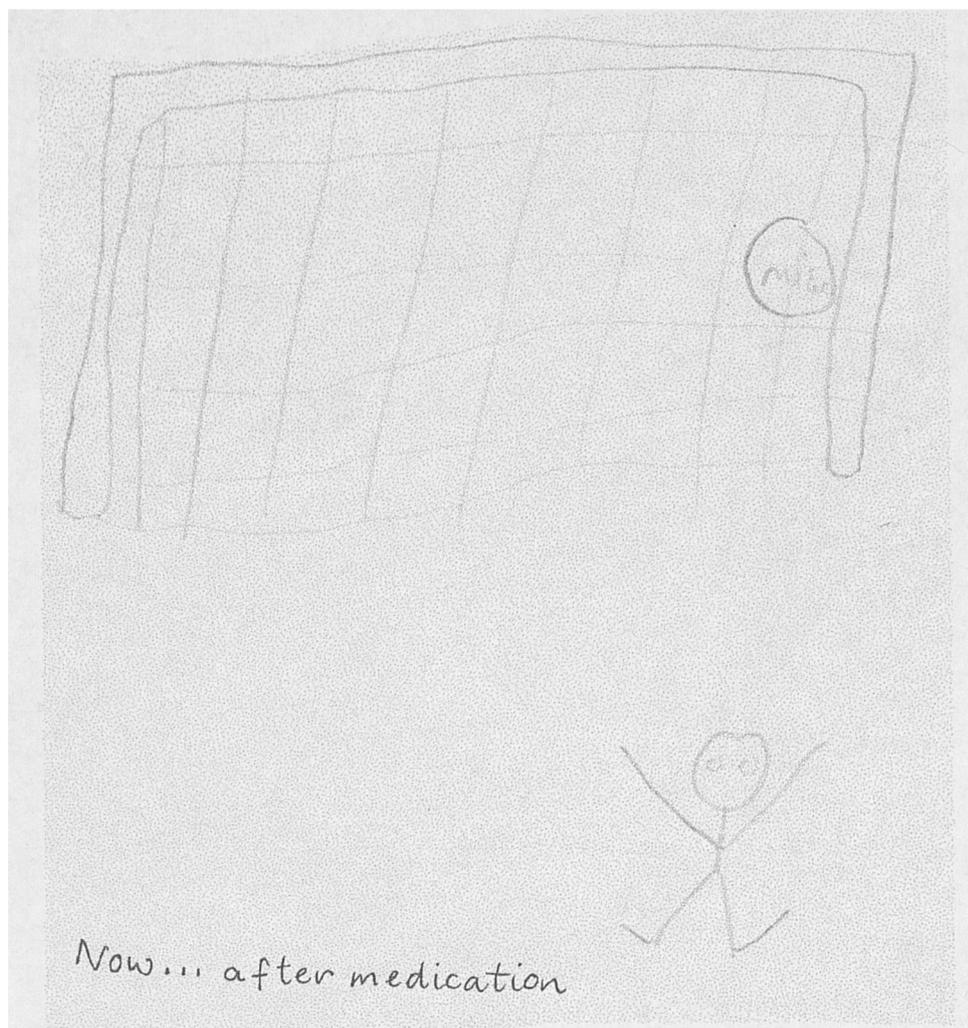


Figure 5: Sean scoring at football, after receiving treatment for ADHD

Through his drawing Sean highlights the contrast between the destructive activity he was once involved in and the constructive activity he now prefers. Many parents mentioned that where they had been called into school to discuss their child's inappropriate behaviour, on average, two or three times a week before diagnosis and treatment, once medication had begun their children were receiving merits, stars and certificates for improved behaviour, and were thus receiving positive rather than negative attention. This, in turn, impacted on children's relationships within the family and interaction was often more positive, and relationships began to improve. One of the most often cited examples of immediate change, was the

newly evident ability to link actions with consequences. Jack's mum told the doctor that she had noticed that Jack used to be like 'a little closed book' but now he seemed able to open up and talk about his feelings. He was now able to learn from his mistakes; he makes the connection between the fact that he's hit his brother and his brother crying, and is moved to apologise; beforehand he would not have felt responsible for the consequences. More fervently, Sean's mother describes the events post-diagnosis and medication in almost evangelical terms:

But the medication has been, it's been like a miracle really. He was in trouble all the time at school before he started taking it. He really sort of blossomed in that first year he started taking it, I could see it in the photographs - he starts off looking almost like a weird, strange, sad looking little boy, he doesn't look happy at all all the way through [school], and then the last year was the first wonderful photograph of him looking really smiley and happy and a most well-adjusted little boy!

The delight in Sean's mother's voice as she tells me this, and then produces photographs to confirm it, cannot be conveyed in words. She clearly felt relieved and hopeful for her son, and for the future development of their relationship.

Being more able to emotionally connect with family members was one of the most valued aspects of the benefit of medication. Parents had found it exasperating that their child did not seem to learn from their mistakes, and would make the same errors of judgement over and over again, despite appearing to know 'right from wrong' when asked. Inability to control the impulse to act or speak had caused numerous problems in the past, including broken friendships and physical injury through accidents. Since Sean began taking medication for ADHD, his mother conveys how their relationship has grown:

Because I don't spend all my time telling him off or trying to stop him from doing things that he shouldn't, we can spend time doing constructive things. You could never do that with Sean, but now we can say make cakes together, he likes cooking, he *likes* cooking, and we can go in there and I can explain to him what he has to do - I could never have done that with him before he was on the tablets. He wouldn't have had the patience and he would have been silly, tipping stuff all over the floor, but now we have much more positive experiences altogether and, like I say, you can sit down and have a conversation with him (Sean's mum).

Parents were often at pains to remind me that their decision to agree to try medication was not made lightly. Ross's mother sums up the feelings of many parents who have agreed to medication, within a society hostile to both the concept of ADHD and the use of stimulant medication; she focuses on the immediate effect on her son's ability to attend to the teacher:

The very first day he took medication I stayed home, very nervous, and I thought, "What am I doing? I'm drugging my son". I thought, if he has a reaction to it, it's best I be home. But he came home from school that night, he walked through the door and I was relieved, and he said "Does this drug help you to hear better?" Not thinking, not thinking, I said "no" and so we talked about what it does, and how it was going to help him and whatever, and it wasn't until I was lying in the tub that night that I thought "Oh my God!" For the first time ever he was able to, it wasn't that he couldn't hear before, his brain was now allowing him to take everything in (Ross's mum)

Ross too described how different his experience in class was before being diagnosed and treated, compared to afterwards, whilst commenting on his drawing (Figure 6).

This was when I didn't know I had ADHD and the teachers used to always be saying 'Please write this down in your folder' and then she'd say 'O.K. if you've finished you can leave and go to your next class' or whatever, and then I'd say 'finished' when I wasn't really finished, and I would just have written, oh, if it would have been about a bird I would have been writing about Mars, and so on. I wasn't really paying attention, I would just be sitting there and worried about everything else

[...] then I'd start fiddling round with my pencil, watching what those two girls over there were talking about, writing notes to my friend next to me, and everyone would have written it all down except for me, and then I'd be off! (Ross, 12)



Figure 6: Ross was unable to pay attention before treatment

When I asked Ross how things were different at school once he had been diagnosed and was taking medication he showed me his drawing:



Figure 7: Teacher asks Ross, 'Where's your homework?' and he replies 'Right here'

Medication could appear to be a 'cure' for ADHD, but it is not; it does, however, seem to help to calm and focus children, giving them time to think through their actions and responses, and make more appropriate choices and decisions. Once their behaviour is not causing problems for teachers or parents, people relate to them in a more positive way, and the relationship becomes reciprocal. It is this element of treatment by medication which is of critical importance. If children and

young people behave in ways which attract praise and encouragement, their self-esteem and identity will be improved, decreasing the chances of feeling marginalised and a 'failure'. Chris's illustration of the difference which he feels medication made to his behaviour needs no explanation:



Figure 8: Chris's self-perception 'after' and 'before' beginning treatment.

In terms of comprehending young people's perception of the benefits of receiving treatment, 'pictures usually speak louder than words'. But the words of one young person were particularly poignant. In Nick's case, diagnosis of ADHD and treatment with medication had begun to make a difference in his life. His parents had been seeking help for much of Nick's life, but it was not until he was 16 that he was diagnosed. By this time, he was not attending school, choosing to spend time alone in a local wood, and had become involved in minor criminal activities. Shortly afterwards, he was imprisoned in a Young Offenders' Institution, from where he wrote this letter to the local ADHD Support Group, in order to make his viewpoint heard:

As An Adhd sufferer, I feel like any normal person (or at least I think I do) I do not understand why people keep telling them me im being naughty, although I have been I think I just do it because people say I am, so I decide to do the stuff im being told I do, when people tell me off I hate it, so in turn I hate the people who tell me off, I do, do a lot of things without thinking about them, but at the time I do not see much wrong in them, yes I know my right from wrong but I do not think off the consequences. So the Advice im giving is to listen to the problems and ask why the your children are doing what there doing, not telling them off because before you know whats happened they'll be in the same predicament as me.

Diabetes Whelan

Figure 9: Nick shares the lived experience of ADHD

Sadly, just two weeks after writing the above letter Nick was found hanged in his cell. His mother told me that the prison doctor had refused to acknowledge ADHD as a 'real' condition, and would not dispense Methylphenidate, despite the request of Nick's parents for him to comply with the prescriptions provided by the consultant psychiatrist who had been treating Nick. When his parents protested they were allegedly told, by the prison doctor, that ADHD was a 'Mickey Mouse condition imported from the Yanks'. This serves to illustrate the dangers of believing myths and misinformation regarding ADHD, and of not acknowledging what children and young people tell us about the benefits to their sense of self.

It would seem that medication has a role to play, it is helping to give children and young people a more positive self-concept. Yet, as with most medications and chronic conditions, there are also disadvantages, both in terms of side effects and psychosocial factors, which need to be considered.

### **Ambivalence and tension: fears of labelling and stigma**

#### Disadvantages associated with Methylphenidate (Ritalin)

The general consensus amongst both parents and young people was that medication had been extremely helpful, but it did have its disadvantages in the form of side-effects and adverse drug reactions. The most common of these was a decreased appetite whilst taking medication. Marcus also experienced headaches and stomach aches, switched to another medication, Dexamphetamine, which, in his case, did not help to improve hyperactivity, so switched back and vowed to put up

with the side-effects. In the meantime his mum looked for strategies that might help, such as changing the contents of his lunch box and the timing of the tablet.

As the dose wore off, children could become very hyperactive, referred to as the 'rebound' effect. Rebound had also been experienced when the timing of the medication dose was slightly out; for example, as the effect of each dose is relatively short lasting (2-4 hours on average) it is regarded as important to take the next dose just before the first runs out, or the child may feel very restless and active in between (Munden and Arcelus, 1999), sometimes more so than previous to treatment. Of the seven children in the in-depth sample Ross, Emma and Chris had experienced this, and a solution had been found in changing the timing of the lunchtime dose. Occasionally, the medication could make the children feel sleepy or drowsy, this tended to occur if the dose was too high, or if taken on an empty stomach and had happened to Marcus only. Such medication management issues will be explored in more detail in the following chapter.

Ambivalence and ambiguity surround this complex condition. Young people did not feel that the diagnosis itself had made a huge difference to their daily lives but taking medication often did. One of the consequences of taking medication which health professionals at CAMHS may not have been aware of, and has not to date been widely explored, was referred to as an 'altered personality' or 'it's not the real me'. The young people that mentioned this were trying to explain how perhaps the diagnosis, but more specifically the medication, had an effect on their self-identity, and on the way others perceived them, notably their peer group. Cooper and Shea (1999), who published the first empirical study of the perceptions and

attitudes of children with ADHD to their condition, found that students perceived the 'real me' to be their non-medicated self, and this person was sometimes associated with enjoyment and fun:

Some students speak of a sense of these effects in terms of their sense of personal identity, often casting their non-Ritalin selves as their authentic selves and the self that is created by the application of Ritalin as a new and different self (Cooper and Shea, 1999:239)

This finding was borne out in the data collected from young people in my study.

Whilst exploring Sean's feelings regarding medication he eventually tells me:

I don't like feeling different, it's boring sitting still in class and it doesn't feel right - it's like, it's like it's not the 'real me'.

Having cultivated the role of 'class clown', a fun but quite volatile character, Sean associates medication with being 'ordinary'. He acknowledges that he behaves in a more socially acceptable way when he complies, which pleases his mum and teachers, but ultimately it is more important to him to maintain popularity amongst his peers. Ross's mother has also noticed that not all the effects of medication are positive:

Getting back to the personality thing, it does change his personality, that is one of the things that makes me very sad about having to medicate him. It mellows him, he loses his appetite, he is not quite as sociable as when he doesn't take it. (Ross's mum)

This was an effect of taking medication that parents had tended not to consider beforehand; although their child exhibited more socially desirable behaviour now, some aspect of their unique character had been lost in the process. Sean's mother appears to have some insight into the possible reasons why Sean does not always take the medication:

I don't know, perhaps it's less fun when he's on it, in a sense. He's a bit of a class clown, the life and soul of the party, and I used to suspect, I think I know, when he was at junior school there were a lot of children who used to wind him up because they liked to watch him explode and do his party piece. I remember originally he said "I can't take tablets" but he soon picked it up. I don't think they make him feel unwell but perhaps ... perhaps he just doesn't feel himself when he's on them? I mean he's had years and years of not being on them and just generally being the way he was, and now perhaps tablets make him ... somebody different. (Sean's mum)

Other parents had been concerned that the medication, known to have a calming effect, would change their child too much:

We still want the same Jack, not an angel. (Jack's mum, speaking before consenting to treatment)

Parents wished for their child to be 'like other children', and to conform; yet they were also keen to retain the features of their child's personality which made them unique. Throughout this research, I was struck by the unusual views, responses and interests of the children, at how vibrant and lively they were. I was constantly reminded of a promotional campaign which ran in *The Guardian* newspaper some years ago which claimed 'Great Minds *Don't* Think Alike' which I perceived to mean that the tendency to conform stifled innovative thought. At my request to draw or write about the things that he would change if he had a magic wand, Michael spent several minutes drawing his picture, which he then explained to me:

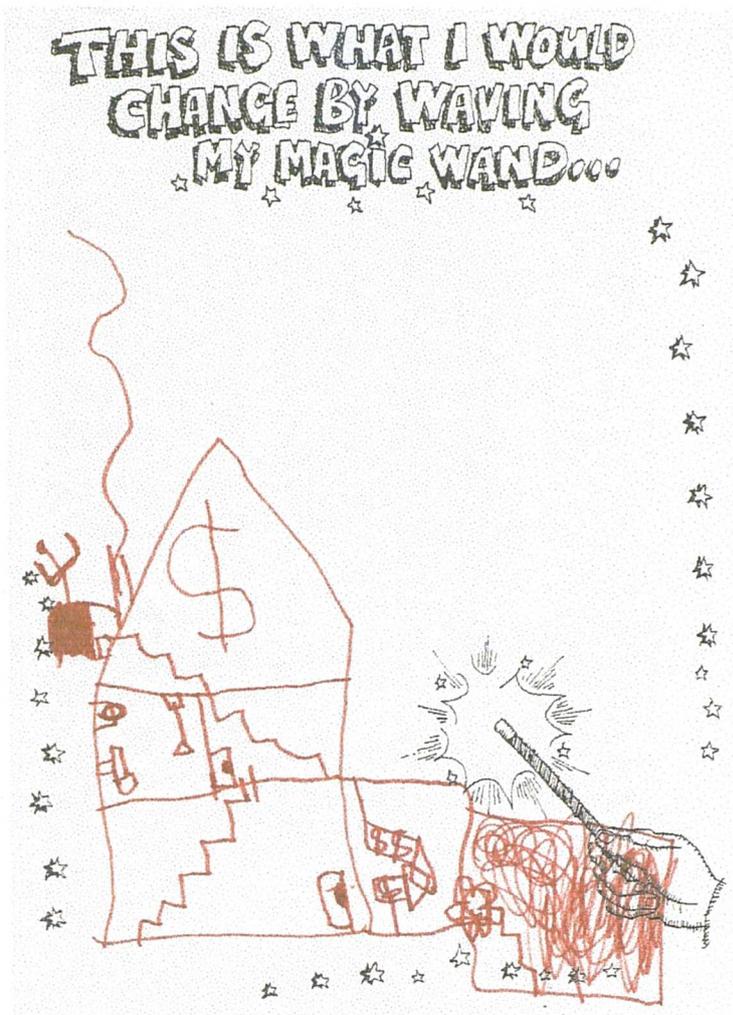


Figure 10: What Michael would change if he could

Michael: This is a brilliant one. What does it look like?

GB: Well, I'd say that's a dollar sign.

Michael: Yeah, cos I'm a millionaire, and look, I just go up the stairs into the other room, and then up the other pair of stairs, right, and there's the pool, and this is the satellite, and then it will be in the newspaper and telly and on the radio, right, and everywhere it's gonna say "Michael is the richest boy, he's bought everything that he wanted".

GB: So what would you buy if you were rich?

Michael: When I saw the poorly babies, right, I said I would like to make a wish, so that I can make them live - and their parents - and when this happens (pointing to his drawing) I'm going to do it.

Michael's Mother: I want to know why it's in dollars and not pounds, watching too many American programmes!

Michael: No, cos I don't know how you write pounds.

Michael's mother contextualised his comments by informing me that they had recently watched a programme about famine, which had upset Michael greatly. She said despite being boisterous, active, and inattentive he had a very sensitive side; he was particularly upset about the cruelty being inflicted on animals during the Foot and Mouth crisis<sup>8</sup>, which coincided with the timing of the fieldwork. His logical explanation for including a dollar sign rather than a pound sign in his picture stumped the adults who were present, but also provided an example of the way in which children said to have ADHD can make their point clearly and precisely, leaving other people to marvel at their no-nonsense approach.

On a further occasion, asked to draw a picture of the nicest day Michael could remember, he drew a set of chimneys, with smoke rising from them, and told me that at school he liked watching the smoke coming from the chimneys. Other children had drawn a picture of themselves on a day trip, a holiday, or receiving

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<sup>8</sup> During 2000 there was an outbreak of Foot and Mouth disease in certain parts of the UK which lasted several months. The government insisted that cattle were slaughtered to contain the outbreak.

presents on their birthday. For example, Marcus' picture was entitled 'Visit to Terror Towers, Disneyland (Figure 11)



Figure 11: Terror Towers, Disneyland - Marcus' nicest day

Michael's drawing of another of his nicest days was also fairly unusual:

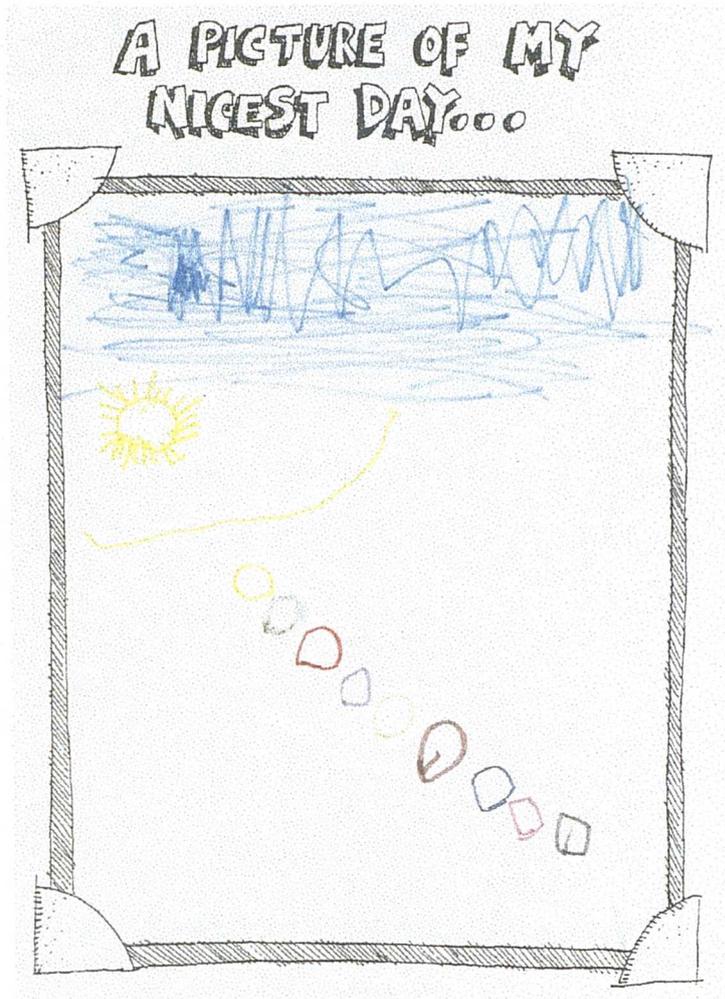


Figure 12: One of Michael's nicest days, watching the sun reflect in the desert

He explained it as follows:

Michael: Excuse me, maybe you don't know what they are? These (pointing to his drawing), you know when you watch a film about a desert and you can see those bright circles? That's what those are.

GB: A bit like a rainbow's colours?

Michael: Yeah, but circles, you know? Remember? What you see when you can see the sun in a film about a desert?

Mother: I find that he uses his drawings to say what he can't say, and what he can't write, he uses them to get across what he's trying to say.

The visual examples presented in this study demonstrate the importance of encouraging non-verbal forms of communication with children and young people; it allows for creative expression, helping us to understand how children's perceptions of the world in which they live may vastly differ from those of adults. In this way, listening to the views and experiences of children can expose the ways in which society is socially constructed. Insight into the workings of children's thought processes may also help us to comprehend why it is so difficult for them to be confined in a classroom, and allotted a relatively passive role.

#### ADHD diagnosis as a 'constraint'

Once a child has a label it becomes difficult to lose it, whether it attends to disability, special educational needs, emotional and behavioural difficulties or mental health difficulties. All labels affect children's self-perception and the perception of wider society. Being regarded as disabled, rather than naughty, is often assumed to lead to improved relationships at both home and school. However, children are affected by the general stereotyping of 'the ADHD child' and they may be cautious about making the decision to reveal to others that they have the condition. In Emma's case her peers discovered that she had ADHD because they asked her why she had to take tablets. Emma told them that 'it was none of their business' but a large group of girls, led by 'the popular one' were 'spreading rumours about me, threatening me, bullying me and calling me a psycho' (Emma, aged 11).

Marcus does not appreciate his mum discussing him with anyone,

When he was first diagnosed, it was such a weight off my shoulders, both mine and my husband's shoulders, cos you just blame yourself, your parenting skills, everything. So I was telling people that he was going to be on this drug, but he was cross, "You haven't told, have you? I don't want them to know! You haven't! You promised me!" (Mrs Baldwin, Marcus' mum)

Children were keen to assert their personal identity, rather than one that was 'medicalised'. Privacy and confidentiality were important to children but, as highlighted in Chapter Four, not widely available, in either the home or school setting.

Situations arose where parents found it necessary to intervene to try to prevent their child being subject to negative comments. Marcus began to attend a 'Boys Club' which provided sports and leisure activities for young people. Having attended for three weeks, his mother was told that he was 'too active' by the leader, so she made the decision to remove him from the club, before he was possibly asked to leave. Clearly, although she had explained that Marcus had a disability called ADHD, the club did not make any allowances or know how to deal with his behaviour. These parents were particularly proactive, and wished to reduce the opportunities for negative encounters which might impact on Marcus' self-esteem. However, parents were less likely to be able to control interaction in the school situation; most felt that their child was at the mercy of the school staff and pupils for six hours per day, and despite regular communication with individual staff members, there was very little parents could do to intervene in the daily activity of school.

From an early age these children are aware that they seem to be reprimanded more often than their siblings or peers; being 'told off' for saying or doing inappropriate things becomes part of daily life, but they are unsure why this might be so. When reprimanded, children invariably were puzzled about what offence they had committed. Inability to foresee the consequences of impulsive actions led children and young people to feel unfairly treated and unjustly accused, as in Michael's case. Michael, aged six, had developed a snorting habit; his teacher had warned him not to snort in class, or he would be excluded. I asked him how he felt about school:

Actually, sad, cos of my snorting, right - but it's not my fault, I can't help it, and cos I keep getting sent out of class I keep missing art and fun stuff when you can play, and 'Choosing Time', it's not fair (Michael, 6).

On the request of Michael's parents, the child psychiatrist wrote to the school, explaining that the snorting was an involuntary motion, possibly a tic, and should not result in punishment. This had little effect on the school's daily practice and the lesson exclusions continued. This kind of adult practice served to draw attention to Michael's different behaviour and to marginalise him from his peers. The following excerpt from Michael's mother demonstrates the teacher's role in helping to create an inclusive or exclusive school culture:

His own teacher was away for the day teacher training and so they had a visiting teacher, and he had multi-sports after school but he'd forgotten his bag, so his dad sent him back into the class to get it but the teacher said, 'Where do you think you're going? Out!' So his dad told her he was going to get his kit for multi-sports. Then when he got to the hall/gym the same teacher was there again, and Michael went off to get changed, and she said to his dad, 'Where's he going now?', so he said he was going to get changed, and she said 'What a naughty child, he never does as he's told!' and this was in front of other children (Mrs Summers, Michael's mother).

The visiting teacher had determined that Michael was intent on disobeying her authority. Making such comments within earshot of Michael's peers helped to consolidate their view of him as being 'other', deviant, and a threat to the social order. In the ongoing educational context Michael was left to wonder why he was excluded from classes, kept in at playtimes, prevented from attending school trips unless accompanied by one of his parents, and generally shunned by his peers. Michael's sense of injustice at his treatment was evident when he told me: 'When I'm going to be grown up and rich I'll tell Miss why she keeps sending letters about me!' This seemed to imply that when Michael was an adult he could question authority, but this did not appear to be an option in his present status as a child.

Teachers featured in each of the seven children's accounts. Those that related well to children and were perceived to be fair were highly regarded. Teachers that were perceived to treat children unequally, often blaming them for incidents when the child was not actually in the class at the time (in two cases - Chris and Jack - were not even on the school premises) were disliked and sometimes overtly challenged. Several young people told of incidents where teachers had made negative comments about them. Chris's teacher was said to have exclaimed, 'I can't manage you and a class full of children, so get out!' then put Chris 'on report' for not doing his coursework, which of course was impossible to do when he was constantly excluded from lessons. Jack, aged nine, reported that his teacher said 'Your tablets are obviously not helping you' when he displayed inappropriate behaviour. Michael's parents informed me that he had been told by his teacher that

if his behaviour did not improve he would have to go back to the Reception class, or be sent to a special school.

Parents found communication within some secondary schools to be ineffectual. The staff member with whom parents had direct contact, either by telephone or face to face, sometimes did not convey important information regarding the young person's ADHD diagnosis to the relevant staff. For example, it was often the case that parents went into great detail with the SENCO to ensure that the school were fully aware of the way in which ADHD was manifested in certain behaviours, and could be exacerbated or alleviated depending on the response of a teacher or peers, but teachers *in situ* either did not know or were unable to respond to this advice, as often the response to inappropriate behaviour was to exclude the young person from class. The situation was then made worse because the child/young person had missed the lesson, was usually struggling with the work, got 'behind', found it difficult to catch up, got into trouble with parents, felt disappointed with themselves, and became either more aggressive or more apathetic, and certainly more marginalised.

Families appreciated that teachers' jobs were challenging, that they had a syllabus to progress and approximately thirty children to teach, but it was evident that if young people were shown little respect by teaching staff, teachers were unlikely to receive respect in return. When asked how the school situation would be different if they were a teacher the children's wishes were a mixture of alterations to school rules, desire for a more creative curriculum, and reflections on the attitude and behaviour of teaching staff:

If I could be a teacher for one day  
I would:

Set lots and lots of easy work for pupils ~~to~~ make them  
be good as possible and be sensible and show them who is boss. Set work  
that the pupils ~~are~~ find enjoyable. Make all lessons fun. Respect  
for the teachers.

If I could be a teacher for one day  
I would not:

Be stupid, lose my temper at naughty children.

Figure 13: Chris's interpretation of a teachers role

If I could be a teacher  
for one day

I would: Be kind and talk to them  
like real people. Not give any Home-  
work. Get them to draw some pictures.  
let them eat or Drink in the classroom.  
Write a story.

I would not: Shout at students. Give extra  
Home work. Complain to students. Send  
to Head Master for something not very  
serious.

Figure 14: Ross's interpretation of a teachers role If he were a teacher

There is a need to take seriously young people's accounts of their teaching and learning experiences (Ruddock, Chaplain and Wallace, 1996). Children and young people particularly felt that some teachers treated them unfairly, and indeed in some cases there was evidence of discrimination against some children/young people. The school expectation was often that children with ADHD would conform to school rules and regulations, but it was not deemed necessary to provide any assistance to meet this expectation. Trevor, Emma and Chris had asked their teacher to allow them to complete smaller pieces of homework, rather than large

assignments, but they had all been told that allowances could not be made: 'They say if they do it for one, they'll have to do it for everyone' (Trevor, 14). Yet, the kind of requests and suggestions made by parents and young people would have benefited all children. Young people with consistently challenging behaviour are at risk of being excluded from mainstream school; this is of concern because exclusion from school can lead young people to be socially excluded, which may in turn have negative consequences in terms of health, housing and employment. Meo and Parker (2004) argue that more emphasis is needed on establishing effective working relationships between teachers and students who have difficulty engaging.

However, the recent advancement of the concept of inclusive schooling, despite the lack of consensus as to what this term means (Clark, Dyson and Millward, 1995; Slee, 1996; Lloyd, 2000), implies that every child has the right to the same classroom and curriculum of any other child their age and to an equal education. In reality teachers find it difficult to be fully inclusive when operating within the existing organisation of schooling which emphasises conformity to the norm, rather than recognising diversity and personal identity (Oliver, 1997). Children with ADHD are more able to succeed when learning is interactive and based on a problem-solving approach, such as that proposed by Skrtic (1991). Given the emphasis on conformity to the norm, schools may be finding the inclusion of children with disabilities or health care needs quite challenging. Chapter Seven provides examples of some of the less inclusive practices employed by schools in relation to children's health care needs.

### **Discussion: the meaning of medical diagnosis**

In asking whether a diagnosis of ADHD can be regarded as a 'lifeline' or a 'label' the complexity of the situation should not be underestimated. Lay voices of parents and children have an important story to tell of the experience and *meaning* of the diagnosis of ADHD; this perspective appears to have been neglected in the literature to date. An exploration of the lay world view indicates that medical diagnosis can be both problematic, having a detrimental effect on self-identity, and beneficial, leading to gains in terms of practical help and resources and, perhaps more importantly, legitimisation of symptoms (Kohler-Reissman, 1989; Broom and Woodward, 1996). Such benefits are a combination of real and symbolic gains. Children may be shown more understanding and empathy if their inappropriate or deviant behaviour is found to be part of a medical condition. Conrad (1980;1992) regards this as the 'brighter side' of medicalisation in that a more humanitarian, less punitive approach is often adopted. The granting of the 'sick role' (Parsons, 1951) may absolve children and their parents of guilt or blame since the challenging behaviour is understood as 'not their fault' and give parents and children access to support and resources. If the appropriate support and treatment are offered the experience for children and young people can be positive and relationships with friends and family can be less strained.

The need for an approach which is more focused on the social system in which children live, rather than on the individual child's physical needs, is more than apparent in the overall responses. Parents appreciate that their child's difficulties have been recognised, and in most cases an extremely effective form of treatment provided. Initially, this seems to be enough, but as time progresses these parents

come to realise that medication does not provide all the answers. There are deep-seated difficulties with self-esteem, and established patterns of negative interaction between family members for which the cure is not instant, but the situation can be slowly improved once time has been taken to understand the dynamics and circumstances of family life. However, this therapeutic way of working is both time consuming and more costly than medication, and involves parents and siblings taking ownership for their part in the cycle of negative familial relations.

Diagnostic labels can also be regarded as a constraint as they create categories. More importantly, they may limit our view of children, by focusing on their deficits or impairments. Labels draw attention to what children cannot do, rather than the things they do well. As McCubbin and Cohen remind us 'People with labels that identify them as different in a negative way are usually stigmatized' (1999:87) and attention is not given to their positive strengths. The power to define a medical 'problem' is often achieved through 'medical surveillance' (Foucault, 1973;1977). Disciplinary power is exercised through the process of observation, examination, measurement, and the comparison of individual bodies against an established norm. However, for Foucauldians 'Power is not a possession of particular social groups, but is relational, a strategy which is invested in and transmitted through all social groups' (Lupton, 1997:99). When medical knowledge is regarded as a belief system, shaped through social and political relations, power can be both positive and productive. There are various institutions, practices and techniques by which the body is disciplined (Foucault, 1979).

There are some concerning aspects to the 'darker side' of medicalisation (Conrad, 1980). Locating the cause of any behavioural and emotional difficulties within individual children seems to suggest that children need to be helped to change in order to better fit in with societal expectations. This approach tends to neglect a critical examination of the ways in which this society positions children. Medical diagnosis is the responsibility of 'experts' and can be said to be a form of social control of young people. However, as demonstrated above, often young people are not being offered any alternative support and without medical intervention may eventually be subject to a more punitive form of social control in the form of the Criminal Justice System.

One promising way of conceptualising the change from pre-ADHD diagnosis to post-ADHD diagnosis is through Bury's (1982; 1991; 1998) notion of 'biographical disruption', whereby the taken-for-granted features of everyday life are disrupted by (chronic) illness. Bury notes that there are consequences and significance to such a diagnosis; life can be disrupted and self-identity and control threatened. The embodied sense of self of the young people in this study did not appear to be greatly altered by the diagnosis of ADHD but the application of medication, used as an intervention, did impact on their selfhood and identity.

Similarly, in Sacks' (1985) account of his work with a patient who had a diagnosis of Tourette's Syndrome - Witty Ticky Ray - he recalls how although Ray perceived the tics associated with Tourette's to be troublesome, they actually enhanced his performance when playing jazz drums and ping pong. When offered medication, Ray contemplated what would be left if his tics were taken away; they were so

much a part of his identity 'he scarcely knew whether it was a gift or a curse' (1985:93). Sacks explains how people need to be gently prepared for treatment which may lead to a new identity. The accounts of young people given in this study may be examples of individuals not yet ready to relinquish their 'ADHD identity'; they are invested in that identity, and know no other experience. In addition, such an identity may be perceived to be positive by young people themselves, such as Sean's expressed sense of loss at no longer being regarded as fun, the 'class clown'. The new persona provided by the application of medication can in some way be *less than* the non-medicated identity therefore the psychosocial effects of diagnosis and treatment should be explained to children and young people .

It can appear that health care professionals are behaving paternalistically when offering to 'help' (Sacks, 1985) young people to be more 'normal' or conventional, assuming that doctors 'know best'. The kind of behaviour associated with ADHD has not necessarily been regarded as disrupting their lives, as they have never known any different. Indeed, Williams (2003) notes that the concept of 'biographical disruption is predicated, in large part, on an adult-centred or adult-centric model of illness' (2003:103), and relates to a shift from a normal state of health to one of illness. Conditions which have been present since the start of life and 'are integral to an individual's biographically embodied sense of self' (2003:103) may be regarded differently to those that are discovered in later life. As such, biographies are not disrupted in a real sense, what takes place at the point of medical diagnosis may instead be conceptualised as *biographical confirmation or reinforcement* (Williams, 2003:103).

## **Conclusion**

The findings presented here illustrate the complex and ambivalent meaning of being given the medical diagnosis of ADHD, and the recognised limitations amongst health care professionals working within CAMHS. Parental reactions to diagnosis mirrored the responses of patients in other studies of chronic illness or disability (Burton, 1975; Voysey, 1975; James, 1993). In addition, some parents also felt absolved of guilt or blame as although ADHD can lead to stigma, having a 'naughty' child was more of a social burden. After a period of adjustment, diagnosis came to be seen, by parents, as an advantage, as it helped to provide access to resources such as Disability Living Allowance, a Statement of Educational Need, and forms of support provided by other services. However, such forms of assistance were not automatically forthcoming, and parents had to act as advocates for their children's needs if they were to succeed in securing financial, educational and emotional sources of help.

Treatment with Methylphenidate had an immediate effect on both activity levels, attention and empathy in all six children in the in-depth interview sample who were taking medication. Young people enjoyed aspects of this change, but also drew attention to the less desirable aspects of the medication, namely certain side-effects and changes in the way in which they perceived their own identity. Children and young people were sometimes subjected to discrimination, labelling and stigma and the environment of school was perceived to be a difficult place for children whose difficulties were often misunderstood. The next chapter turns to look at the

ways in which the child health care division of labour is shared by both professional and lay workers.

## **Chapter Seven**

### **The Child Health Care Division of Labour**

#### **Introduction**

Focusing on the division of labour in child health care entails taking into account the contributions made by both professional and lay persons; the latter's contribution is informal and can often go unrecognised, but in this case both parents and children and young people play a part in managing the condition of ADHD and promoting overall health and well-being. The approach, developed by Stacey (1984; 1988) is distinctive, in that both professional, paid participants and lay participants, carrying out unpaid health care work, are regarded as part of a social process. The concept has since been developed in relation to women's health (Graham, 1984) and the role of women as carers (Read, 2000) and in relation to the active role which children play in caring for their own health (Mayall, 1996). Here I provide an overview of the process which is played out across professional/lay, and adult/child boundaries. Most importantly the data presented in this chapter emphasises the active role which children and young people play in managing the condition of ADHD, and in negotiating their own health and well-being.

#### **Managing the Condition**

The role of the health care professional

At a surface level health care workers based at CAMHS were responsible for assessing, diagnosing and treating children, and performing regular check-ups (generally every three months). As referred to in Chapter Six, their remit was not entirely medical, and their moral concern extended to their client's social situation.

In addition, the ADHD team were aiming to improve the service by linking with other professions; such connections were regarded as very important in order to raise awareness of the condition and to equip other professions to be able to more effectively support children. At the time of the fieldwork national government priorities were beginning to shift towards inter-agency working but this was proving difficult to achieve at an organisational level. A difference in approach across disciplines and agencies was a hindrance to joint working as was poor and ineffective communication. The lack of an integrated, co-ordinated response to need left responsibility for sharing information between the various services up to families.

Dr Mills, the ADHD team leader within CAMHS, was attempting to change working practices wherever possible at a local, professional level. The team were well aware that they played only a part in the management/care of a child with ADHD. Whilst they did their utmost to ensure that children were given an appointment as quickly as possible, assessed thoroughly, and provided with treatment, there was a depressing awareness that without the input of all the other 'players' involved in children's lives the diagnosis and medication would be of little use or value to children and their parent(s). The individual child was at the centre of a complex network of services - school, General Practitioner, possibly Behaviour Support Services, educational psychology, social services, family and friends - neither they nor their condition existed in a vacuum. No matter how improved and comprehensive CAMHS' response was, alone they could not meet all the needs of their clients.

Regular fortnightly team meetings were held at the CAMHS to discuss the allocation of new cases plus ideas to encourage other professionals to gain a better understanding of ADHD in order to be in a position to support children. Contact was made with the Educational Psychology service, the Local Education Authority, Behaviour Support Services, Social Services, paediatricians, General Practitioners, school nurses and various individual teachers and Special Educational Needs Co-ordinators.

Crucially, many of the problems and difficulties experienced by children and young people with ADHD occurred within school. Not only did children have academic difficulties in learning and paying attention, and social difficulties with relationships, they were also trying to manage their own health care, often including a medication regime. Health care professionals were concerned to hear parents and young people tell them that schools, a) had little understanding of ADHD and b) would not take responsibility for the storing or administering of medication. As the diagnosed numbers and prescriptions for medication increased, so did the numbers reporting this very real problem: it became a major issue.

Once a diagnosis had been made CAMHS forwarded resources, such as information regarding medication or appropriate teaching strategies, to schools in order to assist in the care of the child, sometimes directly but generally via parents. CAMHS health professionals felt that it was 'in the best interests of the child' to pass on any information to schools, with the parents' permission. Occasionally schools had co-operated in or even initiated the diagnostic process. Communication

afterwards between health professionals and school staff tended to be on an ad hoc basis; teachers or Special Educational Needs Co-ordinators would call if there had been any 'trouble' with the young person, asking what could be done. The health professionals liaised between teachers and parents and acted as an advocate, sometimes agreeing to see the young person as soon as possible. However, CAMHS found that they were 'hitting a brick wall' (Dr Mills) in trying to liaise with schools. Each school had its own policy on the handling of medication on their premises; there was no cohesive Local Education Authority response in place. CAMHS began to realise that they actually had very little idea of the policies, procedures and practices which governed schools and that they needed to develop a 'health-school' link if the situation for young people was to be improved.

Schools, however, were less willing to become involved at an institutional level. Throughout the period of the research, the ADHD team leader at CAMHS made several attempts to liaise with schools in the local area. Consultation eventually culminated in the arrangement of two training sessions, to which all primary and secondary teachers were invited, but was specifically aimed at Special Educational Needs Co-ordinators. The take-up for these sessions was not high and many of those who did attend already had contact with CAMHS so it was rather like 'preaching to the converted'; the 'converted' had come to find out how to get a child through the referral system and how to persuade their school to manage the medication. The consultant was frustrated not to be able to stimulate a discussion regarding the validity of the ADHD diagnosis as those that did attend confirmed that there was a general resistance to the conferment of a medical diagnosis for inappropriate behaviour amongst teaching staff.

On at least three occasions over the research period Dr Mills met with a representative from the Local Education Authority to ask for their involvement in the process of assessment of children. They were very much opposed to this idea as the process would be far too time-consuming and therefore increase their workload. CAMHS' staff found this frustrating as criticism of their apparent over-reliance on medication often came from educators. By agreeing to help to develop a multi-agency assessment process educational representatives could have challenged the narrowly focused conceptualisation of ADHD and the tendency to use medication as a form of intervention.

Although not involved at the level of assessment schools could not choose to ignore the increasing numbers of children being diagnosed with ADHD or their prescribed treatment, usually psychostimulant medication. A large number of primary and secondary schools in the city resisted taking responsibility for administering medication to children. This was not specific to treatments used for ADHD, but also inhalers used for asthma and other forms of prescribed medication. In an increasingly litigious society, teachers are justifiably fearful of being sued or blamed if anything should go wrong. Indeed, teachers may be resisting being drawn into the health care remit, given their heavy workloads they may not particularly want to effectively be health care workers also (Mayall, 1996; 2003).

Pressures imposed by the current structure of schooling in the UK mean that school staff are working to a formal agenda which emphasises cognitive ability above all other skills and strengths. It is claimed that schools care for children, but actually

schools rarely acknowledge that children are embodied beings; as Mayall (1996:135) says, 'Health care is not formally recognised as a component of school agendas'. This is compounded by the fact that many teachers and other school staff have limited knowledge of ADHD and would benefit from further training in dealing with the kind of health, disability and psychosocial issues which can affect children. This is an important point, as schools may be accountable for medical negligence if treatments are administered incorrectly, but they could just as easily be said to be damaging children's educational experience if they refuse to keep medication on the school premises. Dr Mills and his team felt it important to pursue a school-health link in order to break down barriers and preconceived ideas about ADHD, although I found it necessary to question to what extent the medical practitioners wished to 'win over' other professions or whether they could see a way of working together which allowed for diverse and competing views of the ADHD concept and appropriate treatment.

After further lengthy negotiations a representative from the school nursing body began to attend the fortnightly team meetings and disseminate knowledge of school processes and procedures to the CAMHS team. In a reciprocal fashion she also disseminated knowledge of the workings of CAMHS to the schools in which she was based. The next step forward was to develop an 'ADHD protocol' in conjunction with the Local Education Authority, so that all children and young people in this area could be assured of equitable treatment in school. It was vital that educators perceived this as positive link work, rather than medical professionals encroaching on their territory. This process of negotiation eventually led to two school nurses being seconded to CAMHS for a period of time in order to

carry out the important role of liaising with parents and schools, providing behaviour management and devising a course for children with ADHD. Being more informed about the condition of ADHD and the working practices of CAMHS enabled the school nurse service to be more effective in their work within schools and this was perceived by school staff, pupils and the CAMHS team to be an example of successful joint working.

The education service was not the only professional body to be wary or sceptical of the implications of dealing with psychiatric diagnoses such as ADHD. Requests for help or co-operation from the CAMHS team to services such as Behaviour Support Services, Social Services and the Educational Psychology service met with responses which ranged from indifference to hostility and suspicion, at both a personal, individual level and at a deeper systemic, structural level. In line with an Inquiry into mental health services for children conducted by the Mental Health Foundation (1999) I found that services were often opposed to conceptualising inappropriate and sometimes anti-social behaviour as a child mental health issue and this led to conflicting views on what constituted an effective response.

An approach to assessment and treatment which is multi-modal and involves a variety of professionals with different theoretical orientations might ensure that ADHD is not perceived to be an example of the 'medicalisation' of children's behaviour. Although many constraints to 'joint' working have been identified, some practical, some logistical and some concerned with a lack of resources (British Psychological Society, 2000), a positive attitude at the individual level can help to overcome some barriers. A willingness to engage with professionals from

other disciplines, both intra and inter professionally, accepting that each has a different conceptualisation of children's difficulties, but a shared aim of providing support, would be a more productive way of meeting the needs of children and their parents. At present a lack of co-ordination and communication between services means that parents are left with the responsibility of ensuring that relevant services and agencies are aware of the needs of their child.

#### Parents' role in managing the condition: strategies developed

Parents take further responsibility for managing their child's medication regime. Most children in the intensive study group of seven appeared to have been prescribed 10mg of Methylphenidate to be taken around 8am, and a further 10mg to be taken around midday. The ADHD team at CAMHS were keen for General Practitioners to begin to prescribe medication, to relieve their own workload and to give families a more local point of contact. However, not all GPs wished to become involved in prescription of Methylphenidate, partly because of their lack of familiarity with the condition of ADHD. Ross's GP had recently taken over the responsibility, and had been provided with information to assist in his understanding. Mrs Adams, Ross's mother, describes what happened on one occasion:

I don't believe they've read it [the information], they really cannot have because the last two times I've been to get repeat prescriptions I was quite upset. Ross takes two 5 milligram tablets twice a day, so 20 milligrams, but he [the GP] prescribed 50 milligrams four times a day, so like 200 for the whole day! It would have killed him, would have shocked his heart.

On hearing this, I commented that she must have been relieved to have noticed the mistake, but she says:

But I didn't! I [...] I mean I read it, because not only did he write 50 he actually wrote the word fifty in brackets, it was like he was trying to make them understand that he wanted the 50, and just by a matter of chance the pharmacist questioned it. Now I don't actually know whether they come in 50 milligram form, but she came out and she said 'There's been a very big mistake made with this prescription, and I don't believe the doctor knows what he is prescribing. These are very dangerous levels.' I said 'But he's had it before', thinking, 'here we go again', because I have it with my other son's Tourette's medication [...] every time I go to get a prescription they always question it, and on the packet it says KEEP AWAY FROM CHILDREN, so I thought she was questioning the fact that I've got a child taking this medication, but she said 'No, no, no, no, no - look what he's written'.

Medical errors can occur and parents feel they need to be vigilant in monitoring that the correct dose of medication is being taken, at the suggested time, and that children are not experiencing any ill effects. Parents usually made sure that the morning dose was taken, but it was often not easy to ensure that children took the lunchtime dose, as the arrangement between schools varied greatly.

Parents adopted the role of advocate, mediator (Read, 2000), negotiator; they took responsibility for their children's health and well-being, fighting for their rights and needs to be met, especially within schools. Service provision is often based on assessment, so acknowledging and perhaps highlighting children's 'differences' and difficulties may be the only way to gain recognition and support from the various professions.

Mothers carry out direct caring work and have to involve themselves with a number of agencies and professionals, which can be frustrating, tiring and time-consuming (Read, 2000). Mothers are required to relay information between services, they are the go-between, and often there exists a lack of co-ordination, with large numbers

of professionals involved. Rhetorically parents and professionals may be said to be in partnership, but in reality this is not an equal relationship. Moreover, the capacity of parents and children to complain, disagree or resist is limited as a 'competence gap' (Lupton, 1997) exists and the professions maintain their monopoly on knowledge (Freidson, 1970).

Medicine developed historically as a scientific, objective enterprise, shrouded in mystique (McKeown, 1971). The skilful application of professional knowledge has traditionally been valued and lay knowledge has been largely dismissed, referred to as 'common sense' or 'old wives tales' (Smith, 1988). In the more recent narrative turn, it has become popular to claim to listen to the voices of lay people, and health service rhetoric even claims that patients are now partners with their health care workers, but there has been little or no recognition of the imbalance of power in such a partnership. The rise of the 'knowledgeable consumer' is said to indicate a challenge to medical authority; others are increasingly critical of the growing trend which turns people into lay experts (see Williams, 2003). It has been argued that 'Doctor knows best' has moved in the direction of 'patient knows best', and that a balance is needed, or one extreme principle is in danger of being replaced with another (Fulford et al, 2002). However, this is not quite true in reality. In the case of ADHD, the reality of the situation was that parents may have been informed by other sources, such as the internet or media, but ultimately they placed their 'trust' in doctors, believing them to have high competence, specialist knowledge and concern for their child's welfare, based on the reputation of the profession. Lupton (1996) argues that dependency is a critical feature of the medical encounter and I would suggest that this is reinforced by the power interests of the

doctor/parent/child-patient triangle. Some parents questioned the decisions made by doctors and others attempted to influence their judgement by providing up-to-date information gathered from the internet or by over-emphasising the way in which their child's behaviour caused impairment. This serves to illustrate how power is deployed by individuals and how power relations in the medical encounter are pervasive and subtle (Lupton, 1994).

In some of their negotiations with professionals who acted as 'gatekeepers' to resources, there were instances where parents' status or social class may have influenced the way in which they were treated. Where such differentials were not evident an undercurrent of prejudice and preconception sometimes rose to the surface:

I think my say has helped with Marcus because when I asked for him to be statemented I was told that it wasn't necessary, so I summoned a meeting and said "I'm not happy that Marcus is getting no help, and I'm going to appeal, but he [Learning Support Services representative] didn't want me to appeal, so we had another meeting, and suddenly Marcus is getting much more help. Now I don't know whether that's through my say so, because when I said I was a Social Worker, he went "Oh, I didn't realise". What did he mean, "I didn't realise?" So what! I could have been a dinner lady or anything, what difference should it make? (Mrs Baldwin, Marcus' mother)

Marcus's mother's personal experience and professional training led her to be keenly aware of the possibility of racist assumptions being made about her son so at a previous meeting when the same person was not concerned that Marcus was 10 years old but had a reading age of 6, saying 'there are far worse in his class', she resolved to continue to pursue the matter. Mrs Baldwin's role as a social worker appeared to influence the Learning Support Service representative's action; he responded more favourably once he realised that she was a social worker which

seems to imply that the professional status of parents may positively influence the response of services and practitioners. For many mothers such value-laden beliefs subtly shaped the experience of advocacy on behalf of their child and reinforced a power differential between representatives of statutory agencies, who held resources, and parents who were trying to access such resources. Parental persistence and the right kind of presentation was often key to the success of the negotiation.

Mothers in particular were extremely active in caring for their child. Indeed, the State assumes that the welfare of children is the responsibility of mothers (Graham, 1984; Doyal, 1983; Mayall, 1996; Read, 2000). They are responsible for ensuring that appointments are kept, and medication is taken and that the children are kept safe. Aspects of 'care' and 'control' were apparent in these mother/child relationships. Parents were aware of the tension between really caring about their children and the difficulties with which they were faced, and being 'over-protective' or controlling. They were anxious to help in ways that they could, for instance Chris's Dad designed a card which could be initialled by teachers to let Chris's parents know that he had had his medication. This strategy was to be used to identify if Chris was behaving inappropriately and receiving detention on days when his medication had been missed. Many parents work with their child as far as possible to make life easier for them, and really try to understand what having ADHD means to them. Yet parents, as adults, cannot fully comprehend their child's world-view. Sean (aged 12), was prescribed Ritalin to be taken in the morning and at lunchtime. Quite often he would not take the medication, leading

to a deterioration in his behaviour and concentration at school. His mum assumed that the problem was that he forgot to take it:

He's easily distracted, I suppose he might just think 'Oh, I'll just take my tablet', and then his friend knocks the door to walk to school, all of a sudden he'll think 'Oh, I've got to take my football kit', and go off and look for that and the tablet will fly out of his head! I keep racking my brains thinking of how to get around this, it's the same at school getting him to take it at midday - do I get him a watch that goes 'beep beep' to remind him, but if when it goes 'beep beep' it's not convenient for him to take it, it's not going to beep again in 10 minutes is it? (Ms Jones, Sean's Mother)

Parents did tend to perceive that children and young people **needed to be reminded** to take their prescribed medication, that 'forgetting' was **part of their condition**, but this is not necessarily the case, as a variety of factors affect 'adherence'.

### **Young people's perspective on ADHD and medication: aspects of self-management and the 'taking' of responsibility**

The previous section has shown examples of parents advocating for their children and developing strategies to care for their over-all well-being. This section looks at the role young people play in being responsible for their prescribed medication, particularly within the school domain.

Tensions arise regarding responsibility for medication within school: who should be responsible for looking after and administering MPH - children or teachers? Sean and Ross told me that there was no member of staff willing to take responsibility for their medication at each of their secondary schools, but they were not overly worried about taking care of it themselves:

My mum tapes the tablet to my can of coke, but sometimes I take it off and put it in my pocket. (Sean, 12)

The Head teacher at Sean's school says he will not be responsible for adults in his school giving Ritalin to children. However, reports from school say that Sean's concentration and behaviour are improved when he has taken his medication, and staff are able to reduce the level of special needs help. Teachers claim that it is immediately evident in the afternoon sessions if Sean has not taken his tablet at lunchtime.

Ross relayed how he also keeps his medication with him during the day, tucking it into his jacket pocket to be taken during lunchtime break:

When I take it during lunch maybe I'm taking it a couple of minutes too early, or a couple of minutes too late, so just for like five minutes I feel a bit weird, like zombie-ish, like I've taken too much medication, but after that the other stuff wears away and this kicks in. (Ross, 12)

But is having a controlled drug in their possession endangering some young people? If schools are unwilling to nominate a staff member to be responsible for medications it is possible that medication may be obtained by young people for whom it is not prescribed and perhaps even illegally traded. A designated person would ensure that Sean took the tablet (if he consented), and that Ross had supervision whilst he was going through his 'zombie-ish' five minutes. In these schools no one was available to ensure that the medication was kept safe and administered at school, and no staff member was given recognition for performing a kind of 'key worker' role, offering support to the young person, or a quiet area to which they could go when feeling stressed or upset. Young people would like to know that adult support is available, should they require it, and have a relationship with a key worker who can attend to their practical, emotional and health needs

within school. Both of the above boys appear not to have an issue with taking the medication but 'compliance' amongst young people with ADHD can vary, and is dependent upon many factors, some of which will be touched on later in this chapter.

In a further example, Trevor (aged 14) until recently thought that he was the only person who had ADHD in his large comprehensive school, but he had just discovered that another boy actually in his year had the same condition and was also prescribed Ritalin:

Before, I knew him, but I didn't get on very well with him. But now it's better (pause) we're soul mates, well, tablet mates!! (Trevor, 14)

It seems that these boys gravitated towards each other once they discovered their common identity; their behaviour was similar, and as both were benefiting from medication, they shared an understanding. Sometime later it transpired that on one occasion Trevor had forgotten to bring his afternoon dose of medication to school so the other boy kindly obliged and gave him his tablet. Adults who were later informed of this expressed surprise, firstly that the boy did not think of the consequences (i.e. that he would have no medication for later on) and secondly, that the young people were in a position where they could freely borrow medication from each other. The boy's actions were not constrained by such thoughts, he merely saw a friend in need and helped him out. The example given illustrates that when young people take responsibility for their own health, and their medication, their idea of acting responsibly may differ from that of adults. Striving towards diminishing adult/child power relationships means that we need to recognise that

children and young people may not always share our world view but they have an equally valid view (James and Prout, 1990,1997; Mayall, 1996, 2002; Alderson, 1993, 1995, 2000; Hill and Tisdall, 1997).

Young people do not perceive school to be particularly 'child-centred'; school functions with the imposition of rules, and allowances are rarely made. As Trevor says: 'They say if they do it for one, they'll have to do it for everyone' (Trevor, 14). In Chris's case, when the fieldwork began, his school would take no responsibility for medication and did not appear to accept that he had a medical condition. Eventually the school agreed to keep the medication and nominate a staff member to dispense it at the end of break-time. In common with other young people, the extraordinary amount of negotiation involved in this had caused inconvenience to Chris, and had been influential in his decision not to take medication any more.

I have to take it, and then I miss the lesson anyway. Cos I take it after break, and sometimes the teacher don't turn up for about ten minutes and I miss the lesson, then I have to sit at the front of the class which I don't like doing - sitting at the front of the class is not good.

Asked whether he feels that taking medication has any positive impact, he says 'I fight more when I'm not on medication, and I don't fight when I am on medication'. Other young people confirmed that when schools did authorise a staff member to give out medication, making a special visit to find them drew unwanted attention. At the close of the fieldwork, just one year later, the school's position had changed from taking no responsibility, to stipulating that Chris would only be allowed into school to sit GCSE examinations on condition that he had taken medication, as teachers were not willing to deal with his inappropriate behaviour. This was alarming, and very similar to the international cases referred to in Chapter

Three, where a girl aged ten was banned from school until her parents reinstated her medication regime (The Ottawa Citizen, 28.10.01) and a family court judge ordered a couple to resume giving their son Ritalin, even though, in his parents' opinion, the side-effects were harmful to their child. The latter couple agreed to continue medication in light of the fact that the only alternative was going to be his removal by Social Services (Albany Times-Union, 26.7.00).

There exists a fine line between effective 'care' and social 'control' of children and young people. The above examples serve to illustrate what Mayall (1996) might mean when she draws attention to the ways in which 'care' and 'control' are inextricably linked, across the public/private divide. Public institutions such as school or social services intervene in the private decisions of families, claiming to have the 'best interests of the child' at heart. But does anyone ask children what they feel to be the best decision in such situations? And, if they did, would they consider children to be competent enough to make decisions about their own health and well-being?

There is a commonly held belief that children and young people are generally healthy, yet recent research showed that of a sample of over 500 12 year olds half expressed concerns about their health (Brannen and Storey, 1996) and when mental health issues, such as emotional and psychological problems, are included the number of young people not in good health becomes considerable (Hill and Tisdall, 1997). Children are not a homogeneous group; their needs and interests are diverse, and may include chronic health conditions, learning disabilities and psychological difficulties. Conflict exists between school agendas and children's agendas which

are highlighted when looking at the issue of health maintenance (Mayall, 1996). Recent education policy promotes 'inclusive education', but what is meant by inclusive education is less well defined (Clark, Dyson and Millward 1995). The children and young people involved in this research felt that within school, their specific individual needs were not always appreciated.

Traditionally, both primary and secondary school children have little contact with a school nurse; the school health service provides 'a quick inspection service at fairly rare intervals, it is not geared to listening to children's concerns' (Mayall, 1996: 29). Similarly, young people mentioned that in secondary school pastoral care was not always immediately available to them when in crisis, and those that did seek help risked being reprimanded when arriving late for lessons. Within the classroom, the children's bodies were regarded as non-conforming, and often they became particularly noticeable when out of their seat, or climbing on the desk or being very talkative. Yet, many of the children involved in this study had an affinity for sports, and their above-average levels of activity on the rugby or football field or athletics track were an advantage or strength, provided that they were able to follow instructions and to take turns. This seems to emphasise the social relativity of the characteristics associated with ADHD; even within the location of school, children are required to learn when it is socially acceptable to show off their bodily prowess, and when it is only their mind which is of interest (Mayall, 1996).

Parents particularly appreciated it when school staff were concerned with their child's emotional welfare, not just their academic performance and behaviour. A positive response in the form of strategies, or opportunity for discussion, meeting

the children's individual needs rather than the needs of the whole class, indicated that the school had some understanding of the issues involved and was committed to finding ways of dealing with them. It meant a great deal to young people to know that their teacher understood them, that they 'took a real interest'. School staff can play a crucial role in providing emotional support to children, but this part of their role needs to be acknowledged and given support.

At a wider, more political level, consideration needs to be given to the way in which the structure of education, including the National Curriculum, can disadvantage many children. Schools could be more inclusive by educating staff and children regarding the kind of difficulties which might hinder children's learning or social and emotional development. Many of the children involved in this study seemed to have a learning style which was much more suited to kinaesthetic, visual experiences and active involvement, rather than aural, passive learning. Moreover, the introduction of more 'inclusive' teaching strategies would benefit all children, not just those with 'special needs' (Hart, 1996).

Recently there has been some recognition of the importance of paying attention to children's health within school, with the introduction of the government's 'National Healthy School's Standard' (1999), a framework which aims to make schools healthier places for children to be. This seems to indicate an awareness that children need to be in a healthy state of mind and well-being in order to learn and develop cognitive skills. In addition, the Department for Education and Skills has published a report of the findings of their research which identified the ways in which schools could work more effectively with CAMHS. It was found that

locating mental health services within schools had many advantages, including that it was less stigmatising for children to see a nurse, that children were empowered because school was their own territory, and that problems were identified earlier, before they reached crisis point (Mental Health Foundation, 2003).

### **Issues of non or reluctant ‘compliance’**

Across the clinic population of young people diagnosed with ADHD in some cases, particularly as children grew older, they began to question their need for medication and some made the decision to discontinue it. Referred to as ‘non compliance’, this was deemed to be problematic by both parents and the ADHD team. Yet the concept of ‘compliance’ or ‘adherence’ is problematic, as it implies that patients should dutifully and unquestioningly follow doctor’s orders (Sachs, 1992). Perspectives on compliance which take interaction between the clinician and the patient into account move closer to explaining decisions made by patients concerning their condition and any medication regime.

The focus should be on the patient, his health beliefs, explanatory models and social embeddedness, and on the clinical interaction with the Health Care Provider. Such a focus is interested in understanding and explaining rather than influencing the patient’s behaviour (Wirsing and Sommerfeld, 1992)

### **‘Non-adherence’: irrational behaviour?**

The reasons presumed to underlie decision-making around medication were different for each of the young people in the in-depth study and ranged from a dislike of taking tablets, the inconvenience of a medication regime, and a need to be in control of their own life and body. I set out, with the children and young people who were part of the in-depth study, to discover how the taking of

medication affected their daily life; the answers which were given helped to illuminate the reasons why some children did not want to take Methylphenidate. The following section discusses this issue, regarding it as part of the way in which young people managed their condition.

At their CAMHS consultation Frank's mother told how she was very concerned about her son's aggressive, anti-social behaviour, which had led to exclusion from school. He had been taking medication for around four months but it did not appear to be working, despite him taking it under her supervision. Frank, aged 12, had been 'in a bit of bother' recently, whilst mixing with 'bad company'; on one occasion he was so drunk he had to be admitted to hospital as he was unconscious, and in the latest incident he and his 'mates' had 'torched a car'. Whilst both Frank and his mother were present, his mother did all the talking. Frank languished/lounged in the chair, legs spread apart, looking sullen and unhappy. When the doctor addressed him, he shrugged his shoulders and gave monosyllabic answers. Dr Turner suggested that his mum leave the room for a brief time, to give her a chance to speak with him alone, and confirmed that Frank was comfortable with my presence.

At first, Frank's responses to the doctor's questions were extremely aggressive. Frank had been excluded from school, but had recently won his appeal and was due to return shortly. She asked how he felt about this, but he replied 'I won't be there long, cos I'm gonna batter the lad who got me excluded'. Dr Turner said that this would not be a good idea as if he used his fists at school his 'reputation would be totally destroyed'. From an adult's point of view, this may be true, but amongst

Frank's peer group his reputation could have possibly been enhanced. The doctor intimated that she knew he did not like taking medication and asked why. The following exchange is instructive:

*Doctor:* Why is it that you don't like taking medication?

*Frank:* Don't know

*Doctor:* How often would you say you skip a tablet?

*Frank:* Everyday

*Doctor:* So, most of the time you don't take them? How do you manage that?

*Frank:* My mum brings it up with a drink, and I swallow it, keep it at the back of my throat, and sick it up out of the window (when she's gone)

*Doctor:* How long has it been like this?

*Frank:* I've never took them, I've always done it

*Doctor:* Can I ask, Frank, what do you do if you get a headache?

*Frank:* I take Paracetamol cos that hurts

*Doctor:* Don't you believe in ADHD? Have you read anything about it?

*Frank:* No, my mum's got loads of books, she gives them out to all of the teachers

*Doctor:* Do you know anyone else who takes Ritalin?

*Frank:* Yeah, Tyrone Patrick, he's a psycho, a little fire starter - he comes behind you if you stand still and sets fire to your trousers - he goes to a special school and he's tried to kill himself seven times.

Clearly, Frank does not wish to associate himself with the only other person he knows of who has ADHD, and therefore feels very negatively about the diagnosis. It also appears that he perceives his mother to be on a 'personal crusade'. During the initial consultation she was keen to demonstrate her knowledge of ADHD, and often gathered information from the internet to distribute to teachers and other

adults. She is also an active member of the local ADHD support group. Frank disassociates himself from this, he does not want to be regarded as 'ill' or 'different' and does not want an excuse for his behaviour. It was interesting for Dr Turner to elicit Frank's agreement that if he had a pain, he would resort to pain-relief. This seemed to imply that if he could *feel* ADHD or concretise it in some way, he would see the logic in taking medication. By taking the tablets he may feel a difference and then, in turn, could comment on the embodied experience of ADHD. This excerpt suggests that some young people resist their 'illness identity' becoming their 'master status' (Goffman, 1963; Becker, 1963).

This was an enlightening consultation, both for myself and Dr Turner. It emphasised the importance of talking to young people without their parents present, and of really listening to how they have taken a course of action which makes sense to them. They are not simply acting irresponsibly when declining to take medication, they have their own very valid reasons, which do not come to light during the average clinic consultation that is monitored by a parent. The doctor kept Frank's confidence and did not reveal any of their conversation to his mother. When this case was later discussed at a meeting of the ADHD team, other doctors did not agree, and felt that the mother should have been told, which led to an interesting debate about the rights of children and young people to privacy and confidentiality. This points to a further contradiction between the rights of adults and children in that if mothers/parents are not told that there is an issue they may effectively be denied the opportunity to better support their child and the situation may continue.

Frank's case serves to directly challenge the view of some health care workers who assume that the issue of power and control underlies young people's lack of co-operation regarding medication. It is possible to understand 'non-compliance' in terms of assertion, challenge to parental authority and decision-making, and a battle for control. However, the findings of this study suggest that non or reluctant compliance is far more likely to be connected to the crucial development of identity in this age group.

By examining the contributions of both parents and children to the division of labour around child health it is possible to see that these players take into account the overall physical, psychological and emotional well-being of children. Yet parents, as adults, can still underestimate the clarity of thought of which children are capable. Quality of life is important to young people, and this is self-defined rather than defined by adults. Adults, for example, may not be able to comprehend that 'risk' can be pleasurable (France, Bendelow, Williams, 2000). Any decisions made are based on children's own moral competence, and competence varies, given that it is linked to experience, as well as chronological age. Experience provides children with relevant knowledge, which leads to competent decision-making especially regarding issues important to them (Alderson, 1993; Bluebond-Langner, 1978).

The data revealed that children and young people would have liked the opportunity to participate in decisions which affected them but consultations were very much focused on mainly mothers' accounts of the situation. Of the 55 consultations

which I observed, in only two cases did the doctor speak to the child or young person separately from their parent to ask their opinion. In Hughes' (1999) research with practitioners responsible for diagnosing ADHD she found that the respondents avoided asking children and young people their own perspective on their behaviour. In my study doctors expressed regret; they would have liked consultation situations to be more conducive to allowing children to express their views and would have liked more time to talk to children on their own.. They lamented the fact that even when children and young people were spoken to directly they tended to give one word answers, and realised that the quality of the relationship was affected by their professional status, and the infrequency of visits, in that there was no time to build a rapport. They speculated that the proposed introduction of a computerised appointment system was likely to impact further on the time constraints.

Many factors affected compliance or adherence, not least the masking of 'self' referred to in Chapter Six. Although the young people did not want to be identified as different from their peers, in some cases they had become so used to this identity that once their behaviour changed, through the influence of medication, they did not recognise this as being the 'real' them. This issue appeared to play a significant part in decisions made around taking medication and when considering their overall well being, rather than just their behaviour, young people found ways of resisting and challenging adult prescribed pathways.

For example, the medical profession may consider 'non-compliance' to be deviant behaviour, but this is based on the assumption that doctors give the orders, provide

information and recommendations, and that patients must duly comply (Sachs, 1992). 'Non-compliance' is often associated with irrational behaviour or ignorance, but it can be a rational choice when the social context is taken into consideration. Wirsing and Sommerfeld (1992:17) refer to this as the 'internal rationality of the patient's perspective'. They regard patients as striving for autonomy by not complying, perhaps because they are feeling misunderstood as there has been no reference to their social embeddedness. Adult views are perceived to be 'rational' and sensible, and so if medication is associated with improved behaviour and academic success parents may not be able to comprehend why their child is unhappy about taking it. Of the children attending this particular CAMHS treatment for the behavioural symptoms of ADHD was primarily in the form of medication, although some young people had help with anger management, organisational skills and social skills. Health care professionals will move no further forward in their understanding of children and young people unless they make the effort to ask them about their perceptions of their condition, of how 'biographically disruptive' (Bury, 1982) it may be, and of the effects of any treatment.

Strategies developed by young people to look after their own well-being

The data presented so far have shown that young people make choices and decisions around caring for their health which make sense to them, in the context of their lives. They take their embodied selves backward and forwards across the public and private divide, but decisions are made in a somewhat intermediate domain which links home and school, body and mind, self and society (Stacey,

1984; Mayall, 1996, 2002). The full and detailed explanations provided by Ross seem to capture this complexity:

I'm usually better at drawing and art when I'm not taking my tablet, because when I do take my tablet it's sort of hard to do, because when I don't take it my head's everywhere, and then you think about so many ideas and then it just comes. I drew the collage when the tablet was wearing off.

I think when my tablet's worn off I talk too much, I rabbit away, I think I get it from my mum - a salesperson comes to the door and she's chatting away about her childhood! [...] When I do take the tablet I'm usually concentrating and doing something so I don't really have time to talk, but everything is in my mind when I don't take it, I just can't stop (Ross).

I asked all of the children who were taking medication to share with me whether they felt different and how they experienced the difference when under the effects of the medication. Some were unable to put the feeling into words, but Ross gave a very rich verbal explanation of how medication affects his thought processes:

You can't control it, you say something and then ... just keep on trying to say something more about that thing, so I'm trying to stay on track and say that, but another thought is coming in. But the bad thing about taking the tablet is when I do take the tablet, it's really hard to start a conversation because when you start a conversation you start on one subject and you lead onto another, and another, but I can only concentrate on one subject, so it's hard to go to another.

I ask Ross if it is possible to provide me with an example:

Like my mum earlier was telling you that she saw a dead person at work, then you start talking about "Have you ever seen a dead person?" then someone else says, "Oh yeah, I saw a dead person, my grandma died, we had a funeral". So then you're talking about funerals when you were talking about how she [mum] worked at a hospital, but I'd still be talking about how she works at the hospital.

Wishing to clarify what he was telling me, I asked whether this meant that the medication helped him to focus on one thing, but that he could not then make connections. He tried to explain:

Erm, well you could, but you couldn't go really far, like you couldn't change the whole subject; you could bend to think about the subject, different things about the same subject, but you couldn't just go onto a completely different subject. It doesn't work for classes, I mean, in class like say I was doing maths and then I went to Latin, I could concentrate on the Latin, it's just like when one thing leads onto another. So you can actually bend it, but you can't just change onto a whole other subject.

Ross uses his own 'internal rationality' (Wirsing and Sommerfeld, 1992) to strategically plan when to do which homework. He would tackle his maths homework when first arriving home from school, as his medication would allow him to concentrate; as the medication began to wear off he would move on to subjects that allowed for more imaginative, creative thinking, such as art. This example serves to demonstrate how young people can look after their own well-being by recognising what medication can be useful for, and when it is better to capitalise on their inherent qualities. Ross recognises that certain qualities need to be celebrated, and that ADHD is not all bad. Similarly, taking medication gave him the chance of concentrating long enough to pass the entrance exams of a prestigious public school for boys, where he is now benefiting from being in a class of just twenty-one, and happily succeeding in all areas.

A further case demonstrates how the negotiation of social identities is very important to young people. As James (1993) notes, children with special needs or different physical bodies can become identified as a sub-group of the larger category 'children'. Emma, aged 11, made the move from primary to secondary

school last September, but had found it very difficult to settle in. She found the academic work a challenge, had difficulty in making and maintaining friendships and seemed to clash with authority figures; overall, she felt unjustly treated and perceived school to be a relatively hostile environment. When I made my final visit to her in November 2001 she was no longer attending school (staying home whilst hoping to be able to move to another school) as it seemed 'pointless' to both herself and her mother.

So, when asked what she would change if she could, she wrote 'Get on in school, having ADHD and being bullied'. She was quite definite, these three factors would improve her life, and make school tolerable. The Feelings Flag (Figure 15) which Emma completed helped to expose the kind of situations which might make her feel these various emotions.

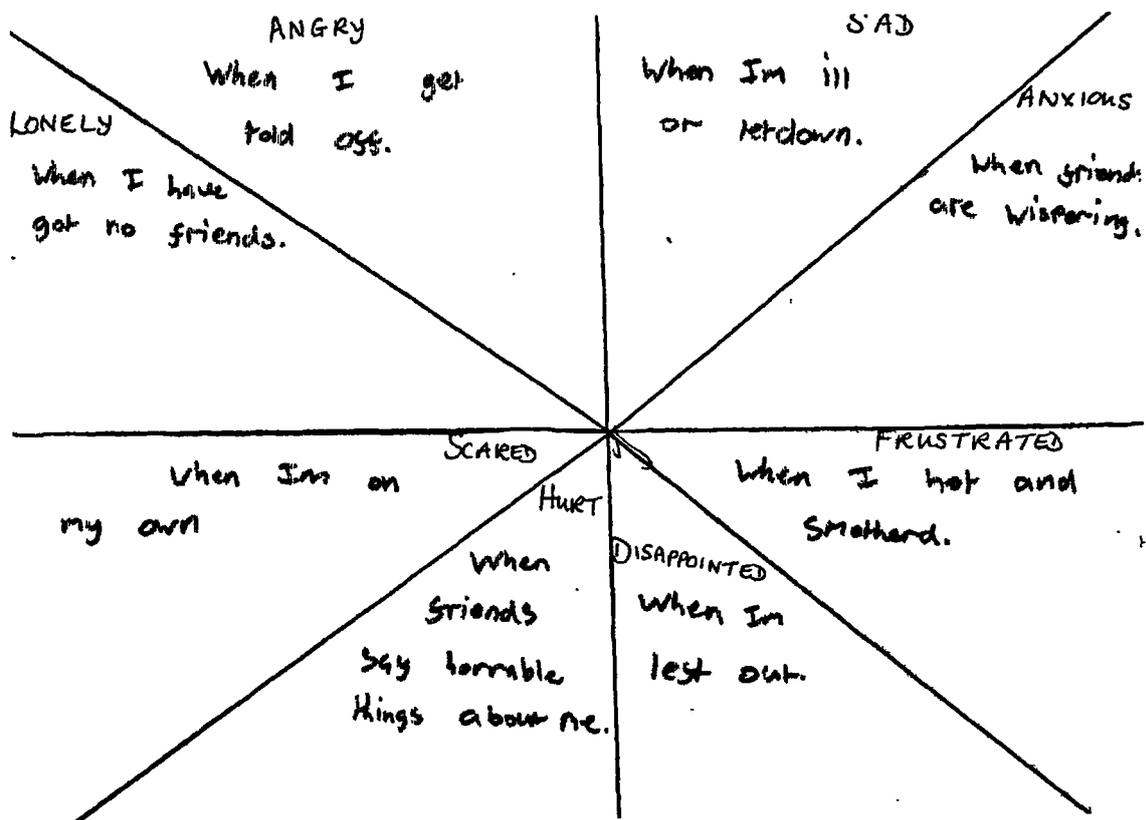


Figure 15: Emma's Feelings Flag

This pictorial representation quite vividly demonstrates the importance of Emma's peer group and friendships to her overall well-being; their approval is crucial to her self-esteem and confidence. She says, 'They all hang out in a gang, if one falls out with me they all do, well they have to really or they're not part of the gang' (Emma). Feeling rejected or disliked makes her feel lonely, hurt, disappointed, and anxious - in fact, to such a degree that she runs away from school to be by herself. Several adults have spoken to her about the risks involved in not being where she should be during the hours of 9-3pm but she prefers her own company to being provoked or mistreated by the school community. To Emma, school is not a 'safe' environment, it causes her a lot of stress. This is a strategy which she has developed

in order to cope; she may feel 'scared' when on her own but she is not being constantly reminded of her limitations or called a 'psycho'. This is the ultimately active way of contesting boundaries, and in terms of effectiveness 'One of the ways children can express their dissatisfaction with schooling is not to attend' (Hill and Tisdall, 1997).

The two cases of Ross and Emma detailed above demonstrate that although children diagnosed with ADHD share the same descriptive label, what is most evident is their individuality. They are not passive, they are active social agents, but their agency is constrained or facilitated by their structural position and by psychosocial factors. Ross's agency was facilitated by living in a large detached house, in a sought-after area, having parents who could afford for him to take part in numerous social activities, including music lessons, sports, day trips, and by attending a public school, with high standards and low student-teacher ratios. Emma, on the other hand, lived in an ex-mining community, where poverty existed, and there was 'nothing to do' for young people. Both fathers were HGV drivers. Both mothers were carers, one worked with older people and one was employed as a hospital auxiliary. Therefore, to use occupation as an indicator of social class and life chances would not have given a true picture of circumstances. Their aspirations and perspective of having ADHD were also influenced by psychosocial factors; Ross saw it as an inconvenience, but recognised the positive aspects of his personality, such as his sociability; he wanted to go to college, get a job that pays well, and tour the world. Emma, however, was more pessimistic, and worried about the future.

# MY 'WHAT-I-WANT-TO-HAPPEN' LADDER...

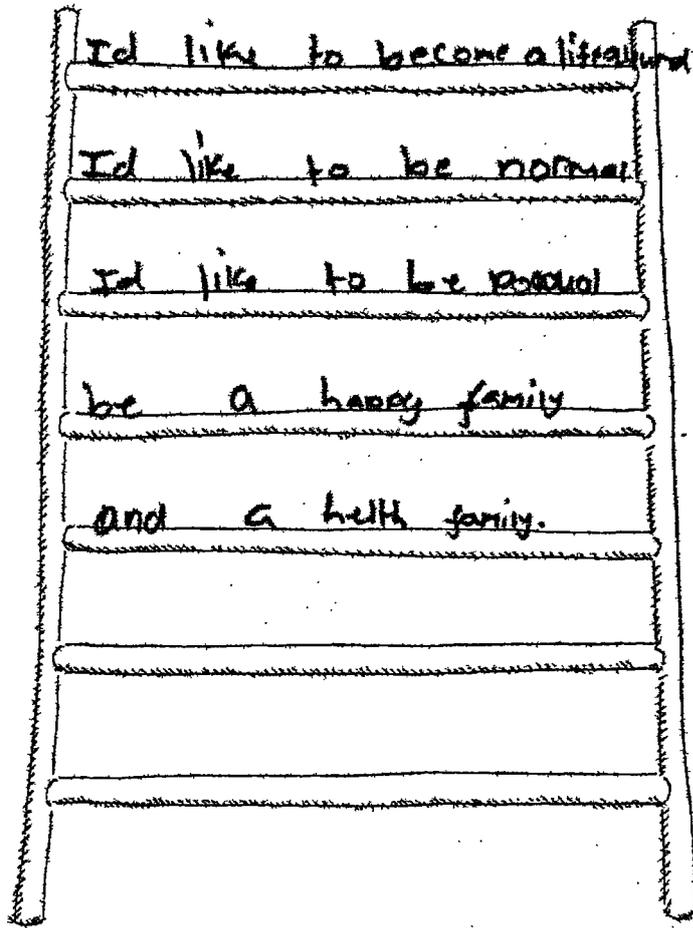


Figure 16: What Emma wants to happen in the future

Emma was concerned with relationships, in that she would like a happy, healthy family, and to be popular and 'normal' herself, finding work as a lifeguard. Home and family relationships are of crucial importance to her, despite the presence of much family conflict, of which she is said to be the cause. The influence of gender

on these answers cannot be overlooked; girls often place more store in the relational aspects of life, whilst boys may be inclined to think in individualist terms.

Similarly, within the family home children and young people develop strategies to deal with their overwhelming need for physical release, as the following example shows. Danny is a 7 year old boy who is very over-active and impulsive, he finds it very difficult to wait, as his mum told me:

On a Saturday I don't think it's fair on the world outside if they're inflicted with Danny any earlier than 10am so I'd said to him he was allowed out at 10, but he kept going on and on until I said 'Danny, if you go out before 10 I will give you a smack!' But he was so desperate to get out, he came up to me at around 9.40am and said 'Can I please have that smack now because I've just got to go out!'

In this case, Danny's needs directly conflicted with those of his parents and other adults (probably for extra sleep at the weekend); no doubt he was delighted to be free from the routine of school, looking forward to tearing around on his bike, exploring the environment and having new experiences. However, in order to accomplish this he needed to enter into negotiation, and made the decision that physical punishment would be preferable to remaining indoors, which can be conceived of as a highly rational strategy. The cases presented above serve to illustrate the emotional complexity of children's lives and their often sophisticated understanding of the precarious nature of the social order.

### **Concluding discussion**

This chapter has focused on the ways in which children and parents play an active role in the child health care division of labour. Health professionals are formally

recognised as providing health care and treatment, but children and their parents also concern themselves with overall physical and emotional well-being. The differing status in lay and professional knowledge helps to explain the lack of attention paid to the contribution of non paid workers to the health care division of labour. As has been discussed, Stacey (1981, 1988) and colleagues' approach to studying the division of labour in child health care included the contributions of both paid and unpaid carers; each participant was regarded as a social actor and part of the social process. Stacey problematises the divisions between public and private, and work and labour, claiming 'Most health care happens at home' (Stacey, 1988:177), away from a formal medical setting. Both the views of lay health workers' and their labour should be valued by health care professionals.

Children actively negotiate the social order of school and home, but generally have more success in the home environment. The accounts given clearly demonstrate that young people care for their own health and well-being in ways which make sense to them. They are neither irrational or incompetent, and their moral reasoning and agency should be recognised and respected as children and young people are clearly competent reporters of their own experience (Alderson, 1993, 1995; Mayall, 1996; Christenson and James, 2000; Begley, 2000). Health care professionals need to take the time to ask young people directly how they feel about both their diagnosis and the treatment. This may involve consulting with them separately from their parents, recognising that the needs of parents and children are not one and the same. The data presented seem to indicate that at the level of individual practice health care professionals realise the importance of lay

contributions, but at the level of health service policy structural practices act as a constraint to encouraging dialogue between professionals and children.

In the three data chapters I have considered the ways in which children are defined both by parents and the medical profession (as 'normal' or 'different'), the complex and ambivalent meaning of ADHD diagnosis and the role which children/young people and parents play in the health care division of labour. In the final chapter I seek to draw together theoretical and methodological strands relating to the findings of this study in order to extend our understanding of lay experiences of ADHD.

## **Chapter Eight**

### **Children, Families and Health Care: concluding reflections**

#### **Introduction**

In this thesis both medicalisation debates and debates in the social studies of childhood have been used as a means of reflecting on the concept of ADHD. By applying medicalisation literature to contemporary research evidence regarding ADHD it has been possible to demonstrate that ADHD is a social construct used to understand the ways in which some children behave. The underlying cause of the condition is open to question, but it is suggested that an interaction of biological and psychosocial factors lead to the kind of behaviours that are categorised as ADHD and that either/or propositions as to its biological or social origins are untenable. The increase in diagnosis of psychiatric conditions in children appears to be a matter of concern. Here I have explored the extent to which the increase in diagnoses of ADHD can be regarded as medicalisation.

At present, biomedicine is the most dominant available frame of reference within which children's differences are understood as a psychiatric disorder which can be treated. Influenced by the prevalence of this discourse parents who are experiencing difficulties with their children's behaviour seek information and support from medical professionals. Medical diagnosis can be narrowly focused on what children lack or have difficulty doing rather than the qualities and talents which they have, in perhaps being more creative or quick-thinking. Interaction between adults and children, children and their peers, children and their social environments crucially influences the confidence and self-esteem of children and

young people and their emotional health and well-being flourishes when relationships are positive.

I have suggested that a conceptualisation of children as competent, active contributors to society coupled with a view of ADHD which recognises it as arising from simultaneously biological and social processes (Shilling, 1993) is a useful starting point for a sociological analysis of the position of children with a diagnosis of ADHD. This final chapter reflects on the key findings of this research. I also reflect on the process of carrying out this project, and flag up some implications for practice along with fruitful directions for future research in this area.

### **Key findings**

The principal aim of developing sociological thinking about children with ADHD has been to draw attention to the social construction of both childhood and the medical diagnosis of ADHD. I found that parental concern regarding the 'normal' development of their child led them to look for explanations for their perceived 'difference'. Parents turned to medicine for an explanation as it was the most dominant available frame of reference. The position of the media in relation to ADHD was somewhat contradictory in that it tended to focus on sensationalist stories and to question the validity of the condition whilst reinforcing the necessity for viewers or readers to seek help from medical professionals and organisations offering advice and support if they were experiencing difficulties with their child. Therefore, at the conceptual level ADHD can be regarded as an example of medicalisation; the acceptance of a medical perspective as the dominant definition

which then leads to intervention to modify deviant behaviour in line with social norms (Conrad, 1992).

[...] the definition and status of children has facilitated and encouraged the expansion of medical jurisdiction to encompass more types of children's behaviour (Conrad and Schneider, 1980:170).

I demonstrated that ADHD is not wholly a biological issue, both the conceptualisation of inappropriate behaviour and the ways in which children are treated are socially influenced.

Parents, and to a lesser degree children and young people, found that gaining legitimisation from the medical profession was of help in social relationships (Broom and Woodward, 1996; Kohler-Reissman, 1989) as family and friends responded more positively to young people once they became aware that they had a medical condition. The medical frame of reference also gave parents an explanation and a way of understanding their children's unusual behaviour. In this way, a medical label can be productive in the absence of other alternatives. Parents who previously felt unsupported were able to access help and resources in the form of health care for their child, sometimes educational or psychological support, and financial benefits. Children and young people were no longer regarded as being wilfully naughty.

However, I have argued that ADHD remains a contentious issue because there is a danger in diagnosis which is based on behaviour and cannot be categorically proven, as 'problem behaviour' is based on the interpretation of various significant individuals - including parents, teachers and psychiatrists - and is highly subjective. It is possible that a new conceptualisation of children's inappropriate behaviour has

led to a tendency to 'look for' and 'find' ADHD. This is the more concerning, 'darker' (Conrad and Schneider, 1980) side of medicalisation in that once a medical frame of reference has been applied, and an effective treatment exists, the problem will only be understood with reference to a medical diagnosis (Zola, 1972; Conrad and Schneider, 1980; Conrad, 1992). For example, although the doctor who regretted that parents had been let down in the past was said to be reflecting on her practice (Chapter Five), her colleague's reassurance that ADHD was not being 'looked for' at the time could be interpreted as supportive of the above claim.

This study has explored the complex ways in which both pre and post diagnosis children and young people's self esteem and identity is affected by their interactive relationships with parents, teachers and other adults. The expectation to conform and to be 'normal' comes from adults, peers and wider society. The social construction of appropriate motherhood and 'normal' childhood impacted on the lives of parents and children in a number of ways. I have built on Allison James' (1993) early research into the formation of childhood identities in which she regards the lived world of childhood as central, arguing that cultural stereotypes about what constitutes a normal child are important to both parents and children. In common with James' study I found that experience of bodily difference amongst children impacts on their development of social identity. The data I have presented will increase knowledge about the child's body as an experienced entity; aspects of body, self and society are crucially linked, in a way which has not been appreciated in the literature surrounding the concept of ADHD to date. A virtual absence of research with children and young people who have been given the diagnosis has led to their views, experiences and opinions being omitted from the debate.

As referred to above, a variety of discourses combined to influence children's perceptions of ADHD including the information given during a medical consultation, parental distillation, and the media representation of ADHD. Children and young people did seem to see the diagnosis as a valid explanation for the fact that they had always been 'in trouble'; previously they had not understood, as they did not intentionally do the things they were accused of doing. Children that offered an explanation for ADHD, as in Cooper and Shea's study (1999), tended to give biologically determinist accounts, referring to ADHD as an 'illness', or 'something not working in your brain'. I have argued that this deficit model had a negative impact on their developing self-identity'.

The findings of my study suggest that being both a medical diagnosis and a social label there are psychosocial consequences to receiving a diagnosis of ADHD, related to children's decision-making around issues as to whether to disclose, who to disclose to, and the risk of becoming stigmatised, perhaps as 'mentally ill'. Therefore, dealing with ADHD meant also dealing with the stigma associated with the condition. Although parents found the conferment of a medical diagnosis to be less stigmatising than being regarded as having a 'naughty' child children and young people were more ambivalent about the changing perception from 'naughty' to 'ill' .

I have argued that ADHD is 'real' to these children; they have been told that they have got 'it', and that there is medication available which can aid their concentration and over-activity. The implications of leading children to believe that they are in some way deficient are that children may not feel responsible for

their behaviour, or, the converse, that children may feel burdened, but powerless. I have therefore suggested that re-framing the concept of ADHD to include social, psychological, cultural and environmental factors would go some way to encouraging children and young people to see 'their own sense of power and control in relation to the condition' (Cooper and Shea, 1999:244) and, most importantly, such an adjustment of perception may have a positive effect on the self-esteem of children (1999:244).

Social constructionist theories of childhood, whilst contributing significantly to the ways in which a concept of agency is central to our understanding of childhood, have overlooked children's embodied relation in the world (Prout, 2000). Many children are not necessarily 'healthy' and some have specific conditions such as ADHD which affect all aspects of their lives. The label of ADHD signifies a commonality of experience for the young people, which has been explored above, but the experience is mediated by a variety of differentials. These children and young people are not a homogeneous group, which means that embodied experience is diverse, even amongst those of a similar chronological age.

I found that children and young people diagnosed with the condition of ADHD develop complex strategies to care for their own physical and emotional health and well-being. The children and young people in this study wished to take responsibility for decisions regarding their health, and some were active in the negotiation of their health care. Medication was, at times, responsible for them re-evaluating their lives; they were now able to refer to two separate selves, namely the non-medicated and the medicated person. Methylphenidate should have made young people feel more 'normal', but instead it seems to have made them aware of

their difference. As Williams and Bendelow note, 'our relationship to our bodies is, for the most part, a largely taken-for-granted one' (2000:66), but conditions such as Tourettes Syndrome (Sacks, 1985) and ADHD can call into question this previously unquestioned reference point.

Throughout the research young people's attitude towards medication has been complex and multi-layered. They acknowledge that medication is a form of control, which can benefit them, but is of particular benefit to the significant adults in their lives - parents, grandparents, teachers. Children and young people especially felt the benefits of medication within the context of school; both their academic work and their social relationships improved to a lesser or greater extent with the help of medication. They spoke of improvements in concentration, ability to pay attention and stay focused on a particular task, ability to stop and think, understanding people's feelings, and communication with their friends and family. Children in this study were desperately seeking social acceptance; above all, they wanted to identify with their peers and not be perceived as 'different' or 'mental' and relationships with others were improved when they had taken medication. Having said that, Ritalin has been sensationally demonised by the media, and young people would rather not be associated with it. Yet adults in generational proximity often failed to comprehend the children's world-view.

In many cases Methylphenidate does help to treat over-activity and inattention and, from what children here have said, it helped to make their behaviour more acceptable, which in turn led to praise and encouragement from adults. The impact on children's self esteem was considerable (at least in the short term) and was

conveyed through their verbal and written accounts, pictorial representations, and, most importantly, their body language (which a written research account such as this fails to capture). The value of medication is in enabling relationships to develop more positively, but the tendency to rely on medication alone to treat ADHD can be criticised. The implication that deficits exist in individual children may have an unhelpful impact on children's self-identity, if they regard themselves as damaged in some way. Fundamentally, 'many of the potential problems of disabled childhood are not caused by impairment, but are outcomes of social relations, cultural representations and the behaviour of adults' (Shakespeare and Watson, 1998:22). Moreover, structural and attitudinal barriers are responsible for children and young people not achieving academically and socially, not any inferred individual deficit.

Building on the work of James and Prout (1990, 1997); Jenks (1996), Mayall (1996, 2002) and Qvortrup (1994), amongst others, I have argued that there is a tremendous pressure on children to conform, yet the boundaries which exist have been artificially created and 'not all children learn the skills necessary to switch or mix behaviour or styles of action between different social environments' (James and Prout, 1996:50). The data presented here indicate that children constitute a social group with interests which cross-cut social settings and often conflict with adult interests. Parental anxiety is such that in general children's futures are prioritised over their present (Mayall, 2002). Taking a critical view of the way in which children are constructed in this society, this study has shown how discourses about childhood are deeply embedded in debates about ADHD.

Prevailing medical discourse does not always acknowledge the agency of children, who actively help to construct their own identities and relationships. Children in this society have been constructed as passive, apparently inculcated with parental norms and values, and not perceived as active agents, capable of shaping relationships. The contributions of children are devalued, in favour of adults, who are there to direct children. The goal of producing socially acceptable children appears to justify the control which parents exhibit, in the name of care; care and control are inextricably linked (Mayall, 1996). Young people's accounts reveal their subordination to adults, yet these young people do not just accept this position, they question it. As Alderson (1994) reminds us, 'Children's 'best interests' are often defined by adults, and may complement or conflict with children's views of their own rights and needs (1994:49).

### **Implications for delivery of services to children and young people**

I believe that this study affords professionals and practitioners working in this challenging area added insight into the experiences and view points of children and young people. As this research has illustrated, children and young people's contributions as health care actors are undeniable, but they 'are also in a structured position in which adults have the power and authority' (Stacey, 2002: 276). Clearly, there remains an unresolved tension, particularly in terms of responsibility for medication. School is not an ideal environment for meeting the variety of physical and emotional health needs amongst children and the social structure of school can exacerbate a child with ADHD's difficulties. Most importantly, children should be recognised as contributing to their own health care; even the very youngest children shared their opinions regarding their health and well-being,

and took some form of responsibility for medication (the youngest for medication for a bowel condition). In many cases mothers' lay knowledge was devalued in favour of 'expert' opinion and children's own contributions were not acknowledged as important. Services for children were not well co-ordinated; despite the efforts of well meaning CAMHS' staff who were reaching out to primary care, education and social services they failed to appreciate how medical encroachment onto the territory of other professions would be perceived. The mental health needs of children should be met through the co-ordinated efforts of health, education and social services, and multi-disciplinary networks (British Psychological Society, 1996; Mental Health Foundation, 1999; DoH, 2004) which requires a commitment to joint working at a strategic level.

A finding of this study which is not often recognised by others (Chetley, 1995; Cooper and O'Shea, 1999) is that some young people felt that medication altered their personality, their perception of 'the self'. This is a crucial factor to be taken into account both in terms of professional practice and in any future research which explores non-adherence to medication. Health care professionals have often considered non-adherence to be a 'typical teenage challenge' to authority but this is to underestimate the complexity of young people's lives. Only by finding ways to listen to children and young people will health services learn about the choices which they make, for reasons which relate more widely to their general sense of well-being. Any reliance on medical treatment will only provide a short term gain. Whilst children's behaviour continues to be medicalised, and individual solutions provided, any move to change societal structures is likely to be neglected. There has been little research conducted with children to study the effects of

psychostimulant medications on daily life (Wong et al, 2004); there may well be benefits and drawbacks but there is little evidence on which to base practice.

This research has shown that parents and children provide a different perspective to that of health workers, which needs to be acknowledged and valued. In this way, the delivery of a service will be influenced by the expressed needs of children and parents. This study also complements the recent Government policy initiative aimed at better supporting children and young people. Under the National Service Framework for Children, Young People and Maternity Services (DoH, 2004) CAMHS are expected to contribute to the development of multi-agency partnership working to meet the needs of children and young people who have mental health difficulties. Particular emphasis has been placed on ensuring that continuity of care is of paramount importance when young people move from child to adult services. It is recognised that the participation of children, young people and their families in the development of services needs to be improved and that creative approaches are needed to increase user involvement.

I hope to have shown that the ADHD trajectory is not linear, not cumulative, not predictable or pathological, but multi-faceted, multi-dimensional, complex, and multi-layered. The 'story' of ADHD is not all 'doom and gloom', there are many positive aspects to these children and to their relationships with others, yet I can find little trace of this in much of the research into ADHD, which focuses on the effectiveness of medication used to diminish symptoms and the 'poor prognosis' for children who do not receive treatment. The views and experiences of children and young people are missing from the ADHD debate, at the level of research and

practice. Children are expert witnesses, both observing and commentating on their condition, shedding light on the meaning and experience of ADHD.

Listening to children's embodied experiences is one way of overcoming the polarisation which exists in the literature and debates which appears to encourage us to accept claims that ADHD is a brain disorder which is biologically rooted or is normal behaviour which is being socially constructed as a medical condition. Children's own accounts challenge the need to accept or reject either of these explanations; when the social context is taken into account it becomes clear that children and young people are able to recognise both the benefits and disadvantages of a medical diagnosis and they neither fully accept or fully reject the medical definition of their experience but actively work to redefine the experience to make it meaningful to them.

### **Reflections on the research**

#### Process

I argue that it is crucial that we let the views of children and young people be heard; adults may dismiss what children have to say and believe that they 'know best'. But it cannot be assumed that children share adults' world-view; young people are at a crucial stage of forming identities and the decisions which they make often make sense when the wider social context is taken into account. Children and young people shared information with me which they may not have shared with their parents or a doctor. Cultural representations of children with ADHD are extremely negative; they reinforce stereotypes and help to fuel prejudice. Meeting children with this diagnosis challenged any preconceptions I

may have had, and I discovered something far removed from the traditional portrayals of 'demon' children, wild, 'out of control', 'nightmare' kids. The children I met were generally very likeable, resourceful, with some unusual coping strategies. Yet, as the data above illustrates, they clashed with adult expectations and social norms and at times their behaviour was regarded as deviant, anti-social and indeed dangerous to themselves or others. I hope that by locating myself in the research account I have reflected on the process of 'doing' research (Maynard and Purvis, 1994; Kelly et al, 1994; Letherby, 2003) rather than focused solely on the production of a piece of knowledge.

The primary contribution of this research is in providing empirical grounding for research which is concerned with children's management of their health and well-being, specifically in relation to ADHD, and to add to the expanding methodological developments in the social studies of childhood, which seek to employ sensitive, appropriate methods when exploring the views of children and young people. The way in which I engaged with the smaller sample of seven children, using methods which ensured that they had the opportunity to 'voice' their perceptions could be described as innovative. I believe that the tools I used elicited authentic accounts, giving young people chance to express themselves in a voice which is rarely heard by the professionals who work with them, and almost never represented in ADHD research accounts.

The conferment of a medical diagnosis ensures that a once 'private' familial matter becomes part of a wider, 'public' issue, namely an individual child becomes part of a cohort of children who share the diagnosis. I used C. Wright Mills concept of

'private troubles, public issues' to demonstrate how 'troubles' are transferred from a private experience to a public health issue. Zola (1972) and Conrad and Schneider (1985), however, argue that the process of medicalising a social problem attributes it to the individual and serves to depoliticize the issue. The individualization of social problems implies that children's behaviour is inherently problematic without reference to the social context in which inappropriate or deviant behaviour occurs. In addition, regarding behavioural problems as a family issue tends to absolve services and the state from supporting families. Families need advice and support; better social support systems are urgently needed for all families, not only those perceived to be 'problem' families and not only at a point when parents can no longer cope. Invariably children live their lives within families, and their experiences are inextricably linked to this context (Brannen and O'Brien, (1996). For this reason, approaches to behavioural difficulties which involve the whole family are likely to increase success in the long-term.

### Limitations

Although the methods which were used yielded rich data and proved to be a way of engaging children, it is important that claims to have been 'child-centred' in my approach are not over-stated. Ultimately, it was an adult, namely myself, that selected from the array of drawings and personal accounts, deciding which to include in the thesis. As Pole et al (1999) point out, given the adult-centred nature of most sociological research, there will inevitably be difficulties as the process will involve adult reflection on the process of childhood itself. Some of the issues raised by Alderson (1997) and Alldred (1998), and addressed earlier in this study,

regarding whether an adult can truly represent the voice of a child, are still pertinent.

As Dockrell, Lewis and Lindsay (2000) note, 'Using drawings to make inferences about a child's personality or emotional state is a highly suspect process' (2000:57). Therefore, it should be emphasised that no claims are being made here that visual methods allow access to children's inner world, only that they provide a meaningful way of communicating with children, a way with which younger children are very familiar. It should also be recognised that using the method with young people can be problematic, as some are reluctant to draw, often because they are discouraged from forms of expression other than written within school, or because they have internalised the notion that they are not skilled artists.

Although not claiming to be representative of all, this research will have meaning for the lives of children and young people who have been diagnosed with ADHD, their parents, and for support services. The findings may not be generalisable to the experience of all children and young people with ADHD or to all professionals working in this area, but it is likely that this research has value in explanatory terms and it will therefore be relevant to others who find themselves in similar situations (Clyde Mitchell, 1983). The study group was gathered from one large city, located in the West Midlands, with an ethnically and economically diverse population. The majority of the children had received their diagnosis from the same CAMHS, although some had been diagnosed elsewhere. The circumstances of the children's lives were diverse, but there were also many commonalities relating to the shared label of ADHD therefore this study makes a contribution to research being

undertaken with children with disabilities, special educational needs and health conditions and research which explores the experience of children/young people as a social group.

In this research children from ethnic minority groups were under-represented. Of the sample of 45 responses (to the questionnaire) 95.5% of parents gave their nationality as 'white British', which seems unrepresentative of the city as a whole. The 'ADHD client list' used by CAMHS confirmed that, at that time, less than 5% of children were from ethnic groups other than white British. Research into the prevalence and distribution of diagnoses of ADHD both across the UK and cross-culturally might be able to shed light on the factors which influence the referral pathways. For instance, a condition which occurs across the population of children would be expected to cut across social class and ethnicity, having the potential to affect all children. The differences in rates of diagnosis highlight the importance of further consideration of social and environmental factors. Both the findings and limitations of this thesis point to a number of fruitful areas worthy of further exploration.

### **Future directions for research**

The stories told by participants in this study about their lived experience provide a complex picture of the nature of cultural constructions of both children and illness conditions. Longitudinal research would be able to explore further the long-term impact of diagnosis, and particularly treatment with Methylphenidate, for children. It would be of interest to follow young people through the transition from school to work, college or elsewhere, and, in particular, to see whether the standard of their

health care altered as they moved from Child and Adolescent Mental Health Services to adult mental health services.

Whilst not exploring the gendered aspect of ADHD diagnosis to any great degree in this thesis, this would be another rich vein of future research. Although it is the case that neurological and developmental difficulties affect mainly boys (Mental Health Foundation, 1999) future sociological research might question whether a 'medicalisation of masculinity' is taking place. For instance, are the traits of hegemonic masculinity no longer valued or acceptable? Is there confusion over the male 'role'? Many reasons are offered for the increase in difficult behaviour amongst boys, including the lack of positive or appropriate masculine role models because of changing family structures, absent fathers (physically or emotionally), violent parental relationships or fathers with poor parenting skills (not demonstrative or tactile). Research in the area of 'masculinities' might examine whether boys who have an aggressive, competitive, confrontational style are no longer tolerated in an educational culture which requires children to be largely sedentary, conformist, and obedient, and has no room for those who will ask awkward questions, divert attention from the National Curriculum, and are unlikely to contribute positively to school's position in 'league tables' based on Standard Assessment Tests (SATS). Or is it the case, as Hey et al suggest (1998), that concerns about boys, particularly their underachievement in school, says more about the differences in the social construction of special needs than of boys' failure to learn.

My research will increase public understanding about adults and children's experiences of ADHD, and provide useful information for those working with children in the fields of health and education. The methods developed in order to listen more clearly to the views of children and young people were particularly successful in allowing those who found it difficult to verbalise feelings to make an effective contribution to the project. Future research might build on the small-scale findings of this thesis to explore the social worlds of children who have the diagnosis of ADHD. When presenting these findings at a meeting of the Association of Child Psychologists and Psychiatrists those present commented that they found the children's accounts 'moving' and 'powerful', and they valued the contribution which such research can make to increased understanding of the *experience* of ADHD. The unique and fresh insights which shine through children's verbal, visual and written testimonies in this study highlight the gaps in our knowledge about their ideas, views, perceptions, and lived experience. More participatory approaches need to be used in research to be able to explore children's views and understandings, allowing them to feel that their contributions regarding their intensely personal experiences are of value.

Difficulties in meeting the demands of society 'inevitably have a range of social, educational and psychological consequences' for children (British Psychological Society, 1996), and many children feel sad that they cannot meet the expectations of parents, grandparents, teachers, and their own peers. 'Ivory tower' theorising about the socially constructed nature of the concept of ADHD is not able to help families deal with immediate situations, which sometimes involve danger to children themselves (such as running across the road without thinking to check for

oncoming traffic, or contemplating suicide) and others (such as firesetting and being violent to family members). The attraction to dangerous pursuits, or 'risk(y)' activities is an underdeveloped theme which arose from the analysis, and warrants further attention in future research papers.

## **Conclusion**

This study has theoretically explored the controversies which surround the medical diagnosis of ADHD in the UK, highlighting the contradictions which abound. I have touched on the validity of the concept but summarised the position which I have taken by regarding ADHD as a psychiatric illness condition which has been socially constructed, whilst recognising that there is an underlying reality to the experience of being regarded as 'different' for children and young people. I have also made reference to the practical and symbolic implications for children and their parents of receiving a medical diagnosis and to the implications of managing a medication regimen. I have explored more fully the social and psychological consequences of being diagnosed with ADHD and drawn attention to the complexity of children and young people's views of both the diagnosis and psychostimulant medication, the usual form of intervention.

Adopting a sociological position enables us to view the situation from a fresh epistemological standpoint. Having conducted empirical research within a CAMHS, and within familial homes, I hope to have given a reasonably balanced account of the differing interests of children, parents and professionals which need to be considered when examining the process of diagnosis. However, it is only children and young people who can recount the *lived bodily experience of the*

*meaning* of ADHD, and therefore their contribution is central to any attempt to understand the condition. Both in research debates and in practice their contributions have largely been neglected; this thesis and the research on which it is based goes some way to redress the balance.

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RESEARCH PROTOCOL

Application submitted to: The Chair, Ethics Committee,  
Health Authority,

Researcher: Geraldine Brady BA (Hons), MA  
Postgraduate researcher, Dept of Sociology/Social Policy,  
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Date of

Submission: 29 June 1999

Research

Venue: Child and Adolescent Mental Health Services

# CHILDREN'S EMBODIED EXPERIENCE OF ATTENTION DEFICIT HYPERACTIVITY DISORDER.

## Research Question/Problem Defined:

Attention Deficit Hyperactivity Disorder is a medical category associated with the challenging and inappropriate behaviour of children; it does not fit the biological model of illness, lying across the divisions of mind/body, individual/society, reason/emotion, yet the dominant approach to conceptualising and treating AD/HD has been biomedical. Children can be regarded as a subordinated, socially marginalised group; tensions between 'care' and 'control' are ever-present in the lived experiences of these children. The ways in which AD/HD children are constructed by adults - parents, teachers, psychologists, psychiatrists, social workers - may leave children themselves largely 'unheard' or 'mute'. Scant micro level research exists about children's own perspectives, which might link or support macro level research regarding the social and political context of the increased diagnosis of AD/HD. There appears to have been a polarisation of the medico-scientific model, which regards AD/HD as biologically based, and the educational psychological model, which regards the condition as a social construct. I intend to show that the two perspectives are not mutually exclusive by moving towards a biopsychosocial conceptualisation. In this qualitative, empirical study I seek to understand AD/HD as a complex interplay of biological, social and cultural factors. I will elicit the meanings, understandings and perceptions of children themselves through the use of appropriate research methods, whilst also representing the views of parents and health professionals who struggle to deal with the emotional trauma of AD/HD.

## About the Researcher:

I am currently undertaking a full-time PhD in Sociology/Social Policy at the University of Warwick, having obtained a three year scholarship from the Economic and Social Research Council. As part of the recently established Centre for Research in Health, Medicine and Society, I belong to a multi-disciplinary body of social researchers and practitioners. My PhD supervisors are both well known in their field; Dr Gillian Bendelow has extensive experience of

researching with children, and Dr Simon Williams has published widely, particularly in the area of chronic illness and disability. Their letter of support is enclosed.

The study I wish to carry out will build on my M.A. dissertation, for which I also obtained E.S.R.C. funding. This was a small-scale study, involving parents and children who attended the local AD/HD support group, the focus of which was to explore the experiential reality of living with AD/HD by carrying out narrative sessions within each family's home. This research raised questions I wish to answer in this current study, particularly in terms of the diverse discourses surrounding AD/HD - lay, populist, medical, educational.

The research has the support and backing of the consultant psychiatrist at whose clinic I wish to be present in order to observe and later interview children (the patients) and their parents. I have enclosed Dr signed consent form, giving me permission to approach his patients; I will, of course, respect the decision of anyone who does not wish to take part, at any stage of the research. Dr is interested in my research and hopes that my findings will prove useful to all of those involved with AD/HD. My overall aim is to use the data gathered to produce a report on the needs of children with AD/HD, together with recommendations on how these needs can be best met.

### **Background to Study:**

#### ***What is AD/HD?***

In general, the terms 'Attention Deficit Hyperactivity Disorder' (American Psychiatric Association's DSM IV) and 'Hyperkinetic Disorder' (World Health Organisation's ICD 10) are used interchangeably, although the list of symptoms for each varies. The use of different criteria has led to differing rates of prevalence for AD/HD, and a possible under-diagnosis in Britain. The three dimensions of the disorder are classed as: inattention, impulsivity and over-activity. Symptoms are said to include: poor organisational skills, a tendency to lose things, clumsiness, poor social skills, excessive talking, inability to think through the consequences of actions, and the lack of a sense of fear or danger. The above may combine to lead to poor school achievement, difficulty in peer and family relationships and low self-esteem.

AD/HD is of importance because it constitutes the most common childhood disorder to psychiatric and psychological services in the United States (Holowenko, 1999) and is increasingly becoming a condition of concern in the United Kingdom. Research into the condition is fraught with difference of opinion, regarding its aetiology, its existence, and the controversial use of psycho-stimulant medication. A biomedical approach is dominant in the research literature, seeking to identify a biological cause for AD/HD. This unitary focus has neglected social, environmental, cultural and historical influences on the manifestation of the disorder, although these factors have recently begun to be given some recognition (see BPS, 1996).

### *Theoretical Context of Research*

The sociology of childhood project promotes a view of children as independent social actors. Empirical research now focuses on the contexts of children's daily lives and regards the views and actions of children as making a vital contribution to the social order. Childhood is not just a preparatory stage for adulthood, but is important in its own right; children are human beings, not human becomings. A variety of powerful groups construct children's behaviour as a problem. Research which tries to address children's own concerns and devise means of getting at their own understanding of their AD/HD disease label moves away from the discredited image of 'top-down' research, and towards a less hierarchical relationship.

The research is also informed by debates on issues of 'medicalisation' and the contested nature of professional boundaries. The concept of medicalisation has not been popular in recent years, but is quite relevant to this study, referring as it does to the way in which social and environmental problems are increasingly coming under medical jurisdiction (Zola, 1975; Illich, 1975). More importantly, biomedicine is invested with the power to define 'normality' and has been criticised for its rigid concept of normality (Conrad and Schneider, 1980). Diagnostic categories can be viewed as convenient labels to identify deviance, allowing legitimate surveillance and investigation of children's bodies (Donzelot, 1980). On the other hand, medicalisation may actually be sought by groups other than medical professionals; many parents and support groups are engaged in a struggle for medical recognition of AD/HD, such as occurred with dyslexia or repetitive strain injury. Medical definition can be advantageous; being part of the generic category of Emotional and Behavioural Disorders, AD/HD children

can be considered to have special educational needs. It can also be seen as a resource, not a constraint, and 'humanity often benefits when some form of distress becomes defined as an illness and is incorporated into the orbit of medicine' (Broom and Woodward, 1996:359).

A growing body of theoretical and empirical work on the emotions is emerging from a variety of disciplines, including psychology, biology, psychoanalysis and sociology, which reflects the complexity of the debate (Williams and Bendelow, 1996). Interactionist theories of embodiment 'bring the body back in', seeking 'to interlock biological and social factors in a dynamic, rather than reductionist, monocausal way' (Williams and Bendelow, 1996:128). Emotions are both biological and social, therefore Hochschild's (1979) work on 'emotion management' is also of importance to this research; she draws attention to the expectation that we are to 'manage' our feelings in line with institutional and societal values. 'Feeling rules' exist to socially regulate the expression of feelings to appropriate times, locations, social relationships. Children with AD/HD are said to lack social skills, act inappropriately for time and location, and be 'out of control'; I will observe their behaviour across different settings.

Feminist methodological studies have tended to open up and discuss the problems involved in researching sensitive and contentious issues, such as the establishment of non-hierarchical research relationships, and empowering research participants by providing them with a 'voice'. Sensitivity in social research arises from the relationship between a topic and its social context, but what is regarded as sensitive is highly subjective; sensitive research has the potential of leading to both personal and professional difficulties (Renzetti and Lee, 1993). This sensitive, contentious area of research uses accepted methods of qualitative research in order to access the views and experiences of children and young people (the patients), their parents, teachers and health professionals involved in their care.

### **Research Timescale:**

Subject to ethical approval, I will begin my research during the first week of October 1999 and complete the fieldwork in June 2000. The main AD/HD clinic takes place on a Monday morning, but other appointments are made during the rest of the week, and I intend to spend approximately two days or three mornings, whichever is most appropriate, at CAMHS. I will

be analysing the data as it is collected but I anticipate spending the following twelve months carrying out analysis and writing my thesis.

### **Sample:**

Patients will be recruited at their initial appointment. I will observe 30 initial consultations over a period lasting from October 1999 to January 2000. Of these 30 children, I will attend follow-up appointments (between October 1999 and April 2000) of 15-20 and follow the trajectory of their treatment. I intend to observe 30 children initially but will be aware that some may wish to withdraw from the research at a later date and some will not receive a diagnosis; my intention is to carry out more in-depth research with a minimum number of 15 and a maximum of 20 children, the ages of whom will vary between 4 and 16 years.

The children will be selected using an opportunistic sampling technique, but I am aware that within the AD/HD population there is a strong gender bias towards boys, and a tendency (at least in this area) for patients not to be from ethnic minority groups, although this is far from idealistic. The consultant psychiatrist agrees, in principle, to the *Parent Information Sheet* and *Children's Leaflet* to be included in the letter which the clinic send regarding an appointment for an initial consultation. On attending their appointment the parents and the child will be verbally informed of my research by \_\_\_\_\_ or one of his colleagues. I will be outside the room when the Consultant asks for the parents consent for me to observe, so that they will not feel coerced into taking part in my research. If they agree to my presence in the consulting room and have read the Information Sheet, I will ask both parents and child to sign a Written Consent Form.

### **Methodological Choices**

I will be using a combination of methods in order to enhance the validity of my research. Triangulation of methods is a useful way of avoiding criticisms of researcher bias and of research being too subjective, specific and not generalisable.

**Observation** - (Of all interaction, On-going) -I will begin my fieldwork with a period of non-participant observation at the clinic/mental health unit. I will familiarise myself with the layout

and the staff, some of whom I have already had contact with. I will observe approximately 30 children who have been referred with suspected AD/HD at their initial consultation.

I have explored the idea of carrying out an ethnography of the mental health unit but believe that this will not prove fruitful as my research problem involves looking at how AD/HD is constructed across a variety of settings, rather than focusing on the actual process of diagnosis. Of course, observation will be on-going throughout my fieldwork, particularly as the 'symptoms' of the condition are displayed through impulsive, inattentive and over-active behaviour. The clinic uses video recording equipment to help in diagnosis, and I will also have access to this information whilst on their premises. Observational field notes will be kept at every stage of the fieldwork in order to enhance my analysis. Once I have observed the interaction between children and their parent(s) and the clinic professionals, I will move on to interview the health professional required to make an assessment.

***Semi-structured Interviews*** - (with Health/Education professionals) - This method is most appropriate for interviewing the various health and education professionals involved in this study. I imagine that I will have informal discussions with health workers soon after consultations, after which I will write notes. Within the first month of fieldwork I plan to interview those directly involved in diagnosis and treatment for one hour using an interview guide to help me to use my time constructively. I will have some open ended questions to ask, but will be flexible enough to allow for the interviewee to expand on any point. The interview schedule used will have been piloted in collaboration with the health workers in the unit, and later amended if necessary. Individual school teachers will be interviewed at a much later stage in the research, once I have gained the trust of parents and children. I consider that a structured interview or questionnaire would not allow for additional information which I had not considered, and narrative interview would be too time-consuming both for me and the health or education worker.

***Narrative Interviews*** - (with Parents and Children) - I have chosen to use narrative interview as a method because it is a way of encouraging rich, in-depth data, and 'an appropriate vehicle for exploring (women's) experiences in ways that may be hidden from view in more 'traditional' academic formats' (Ribbens, 1993). Feminist writing has shown that personal experience

should not be excluded as 'subjective and emotional'; analysis of personal relationships relates directly to wider social processes (Stanley, 1990). I found the narrative method to be very useful when carrying out data gathering sessions for my M.A. dissertation as it allowed the participants to define what they considered relevant to help me understand what it was like to be the parent of a child with AD/HD or indeed a child diagnosed with the condition.

I consider that narrative will allow me to elicit the meanings which social actors give to their situations and experiences in a way in which a more structured approach would not. Radley and Billig (1996), building on Cornwell's (1984) conceptualisation of illness accounts as 'public' or 'private', suggest that moving away from structured question and answer sessions is more likely to produce reflective, 'private' accounts of illness experience, rather than 'public' accounts which tend to be concerned with presenting an 'acceptable face' and justifying illness beliefs. When collecting narrative accounts I will be especially interested in how the speaker's experience relates to the concept of 'biographical disruption' (Bury, 1982; Williams, forthcoming). It will be of interest to discover how children and parents' on-going lives and identities are affected differently by AD/HD. Hyden (1997) contends that 'Narratives offer an opportunity to knit together the split ends of time, to construct a new context and to fit the illness disruption into a temporal framework'(p53), which is very different from a biomedical approach to illness. I realise, from experience, that both the data gathering sessions and the transcription can be extremely time consuming, so I will limit this method to the interviews with parents and the children themselves.

*In-Depth Qualitative Session-* (with children and young people) - Visual imagery is a further way of exploring subjective experience, and can be a very useful tool in research with children (Oakley and Bendelow et al, 1995; Pridmore and Bendelow, 1995; Bendelow, Williams and Oakley, 1996). I intend to use both drawing and writing stories, poems, letters as a key to unlocking children's feelings and emotions, which they may be unable or unwilling to talk about. On meeting the family for the second time at the clinic I will book a two hour slot, to be held in their home, which will involve encouraging the children to draw pictures in response to my enquiries, labelling them if possible, and the emerging themes will lead me into narrative interview. I will carry out three of these in-depth sessions with each child, near the beginning, middle and end of my fieldwork period. The drawings will form a collection which the child

will assemble in the format of a personal book which tells a story, either about their own life or of their outlook on the world. Children who may have difficulty in communicating verbally may prefer to communicate visually (Johnson, 1995) and this should lead them to gain a sense of achievement when they are presented with the end-product to keep. I feel very strongly that it is important that I give something back to those children who take part in this research. Child-centred and impossible to standardize, I anticipate each of the sessions to be different, depending on the response of the child. Being engaged in an activity of interest may help in the building of a relationship between myself and the children. Although my M.A. research was on a small scale, this method proved to be quite positive and certainly suitable for children with a need for constant stimulation.

*Document Analysis* - This will be a vital part of the triangulation of methods mentioned above. Information regarding local health and educational policies and the availability of resources will serve to contextualise the data gathered from the relevant professionals, parents and children. In turn, this will enable the research to be generalised to a wider population, or to be used in future comparative work. In addition (and with permission), I will examine treatment diaries, clinic records, school reports, media representations of AD/HD, and any other documents which seem relevant once in the field. I hope that this would add weight to my argument that AD/HD is constructed differently across a variety of settings, and that there is no unified approach to the treatment of such children.

### ***Intended Contribution to Methods:***

Narrative interview and the 'draw and write' method are significantly important research tools with which to access the beliefs, views and experiences of both lay people and children, allowing previously 'muted voices' to be heard. I hope to show that lay accounts and perspectives on AD/HD, especially those of the 'sufferers' themselves, should be admitted to the on-going debate between professionals from the fields of medicine, psychology and education. The use of such methods in research with children is still in its relative infancy, but I would hope that by sharing my fieldwork experiences with other social researchers I might encourage a move away from a reliance on the written or spoken word to express feelings.

### *Informed Consent:*

As a member of the British Sociological Association, I am bound by their 'Statement of Ethical Practice' to act responsibly and ethically at all times. Particular attention is drawn to the issue of inequalities of power, and researchers are urged to ensure that the 'physical, social and psychological well-being of research participants is not adversely affected'. When researching a vulnerable group such as children, it is vitally important to be aware of the dynamics of power involved in the research process; I am fully aware that in all adult/child interactions there is a power imbalance. I do not wish to be regarded as yet another adult who wants to probe and question children, and I feel I need to emotionally invest in the research relationship, and not be merely 'a data-gathering machine' (Oakley, 1981). Building on my previous experience of research with children, I know it is difficult to leave the field once a rapport and relationship have been established, but staying in touch with them and their parents and caring about their progress should make for a gradual withdrawal, rather than a complete break.

I feel that it is important to get the child's informed consent, and I will produce a small leaflet which explains, in simple terms, who I am, what I am doing, why, and how my research should benefit children. In research with children such a leaflet helps to allay any fears of the unknown, and allows children to make an informed choice about taking part (Alderson, 1997:24). The '*Parent/Guardian Information Sheet*' will be sent to parents, inviting them to take part, along with the leaflet designed for their child. Parents and children will then be required to complete a '*Written Consent form*', where they are reminded that they are free to withdraw from the study at any time. If parents agree to take part but a child refuses, I will not coerce the child into participating, and will discourage the parents from doing so, since this would be an abuse of a power relationship - that of researcher/researched and adult/child. Ultimately, this is research *for* not *on* children.

### *Confidentiality:*

Anything which I discover about the patient in the course of my research will be kept confidential, but in the case of a child who reveals that they have been abused I would encourage the child to speak to adults who could help (Alderson, 1997). I would need to act both ethically and morally in the best interests of the child by seeking the advice of my more

experienced supervisors. When carrying out research with children, one needs to be aware of this possibility and have strategies for dealing with such an occurrence.

The data in its raw form will be available only to me - I will transcribe my own audio-tapes, and use numbers or pseudonyms when writing-up my thesis. Any audio-tapes used will be stored in a locked cupboard at my home address and destroyed on completion of this study. I will not discuss any individual patients or their parents with anyone, and neither will I reveal information which CAMHS staff may impart to me to any outsider.

### **Data Analysis:**

I will not be looking for meaningful statistical relations, but will be able to draw concepts relating to social structure and processes from the data gathered. I will seek to identify patterns in the data, tease out the key concepts which emerge and develop a coding frame so that I may reduce the data to several key concepts/areas. I have no preconceived ideas about these themes, but expect them to become evident in the context of the interview, or at the stage of analysis. With the recent rise of evidence based medicine, clinical judgements have been presented as objective facts, scientific truths, but the facts which the psychiatric team discover are limited and tell only a partial story. Evidence alone is not enough, doctors are also responsible for interpreting symptoms and physical signs, using their professional judgement and the typicality of the case (Greenhalgh & Hurwitz, 1998). Therefore narrative provides an additional dimension, driven by the patient, which moves towards a multifaceted understanding of the condition. Narrative stories give meaning to such illness/life experience, they are used to help make sense of the sometimes anti-social and defiant behaviours which are associated with AD/HD. An analysis which draws on narratives adds an experiential aspect to the health professional's medical recordings but also aims to locate the telling of personal stories within a wider structural framework.

Children's drawings will be scanned and entered onto a database using software which reproduces and stores graphic images on screen. This will allow me to retrieve and analyse the pictures in a similar way to analysing other forms of data, exploring how the children perceive parents, health professionals, teachers, peers and siblings and their own lives.

### **Limitations of Study:**

In my experience of working with this subject group, I have found children to gain positive enjoyment from the drawing/narrative sessions and have not perceived any risks or damaging effects. The methods which I will use have been employed extensively by Gillian Bendelow, my supervisor, in her work on children's beliefs about cancer (Oakley et al, 1995; Pridmore and Bendelow, 1995), after consultation with the eminent child psychiatrist Dora Black.

I cannot foresee any major ethical problems with this study, and I believe a well-thought out research design helps to overcome such difficulties. The children's participation in this study will be clearly indicated in their patient records. It could be argued that the findings of this study may not be generalisable to other geographical locations or the wider AD/HD population; but the intention of this in-depth qualitative study is to represent the key players involved with AD/HD in this area. In future, a longitudinal study may show how processes improve over time and with better understanding of the impact of the condition on families and wider society.

In researching a contentious issue such as AD/HD, I need to consider how my findings might affect the wider population of children who have this condition. Public attitudes towards such children could be influenced by my conclusions and I therefore need especially to avoid 'pathologising' the children, blaming parents or the medical profession.

### **Benefit of Study for Individual Patient and Wider Population:**

I am required by the ESRC to make specific how the children I research, policy makers, and service providers will benefit from my findings. In Britain, for the first time, the Department of Health's National Priorities Guidance to Health Authorities and Social Services gives priority to improving mental health services for children and adolescents (Community Care, Nov 1998). Although children with such needs should undoubtedly be cared for, the creation of an ever more powerful 'psy complex' (Donzelot, 1980) involved in surveillance and control of children - 'spotting' mental health problems in non-conforming children - should be avoided. Many children's problems originate or are influenced by the way children are 'treated' by adults. Regarded as incapable of understanding, talked about negatively in their presence, forced to 'fit

into' adult devised routines, such children may have problems of living rather than mental health problems. AD/HD is not just a health issue but an issue for wider society; investigation of the condition would be best achieved through a multi-disciplinary approach to research, policy and practice.

This research will raise awareness of the long-term problems for society which will occur if the experience of living with AD/HD continues to be ignored. Neglect of children and family difficulties is leading to long-term social problems - exclusion from school, parental marital break-down, petty crime and psycho-stimulant over-use. This research will move towards a shared understanding of AD/HD, and promote the view that provision for such children should be underpinned by a holistic approach to care, rather than the current situation where parts of children are dealt with separately by the various agencies, sometimes with a lack of communication, instead of in partnership. It will become clear that the themes of this research are relevant to a variety of disciplinary fields - sociology, psychology, psychiatry, educational psychology, health research. A sociological theorisation of AD/HD is crucial to the commitment to seeing AD/HD as an 'evolving concept'. I have no 'imperialist' tendencies to establish a superior conceptualisation, I merely wish to see a sociological perspective represented in the on-going debate. The study's over-arching significance will be to draw attention to the invisibility and marginality of children's views and voices in a society which reifies the concept of 'the child'.

### ***Theoretical Relevance***

The sociology of childhood, embodiment, and emotions are all topical areas of debate; this research will make both theoretical and empirical contributions to these developing areas of sociological significance. It has been suggested that 'good sociology requires attention both to theory and to empirical data' (Busfield, 1996:xiii). A large amount of empirical sociology remains under-theorised and the work of theorists remains empirically ungrounded. This research empirically observes and theorises an under-researched area of contemporary social life.

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## PARENT/GUARDIAN INFORMATION SHEET

Thank you for thinking about taking part in this study. This sheet will help to explain what will happen.

### Background of the Study:

**AD/HD is a medical category associated with the challenging and inappropriate behaviour of children. It is an issue of concern for parents, teachers, health professionals and, of course, children themselves. I wish to examine how AD/HD is constructed across the settings of the clinic, home and school, and how this affects the daily lives and experiences of children. The ultimate aim of the research is to assist in improving services for children with emotional and behavioural difficulties.**

### Details of Researcher:

**My name is Geraldine Brady and I am a full time PhD student based at Warwick University. I am carrying out this research on children's, parents, and health professional's experiences of Attention Deficit Hyperactivity Disorder to help draw attention to the complexity of the condition, and to seek a better understanding.**

## SECTION I

### *What do I have to do?*

If you decide to take part in the study I will ask you to consent to me being present at your consultations at the Child and Adolescent Mental Health Unit, in order to observe the interaction between parent(s), health professionals and child. I will also ask you to complete a questionnaire, and may wish to interview you, preferably in your own home, later in the study.

I may ask for your consent to talk to your child, a total of three times; at the beginning, the middle and the end of the research period. These sessions will be a mixture of drawing and talking, helping your child to express him/herself in whatever way feels most comfortable. Each of the above meetings should last no longer than one hour and will be tape-recorded. All tapes will be heard only by myself, and will be erased on completion of the research project.

### *Do I have to take part in this study?*

No, taking part in this study is voluntary. If you decide not to take part, your child's future medical care will not be affected in any way.

*What happens if I do not wish to continue with the study?*

If at any time you, or your child, wish to withdraw from the study you are free to do so and this will not affect your child's future medical care in any way.

**Further Information:**

*What do we hope to find out from this study?*

This study will represent the voices of children and parents, which are sometimes lost in the debate between various professional agencies - health, education, social work. I will discover how children feel about ADHD and how they deal with the problems which they may face.

The study will show that AD/HD is an issue of concern for wider society, not just for individual children and their families.

The evidence I will gather will lead health, education and social workers to a shared understanding of the needs of such children, allowing for the best possible provision, and pointing to the need for an approach to care which emphasises partnership.

*How long will the study last?*

This part of the three year study begins in October 1999 and ends in June 2000. Preliminary findings will be disseminated some time after this date.

**Ethical Approval and Confidentiality**

Your participation in this study, and all information received, is treated as confidential. You will be identified by a number or pseudonym, not your real name. The details of this study have been submitted to an Ethics Committee which has given approval to the study taking place.

**SECTION II - WRITTEN CONSENT**

PLEASE COMPLETE THE FOLLOWING SECTION YOURSELF:

Have you read the Parent Information in Section I? YES/NO

Have you had an opportunity to ask questions and discuss this study? YES/NO

Have you received satisfactory answers to all of your questions? YES/NO

Have you received enough information about this study?  
YES/NO.....  
.....

Who has spoken to you about this study and where are they based?  
.....  
.....

Whereabouts did you speak to the above individual?.....

Do you understand you are free to withdraw from the study:

- At any time
  - Without having to give reason for withdrawing
  - Without affecting your child's future medical care
- YES/NO

It is agreed that I will not be referred to by name in any report concerning the study in question or disclosed to any other person.

**YOU SHOULD ONLY AGREE TO TAKE PART IN THIS STUDY WHEN ALL YOUR ANSWERS TO THE ABOVE QUESTIONS ARE 'YES'.**

Do you agree to take part in this study?..... YES/NO

Patient Name.....

Signature..... Date.....

Address.....

.....

Researcher's Name.....

Signature..... Date.....

Copy for Information

Child and Adolescent Mental Health Services

23 June 1999

Dear Dr ~

Re: Forthcoming Doctoral Research -  
**CHILDREN'S EMBODIED EXPERIENCE OF AD/HD**

Further to our meetings and telephone conversations regarding the above doctoral research, I should be grateful if you would complete the proforma enclosed, giving your consent for me to approach and include in my project individual named patients in your care at the time of my research. I confirm that the name of the patient will not be published at any time during or on or following completion of the research.

Thank you for your assistance and co-operation. I would be pleased to answer any questions you may currently have, or any that arise throughout the duration of the research. I shall provide you with a report of the main findings when the research is concluded.

Yours sincerely

GERALDINE BRADY, B.A.(Hons), M.A.

**CONSULTANT CONSENT FORM**

TITLE: **CHILDREN'S EMBODIED EXPERIENCE OF AD/HD**

I give below my signed consent giving permission to **GERALDINE BRADY** to interview/include individual patients who are in my care throughout the duration of the above project. I note that the name of the patient will not be published at any time during or following completion of the above project.

I shall expect a progress report and summary of the project on completion of the study.

Name of Consultant..... Dr .....

Signature..... ..

Date..... 24/6/99 .....

Speciality/Directorate..... CHILD PSYCHIATRY  
(CAMHS) .....

# ATTENTION DEFICIT HYPERACTIVITY DISORDER PARENT QUESTIONNAIRE



UNIVERSITY OF WARWICK

***FIRST NAME OF CHILD:***

***AGE OF CHILD:***

***YOUR RELATIONSHIP TO CHILD:***

Thank you for taking part in this research. Some of the questions may seem intrusive but they have been designed to find out about your lives and experiences of ADHD. If your child lives with both parents, *both* your views would be appreciated, therefore please complete two separate questionnaires. I am interested in similarities and differences of opinion, so please feel free to express your own views, whether or not they agree with those of your partner.

All of your answers will be treated as CONFIDENTIAL and ANONYMOUS.

Researcher: Geraldine Brady  
University of Warwick

Tele:

## SECTION 1 - ABOUT YOU

1. How many adults live in your house?

What is their relationship to your child? (Tick box)

Mother

Father

Step-mother

Step-father

Grandfather

Grandmother

Other (please state)

2.a. How many children do you have?

2.b. Where do they live (Tick box)

At your home

With other parent

With grandparents

With foster parents

Other (please state)

3.a. Do you own a car? YES/NO

3.b. Do you have access to a car? YES/NO

4.	Are any members of your family in paid employment?	YES/NO
		TYPE of JOB?
	F/T	P/T
Father	<input type="checkbox"/>	<input type="checkbox"/>
Mother	<input type="checkbox"/>	<input type="checkbox"/>
Stepmother	<input type="checkbox"/>	<input type="checkbox"/>
Stepfather	<input type="checkbox"/>	<input type="checkbox"/>
No-one	<input type="checkbox"/>	<input type="checkbox"/>
Other		

5. Is the place you live in:

- Rented from the Council/Local Authority
- Rented from a private landlord
- Rented from a housing association
- Owner Occupied
- Other (please state)

6. Which of the following best describes you? (Tick one box)

- White British
- Black British
- Black Caribbean/West Indian/Black African
- British Asian
- Indian
- Bangladeshi
- Pakistani
- Chinese
- Other (Please state)

7. Which is your family's main language at home?

8. Which religion (if any) do you belong to?

## **SECTION 2 - PATHWAYS TO CARE**

9. a. Have you ever thought your child was 'different' from other children?

YES/NO

If YES, when did this first become apparent?

From Birth

Pre-school

Primary School

Secondary School

9.b. In what ways were they 'different'?

9.c. How did you explain or make sense of this 'difference'?

10. Did you take steps to find help and support? YES/NO

If YES, what did you do about it?

11. When did you first hear of the term ADHD - Attention Deficit Disorder (with or without) Hyperactivity?

12. From which source did you first hear of ADHD?

G.P.

Health Visitor

School

Educational Psychologist

Media

Friend/Family member

Support Group

Other

13. What involvement has your G.P. had in this process? (Tick all appropriate boxes that apply)

IN PRACTICAL TERMS:

Mentioned possibility of ADHD

Explored the issue

Referred/took issue further

Diagnosed ADHD

Prescribed medication

Other (Please state)

ATTITUDE:

Concerns taken seriously

Empathetic

Disregarded your concerns

Implied your parenting was at fault

Unhelpful

14. How would you rate your satisfaction with your G.P.'s response? (Tick box)

	PRACTICAL:	ATTITUDE:
Very satisfied	<input type="checkbox"/>	<input type="checkbox"/>
Fairly satisfied	<input type="checkbox"/>	<input type="checkbox"/>
Mixed	<input type="checkbox"/>	<input type="checkbox"/>
Fairly dissatisfied	<input type="checkbox"/>	<input type="checkbox"/>
Very dissatisfied	<input type="checkbox"/>	<input type="checkbox"/>

15.a. Have you paid for any help or treatment for your child? YES/NO  
If YES, please say what you have paid for.

15.b. Which (if any) of the following have you made use of (Tick boxes)

Please Give Details

- Homeopathic remedies
- Complementary therapies
- Private medical treatment
- Respite care
- Therapy
- Advice from support/self-help groups
- Conferences
- Other (please state)

16.a. How long did you wait for your child's initial consultation with the Child and Adolescent Mental Health Services?

16.b. Do you feel that this was a reasonable amount of time to wait? (Tick box)

- Yes
- No

16.c. Has your child had previous contact with this Service? i.e. is your child's case a 're-referral'? YES/NO

If YES, please give details of when they were previously seen and by whom (if you can recall).

17. Are there any social or medical factors which you feel have influenced your child's access to health care?

### **SECTION 3 - IMPACT OF ADHD ON HOME AND SCHOOL**

18. In which contexts does your child experience difficulties? (Tick all that apply)

Home

School classroom

School playground

Visits to friends houses

Visits to other family members

Supermarkets/shops

Holidays

Other (say where)

19. How supportive has your child's own tutor/teacher been?

- Very supportive
- Fairly supportive
- Mixed
- Not very supportive
- Very unsupportive

20. How supportive has your child's school, in general, been?

- Very supportive
- Fairly supportive
- Mixed
- Not very supportive
- Very unsupportive

21. a. Has your child been assessed as having Special Educational Needs? YES/NO

21.b. Has your child been 'statemented' by the Local Education Authority?  
YES/NO

If YES, please give date of statement.

22.a. Have your family requested any support from Social Services? YES/NO  
If YES, what kind of support?

22.b. What form of support have Social Services provided?

23. Have your child's 'difficulties' impacted upon the rest of your family?

YES/NO

If YES, in what ways.

24. Have your child's 'difficulties' impacted upon your friends? YES/NO

If YES, in what ways? E.g. are friends unwilling to look after your child?

25. Listed below are some possible characteristics that your child may display. Which do you find the most difficult to deal with? Please tick one box per question.

0 = Does not apply. 1 = Not difficult. 2 = Sometimes difficult. 3 = Very difficult.

	0	1	2	3
Forgetfulness and losing things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not listening or following instructions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fidgeting or restlessness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Interrupting or butting into conversations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Running, climbing, being 'on the go'	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Excessive talking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Careless mistakes in school work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Aggressiveness, losing temper	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Irritability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tearfulness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sensitivity to way they perceive they are treated	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of tearfulness/emotion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bed-wetting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Over-demanding	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Uncooperative	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Lack of understanding of cause and effect,

or consequences of actions

Verbal abuse

Physical abuse

Lack of respect for other people's feelings

Lack of respect for other's belongings

Poor concentration

Bottling up feelings, not talking about them

Blaming others

Not taking responsibility for own actions

Resentment

Other (Please specify)

26. Would you say you are 'sympathetic' towards your child?

Very sympathetic

Fairly sympathetic

Mixed

Not very sympathetic

Not sympathetic

27.a. Would you say you are more or less understanding than your partner (if applicable)?

More

Same

Less

27.b. Why might this be the case?

28. Please indicate how strongly you agree with the following typical statements about ADHD:

	Strongly Disagree	Agree	Strongly Agree	Not Sure
a. ADHD is an excuse for naughty children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. ADHD is an over-diagnosed condition in the UK	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. ADHD is a label middle class parents want for their children who are poor achievers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. ADHD only affects children from disadvantaged backgrounds	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Teachers do not understand the condition of ADHD	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. ADHD is misunderstood by family, friends and society	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. More understanding is shown towards children with physical disability than those with ADHD	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Some professionals encountered know little of ADHD and do not wish to discover the facts	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Some professionals imply that a child's behaviour is the result of 'bad-parenting'	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Living with a child with ADHD is a series of emotional ups and downs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. Brothers and sisters have to make sacrifices when there is an ADHD child in the family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- l. Only those who have lived with an ADHD child  
can fully appreciate the stress caused to the family
- m. Parents can become worn down and lose sight of the  
positive characteristics of their ADHD child
- n. Parents tend to blame themselves because their child  
is 'different'
- o. Parents of children with ADHD need practical social support
- p. Medication for ADHD should not be given to children
- q. Children with ADHD have a poor self-image
- r. Medication which helps to build a child with ADHD's  
self-esteem is welcome

29. What are your concerns for the future, regarding your child and your family?

30. Please write, in your own words, about the hopes you have for your child, and your expectations of what you would like the Child and Adolescent Mental Health Services to do.

Thank you for your help in this study. I am going to carry out a small number of follow-up interviews to further explore the views of parents of children with ADHD, and may contact you. Any of the information you share with me will be strictly confidential.

## Summarised biographical profiles of research respondents.

### Children, young people and their families-

Chris was 15 years old and lived with his mother and father in an area of the city largely populated by students and academics from the local university. He had no brothers and sisters as all of his mother's pregnancies had unfortunately resulted in miscarriage. Mrs Clarke worked from home as a registered childminder and Mr Clarke was a civil engineer. Mr and Mrs Clarke were very anxious about Chris's future and worried particularly about his difficulty in keeping his temper when situations led him to feel angry or frustrated. He often punches the wall or doors or throws objects (he broke the front room window by throwing a bin at it once when he had been reprimanded). Chris's parents clearly cared about him a great deal, and looked for ways of accommodating his needs. Family members and friends had always found him difficult to deal with and did not offer much support; his parents were exhausted and exasperated with his disruptive behaviour. He exhibited aggressive tendencies, and had many outbursts, but always felt sad and remorseful afterwards.

Chris's parents were surprised to find that their Health Authority did not diagnose or treat ADHD. Their G.P. referred Chris to the nearest clinic outside of this H.A. Chris was on the waiting list for nine months; it would have been sufficiently longer, but he was given an appointment as a matter of urgency when he set up a noose and attempted to hang himself. Over several appointments and after completion of forms requiring a complete case history, rating scales, visits to an Ear Nose and Throat specialist and an Educational Psychologist, Chris was diagnosed with ADHD in 1998, aged 12. Receiving a diagnosis did not resolve all the difficulties. Much damage had been done to family relationships and, more importantly, to Chris's confidence and self-esteem during the previous twelve years.

\*\*\*\*\*

Ross was 12 years old. He lived with his mother, father, younger brother and younger sister in a large, detached house on the outskirts of the city. The house was rented as the family had recently arrived from the United States of America and had not decided where they wished to settle. Ross's younger brother has Tourette's Syndrome and his father has both Tourette's and a heart condition; both of these factors influenced their decision to relocate to the UK as the cost of health insurance was becoming prohibitively high in the U.S. Ross was an extremely articulate boy and able to express his feelings both verbally and through art. He found mainstream education in the UK to be quite different from his experience of school in the U.S. Most noticeably he was surprised that young people in the UK appear to be less respectful of teachers and that teachers did not always challenge or reprimand inappropriate behaviour. Ross passed the entrance exams of a prestigious boys' school and began Year 8 at this school, in a class of 22 rather than 31. He benefited enormously from the reduced class sizes, the structured environment and the emphasis on personal development. Ross was diagnosed with ADD in the States when he was seven. He was taking the medication Adderall when he lived there, and

here takes Dexamphetamine. Ross's father, Mr Adams, is a lorry driver and Mrs Adams works as a hospital auxiliary nurse.

\*\*\*\*\*

**Sean** was 11 years old and lived with his mother and fourteen year old sister. He also had a brother of 27 who lived elsewhere with his own family. Sean felt close to his older brother and two year old nephew. Sean still saw his father, who lived approximately six miles away on the other side of the city. Sean was diagnosed with ADHD when he was in Year 6 of primary school. He takes Ritalin to help with the symptoms of the condition. Sean's mother, Ms Jones, is a secretary and works full-time. Their home is rented from the Local Authority and is located in a disadvantaged area of the city, close to a railway line. Sean's mother found his behaviour extremely challenging over the years since his birth; his brother and sister were relatively placid in comparison to Sean, who was always very energetic and demanding of attention. Sean had been involved in criminal activity and had only narrowly avoided gaining a criminal record. The future was of great concern to his mother. Sean did not dislike school but he preferred to have fun rather than concentrate in lessons.

\*\*\*\*\*

**Marcus** was 11 and was in Year 6 at primary school. He had always lived with his mother but his mother had recently got married and he now has a step-father, who he seemed to have a good relationship with, but was perhaps less compromising than Marcus was used to. Marcus, his mum and step-dad were a warm, welcoming family who enjoyed a good lifestyle, including holidays abroad and new cars, in a desirable part of the city. Mrs Baldwin is a social worker and Mr Baldwin is a technical sales manager. Marcus appeared to have spent a lot of time in the company of adults and conversed on a mature level. He had some difficulties with his school work which concerned his mother; she was very aware that he could 'fall behind' his peers if he did not concentrate and work hard. She advocated on his behalf with the various support services to ensure that Marcus received all the help to which he is entitled. Marcus had always been fascinated with technical detail and liked to take objects apart to discover how they work; he seemed to be a practically gifted child and his mother recalled several examples which demonstrate this ability. Marcus was diagnosed with ADHD in 2001, during the fieldwork conducted for this study, and prescribed Ritalin. He experienced some side-effects so was then prescribed Dexamphetamine, but this did not help, so he was persevering with Ritalin.

\*\*\*\*\*

**Emma** was 11 and lived with her mother and step-father, an older brother and two younger sisters. Mr and Mrs Ling lived in an ex-mining community on the outskirts of the city. The area was a large Local Authority housing estate and was quite run down, with little for children and young people to do when not at school. Emma's relationship with her mother was often quite tense; although Mrs Ling tried to empathise and understand the condition of ADHD she felt that her daughter could be defiant and disobedient and that this is unrelated to ADHD. Emma had been very active and challenging since she was approximately one year old and had contributed to her mother feeling exhausted and sometimes unable to cope with the regular disagreements within the house. Mrs Ling works as a carer in a home for older

people and Mr Ling worked in a blue collar occupation. Emma was assessed by numerous health professionals and ‘passed from pillar to post’, sometimes because of confusion over which health authority were responsible for her as the family lived on the boundary between two health authorities. She also had at least two different diagnoses applied to her before being diagnosed with ADHD at the age of 8 and prescribed Ritalin.

\*\*\*\*\*

Jack was 8 and lived in a village on the outskirts of the city. His mother was a Community Psychiatric Nurse at a Child and Adolescent Mental Health Service and his father was a sales representative. He also had a younger brother. Jack attended the village school and although he was perceived to be bright he was often in trouble for being disruptive. Expectations at the school were high and it was assumed that he was not applying himself to the work, rather than that he was having difficulty in following the teacher. From an early age he had been a very active baby and child who rarely played with toys for longer than a few moments. He was a keen and very able footballer and enjoyed competing in all sports. He was diagnosed with ADHD during the course of the fieldwork; his mother found this to be ironic as she was directly involved in the assessment of children with ADHD in her role as CPN.

\*\*\*\*\*

Michael was 6 and lived with his mother, step-dad and baby brother. Michael had been recently diagnosed with ADHD. His step-father worked as a security guard, both his step-father’s father and grandfather had been Head teachers. Michael’s house was located on a Local Authority housing estate in an economically deprived area of the city; it was clean, well decorated and comfortable within. Michael’s mother did not engage in paid work at the time of the fieldwork as she stayed home to look after her two year old son. Mrs Summers had voiced concerns about Michael’s raised activity level from a very early age, but conferred mainly with family members.

Michael had been diagnosed with a bowel condition from birth, and eventually saw a paediatric specialist when aged six. At this clinic appointment his over-activity and lack of concentration was noticed, and the paediatrician suggested referring him to CAMHS for assessment. Michael waited three months for the initial appointment and was assessed, with the use of rating scales, parent and teacher observations, a detailed case history and clinic observations, over a period of one month. The diagnosis of ADHD helped to explain Michael’s difficulties, but did not automatically lead to access to support or resources as each of these was provided by separate services and agencies outside of the health profession.

\*\*\*\*\*

## **Child and Adolescent Mental Health Service respondents:**

**Dr Mills** was a male Consultant Child and Adolescent Neuropsychiatrist. He had considerable experience of assessing and treating children with neurological difficulties. Colleagues who were perhaps more sceptical about the concept of ADHD described his approach to the treatment of ADHD as 'inclusive', which implied that children coming to him for assessment were likely to receive a diagnosis and be offered medication as a treatment if they appeared to fit the ADHD criteria. He helped to establish a specialist psychiatric team to assess and treat children in the city who were suspected of having ADHD. This way of working helped to reduce waiting times for families. He was also keen to work jointly with other professionals from the fields of education and social care and encouraged secondment to his team in order to improve working relationships.

**Dr Turner** was a Clinical Assistant and had worked at this CAMHS for several years. She trained as a Family Therapist and her practice is very child-centred. She had witnessed many changes in personnel and practice during her time at CAMHS. It was only since the arrival of the present Consultant that Dr Turner had felt able to diagnose ADHD. Before this, the Consultant in charge did not feel comfortable in diagnosing the condition as he knew little about it. Suspected cases were referred outside the region for assessment and diagnosis. Dr Turner had a very gentle but assertive manner and clearly wished to help both parents and children as much as possible. She strongly felt that children were often not given the chance to express how they experienced family life. She tried to help parents to understand their children and to take some responsibility for changing long-standing ways of dealing with behavioural issues. She suggested alternative ways and offered support during the initial stages. She regarded medication as having a role to play in some cases but was concerned that the approach taken when dealing with children with ADHD focused solely on the individual child, rather than the child located within a family system. Dr Turner does prescribe medication to children who appear to have ADHD but she often wrestles with her conscience, questioning whether enough is known about the long-term effects of medication to be totally comfortable about prescribing it to children of six years and above

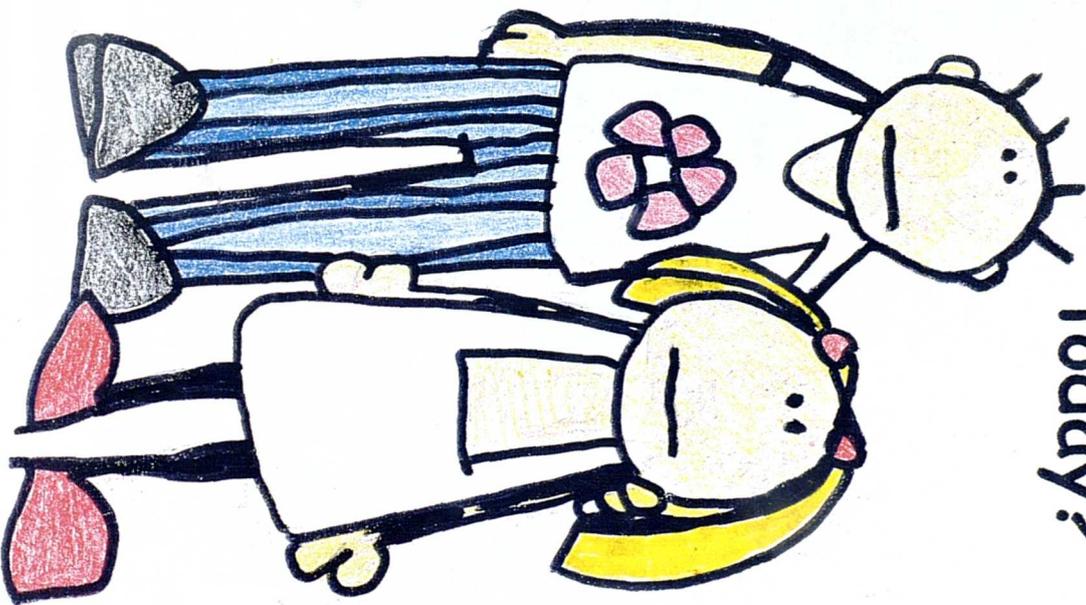
**Dr Watson** was also a Clinical Assistant and had worked at the CAMHS for several years. She trained as a General Practitioner. She has assessed many children during her time at CAMHS and has been frustrated not to have been able to offer a diagnosis of ADHD when it seemed evident. Many of the children that she treats for ADHD are cases that have been re-referred, the parents having persisted in seeking medical assistance for their child, sometimes for five years or more. Once she felt satisfied that she had carried out a full assessment of the child she would prescribe medication if appropriate. She took part in discussions with her colleagues regarding the appropriateness of prescribing but ultimately regarded it as part of her duty to relieve the suffering of parents and children wherever possible. Dr Watson would have also appreciated more assistance with behavioural therapies alongside medication but a lack of resources meant that therapies other than medication were often not available or only available on a short-term basis. The effectiveness of short-term therapies was

difficult to assess and often more time was needed before positive changes in behaviour became evident.

Doctors Mills, Turner and Watson were keen to read all available evidence regarding the cause, assessment and treatment of ADHD and shared with their colleagues the latest published journal articles and evidence of good practice elsewhere in the country. The Doctors were committed to liaising with other support services, parents and school teachers in order to provide a service which took account of all aspects of the lives of children, and was not limited to focusing on health. The assistance and advice which they provided was not always looked on favourably and was sometimes treated with suspicion by other professionals.

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How do YOU feel  
today?



**Hello**

My name is **Geraldine Brady** and I am trying to help others to understand young people who have difficulty concentrating and paying attention at school and at home. Lots of young people are not having an easy time. It may seem that you are always in trouble because of over-activity or not being able to concentrate, perhaps you feel that no-one understands you? It is hard for parents, teachers, and doctors to understand what it feels like to have ADHD, but I would like to speak to you to understand the experience from *your point of view*.

\*Maybe you wish your mates knew what it was like to want to get on with your work, but not be able to?

\*Maybe you feel as if you have no mates - they're friends with you one day, but not the next?

\*Maybe taking medication is not that easy for you?

**I GUESS YOU'D LIKE TO KNOW A BIT MORE ABOUT WHAT TAKING PART IN THIS STUDY WILL ENTAIL?**

I have already met you at your last visit to the doctor at CAMHS, and if it is OK with you and your parent(s), I would like to come and see you at home, where we can talk about school, you and your family. I'd like us to work together through talking

and using art to build a book of your life story - 'This is Your Life', which you will be able to keep.

**WILL THE MEETING BE PRIVATE?**

It will be your choice whether to have your parent(s) there, you can let me know what you have decided when I arrive.

**WHAT IF I SAY YES TO TAKING PART, THEN CHANGE MY MIND?**

No problem. You can choose to help me or not, and you can of course change your mind at any time.

**WHY SHOULD I HELP?**

Didn't you ever wish other people knew what you were on about when you tried to explain how it feels? By speaking to several young people about ADHD and similar problems I will be able to build up a picture of what you are experiencing. If more people understand, then more teachers, parents and doctors can be of *real* help to kids who are having difficulties.

*If you have any other questions about this research, please call me on Coventry 447593.*